



# Brain & Central Nervous System (CNS) Cancer Clinical Guidelines

## Brain and CNS EAG on behalf of NCA

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### Guidelines agreed by:

Agreed by: Brain and CNS EAG members  
Date Agreed: Emailed out to group on 10.03.2021



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## Terms of reference

- These Guidelines had been initially written by Professor PJ Kane, previous Chair of the NCA Site Specific Group for Brain and other CNS Tumours and presented by Mr John Crossman. This was later updated by Dr Joanne Lewis and by Mr Anil Varma in 2018. The guidelines have recently been updated by Mr Anil Varma and Mr Damien Holliman in 2020 and later circulated and approved by the members of the EAG.
- The Guidelines are drawn from various sources including previous Guidance in the Cancer Care Alliance/Northern Cancer Network, published clinical guidance for Brain and CNS Tumours in other networks and elements of “good practice” included in clinical guidance for other tumour sites within the NCA.
- The Guidelines have been circulated to all members of the Network Site Specific Group for Brain and CNS Tumours and cascaded to relevant MDT’s for comment before publication.
- Grateful thanks go to those members who contributed to the Guidelines and reviewed and checked the text.
- It should be noted that these are Guidelines and not a policy and that across the NCA there may be some variation according to local arrangements. The Guidelines have been compiled with reference to national documents published by the National Institute for Clinical Excellence including Improving Outcomes Guidance for patients with Brain and other CNS Tumours (2006) and referral of patients with suspected brain tumour. Link to guidance:  
[NICE Guidance](#)
- It should be noted that these Guidelines relate to the management of adult patients (those aged greater than 19 years) and not children. The management of children with brain and other CNS tumours is covered by separate Guidance and NICE documentation.
- The Guidance does relate to the young adult population (those aged 19-24 years). This patient group is also addressed in separate NICE Guidance [NICE Guidance](#) and specific Guidance is issued in the Network for this patient group to manage the interface between paediatric and adult services.
- This Guidance does not relate to the management of patients with neurological symptoms arising from metastatic spinal cord compression. This patient group is addressed in separate NICE Guidance and a specific Guidance is issued in NCA for this patient group.

## Introduction

- The National Institute for Health and Clinical Excellence (NICE) published the Improving Outcomes Guidance (IOG) for people with Brain and Other Central Nervous System (CNS) Tumours in June 2006. Further NICE guidance, Brain tumours (primary) and brain metastases in adults Tumour was published in July 2018.
- The IOG is unique when compared to similar guidance for other tumour sites in as much as it relates to both malignant and benign tumours affecting the brain and central nervous system, whereas other IOG relate only to malignant tumours (cancer).
- The IOG acknowledges the devastating effect that both malignant and benign tumours of the central nervous system can have on affected patients.
- The IOG describes key aspects of services that are required to achieve the best outcomes for adult patients with tumours of the brain and central nervous system and covers all aspects of care from diagnosis onwards.
- The IOG deals predominantly with primary tumours although metastases from other primary sites that need complex neurosurgical interventions are also included.
- The classification of CNS tumours is complex. The IOG simplifies this by classifying tumours as brain tumours or rarer CNS tumours (intradural spinal cord tumours, skull base tumours, pituitary tumours, optic tract Gliomas, primary CNS lymphomas, Medulloblastoma and pineal tumours).
- The IOG acknowledges that primary CNS tumours are uncommon: among them brain tumours are more common but only account for approximately 1.6% of all cancers in England and Wales. However, the IOG acknowledges that in general, these tumours have a poor prognosis. The anatomical position of the tumour and its pathology play an important role in prognosis and decisions regarding investigation and treatment. In some patients 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 alone.
- The position of the primary brain tumour can show symptoms which include physical, cognitive and psychological components. Adult patients with CNS tumours pose a unique challenge to health care professionals and the IOG recognises this in its comprehensive approach to core membership of multi-disciplinary teams (MDT). Importantly it recognises that due to the poor survival of many patients with primary brain tumours, an important aspect of improving outcome is maximising quality of life.
- Although the number of patients involved in each of the designated tumour groups may be relatively small compared to other tumour sites (e.g. lung, breast), the IOG

recognises the need to develop highly specialist MDT's to deal with these tumour groups.

## **Public health and prevention**

- There are no clear factors which have been identified as being directly related to the development of brain or other CNS tumours. Consequently, there are no public health or prevention issues that can be addressed at this time.

## **Screening**

- At present there is no proven effective screening process available for brain and CNS tumours.
- Patients with genetic conditions, which are known to be disposed to the development of brain and CNS tumours (e.g. neurofibromatosis, von Hippel-Lindau disease, Tuberous Sclerosis, multiple endocrine neoplasia) may have cranial imaging performed as part of baseline investigation in the diagnosis of their condition. This in turn may identify asymptomatic tumours within the brain and elsewhere in the CNS, which will require discussion by the relevant Neuroscience MDT (brain and other CNS tumours, pituitary, spinal, base of skull) dependent upon their position and treatment advice given.

## **Genetic counselling**

- Patients who have a tissue diagnosis of a brain or other CNS tumour which, in combination with their clinical history, raises concerns regarding the possibility of an inherited condition will be referred to genetic services for appropriate investigation, counselling and family support.
- The neurosciences MDT should consider the need for referral for genetic advice in patients with the following diagnoses:
  - haemangioblastoma - von Hippel-Lindau disease
  - bilateral acoustic neuroma - neurofibromatosis
  - subependymal giant cell astrocytoma - tuberous sclerosis
  - pituitary adenoma with other endocrine tumour-multiple endocrine neoplasia
- Occasionally patients with primary brain tumours will report that another first or second degree relative has previously been diagnosed with a primary brain tumour. Although a genetic predisposition is unlikely in this situation, the MDT should give consideration to referral for genetic advice to provide reassurance for the patient and their family.

## **Risk factors**

- The aetiology of brain and other CNS tumours is unknown and so specific advice on avoidance of risk factors is not possible.
- The development of brain and other CNS tumours in relation to inherited conditions is described above.
- There is an association between the development of brain tumours and exposure to radiation. The potential development of late secondary tumours following the use of therapeutic X-rays must be considered. Consideration must also be given to the multiple use of cranial CT imaging.
- The role of mobile phone usage and the development of brain tumours remain controversial and unproven.

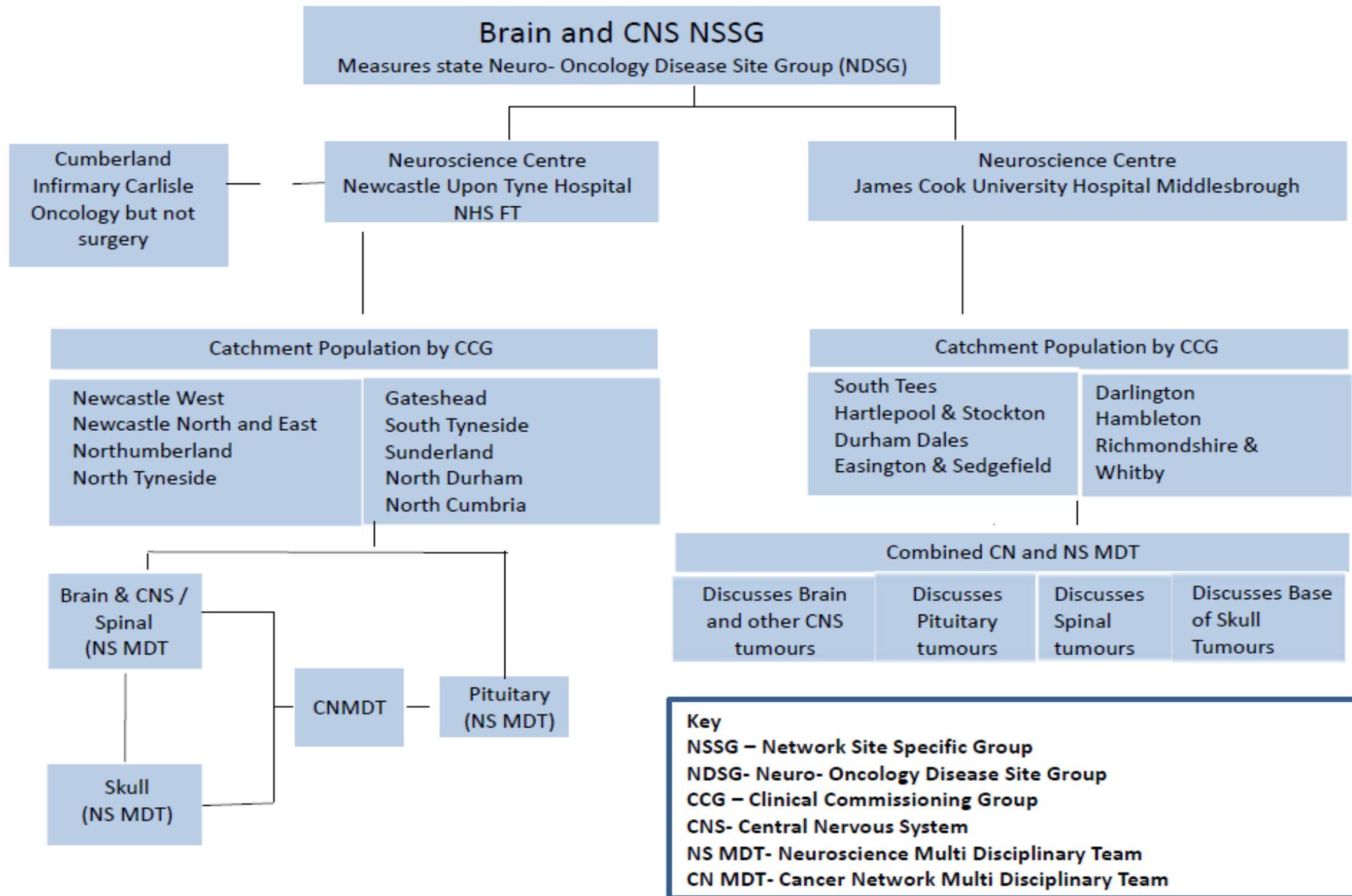
## **Multi-disciplinary teams**

- All patients with a radiological diagnosis of a brain or other central nervous system tumour must be reviewed in a multi-disciplinary team meeting to allow adequate discussion of the case and ensure appropriate decision making regarding management.
- The IOG for Brain and CNS Tumours identifies that the initial decisions regarding the need for surgical management and obtaining a tissue diagnosis should be overseen by the Neuroscience MDT. Subsequent oncological management and arrangements for rehabilitation/supportive care will be overseen by separate “Network” MDT.
- The IOG acknowledges that separate Neuroscience MDT arrangements should exist for brain and rarer CNS tumours (including intracranial metastases), pituitary tumours, intradural spinal cord tumours and base of skull tumours.
- It was initially envisaged that all Neuroscience MDT’s would feed patients into a single Network MDT for oncology management. It has been acknowledged by the National Cancer Action Team that due to the geography of NCA and the population distribution that 2 Network MDTs will function and these will be co-located at the sites of the Neurosciences MDT.
- As might be expected the Neuroscience MDT will be located at the 2 Neuroscience centres within NCA; one based in the Newcastle Upon Tyne Hospitals NHS Foundation Trust (NUTH) and the other based in South Tees Hospitals Foundation Trust (STH).
- At the NUTH site, separate MDTs for brain and other CNS tumours, intradural spinal cord tumour, pituitary tumour and base of skull tumour will work independently and feed patients into the Network MDT at that site.
- At the South Tees site the brain and other CNS tumours, intradural spinal tumour, pituitary tumour and “Network” MDTs will form as a combined MDT. The base of skull

MDT will join with brain and CNS tumour MDT and will also work closely with the Head and Neck cancer teams, thus providing an effective use of the resources by providing access to all relevant specialities.

- The configuration of the individual MDTs are defined in the IOG for brain and other CNS tumours and also in the relevant peer review measures.
- The MDT arrangements within the NCA at the Royal Victoria infirmary Newcastle and the James Cook University Hospital Middlesbrough are shown diagrammatically in figure 1.
- The MDTs will be configured in accordance with the recommendations of the IOG for brain and other CNS tumours and also the manual for cancer services: brain and CNS measures documentation.
- The geography of the region covered by the NCA poses significant logistical difficulties for significant numbers of patients and their carers; travelling long distances for diagnostic investigations and treatments can be physically and psychologically exhausting as well as being time consuming and costly. Consequently some patients may request that diagnostic investigations and outpatient follow up are undertaken in their local hospital.
- Work is in progress to harmonise radiological investigation practices at all referring hospitals in order to facilitate the diagnostic pathways prior to MDT discussion.
- Following discussion by the relevant MDT in Newcastle, the oncological treatment (radiotherapy and chemotherapy) for most patients residing in Cumbria will be delivered at the Cumberland Infirmary, Carlisle.
- All patients will be given the opportunity for follow up in a multidisciplinary clinic following treatment but it is accepted that some patients will prefer follow up more local to their homes. In these cases the follow up will occur in specialist clinics (oncology, neurosurgery, endocrine) based in the local hospitals with the caveat that all patients exhibiting clinical or radiological signs of tumour progression will be referred back to the MDT for further discussion.

Figure 1



## **Teenage and young adult patients**

- This clinical guidance relates to management of adult patients.
- The management of young adults, age 19-24 years, is also addressed in separate specific guidance.
- Within NCA the TYA MDT is based within the Newcastle upon Tyne NHS Foundations Trust (TYA MDT alternates weekly between Freeman Hospital and Royal Victoria Infirmary Newcastle upon Tyne).
- The James Cook University Hospital, Middlesbrough, is a designated TYA hospital.
- All young adult patients with brain and other CNS tumours will be notified to the TYA MDT (Referral pathway guidance is given in Appendix 2) and the outcome of this discussion will be documented.
- All young adult patients presenting to the Neurosciences MDTs will be offered the opportunity to receive age appropriate psycho-social support via the TYA MDT, which is in addition to the treatment plan overseen by the brain and CNS tumour site specific team.

## **Communicating the diagnosis to patients and carers**

- Effective communication is an essential part of every element of the patient pathway. The complex constellation of physical, cognitive and psychological symptoms which can arise in patients affected by brain tumours can affect their ability to assimilate information. Patients should be given the opportunity for relatives or a close friend to be present during each consultation. Patients should be encouraged to bring the same relatives or friend to each consultation to assist with continuity.
- Facilities should be available for each consultation with the patient and their carers to take place in a quiet environment in a private and uninterrupted fashion.
- The IOG for brain and CNS tumours identifies that the patients are designated a neuro oncology clinical nurse specialist, who should be available during key consultations (initial consultation with discussion of MDT recommendations, discussion of histology results, discussion of further treatment options).
- The IOG specifies the need to allocate a 'key worker' to all patients affected by brain and other CNS tumours. The key worker will act as a source of contact, information, support and advocacy throughout the treatment pathway. The IOG indicates that any member of the relevant MDT can undertake this role, but in the majority of instances the neuro-oncology nurse specialist will fulfil the role.

- Opportunity to contact the neuro oncology clinical nurse specialist for further counselling should be offered at each meeting and follow up arrangements should be clearly planned.
- Patients should be given time, information and support to make fully informed decisions about their treatment. It should be acknowledged that patients may require additional 'thinking time' and opportunities for discussion.
- The patient should be informed of their diagnosis by a consultant or an appropriately experienced member of the MDT. Written information concerning treatment should be available and offered to all patients.
- All members of the MDT who are involved in direct "face-to-face" contact with patients affected by brain or other CNS tumours will have undergone appropriate advanced communication skills training in accordance with national guidance.

### **MDT communications policy**

- Patients with an initial imaging diagnosis of a CNS tumour should be logged on to a dataset of the Neuroscience MDT (NSMDT) within one week of the date of the image report. (The NSMDT is the MDT which is required to make the multidisciplinary decisions on several stages of the pathway which form the essential part of the treatment plan).
- A clinical summary from the clinician in charge of the patient at the time of the imaging diagnosis should be received by the NSMDT within two working days of the date of the imaging report
- A written summary of the proposed management plan should be sent out from the NSMDT within one working day of the MDT meeting to the referring clinician, the Cancer Network MDT (CNMDT) and the GP. (The CNMDT is the MDT which oversees the ongoing delivery of the non-surgical aspects of the patient's treatment plan).
- The patient or their carers are informed of the management plan by the NSMDT within one working day for inpatients and five working days for outpatients of the NSMDT meeting at which it is decided
- A referral for relevant patients should be sent to the rehabilitation or palliative care service within one working day of the decision being made
- A referral of relevant patients for management by a member of the CNMDT should be sent within two days of discharge from neurosurgical care

- Patients or their carers should be informed of the identity and role of their key worker within one working day for inpatients and five working days for outpatients of the NSMDT meeting
- A referral back to the NSMDT for further management of possible recurrence should be sent from the multidisciplinary specialist clinic within one working day of the decision.

## **Referral guidance for General Practice**

- These guidelines are for adult patients (patient 18 years and over) with suspect brain or CNS cancer.
- Increased awareness and a low threshold of suspicion are probably the most important means of decreasing a delay in diagnosis of brain tumours. A national programme to increase the awareness of general practitioners to the symptoms/signs of brain tumour in the paediatric population is in place. A similar programme for the adult population does not exist at present.
- National Guidance exists for general practitioners for referral of adult patients with suspected brain tumour under the two week rule and these should serve as the basic threshold for GP referrals to the Neurosciences MDT.
- Initial investigations such as MRI (Magnetic Resource Imaging) brain scan could be organised by the general practitioner as an outpatient, unless the patient needs urgent admission. It is noted that most brain and other CNS tumours are diagnosed during emergency admissions. These patients may be admitted with a suspected stroke or after a first fit.
- NICE (National Institute for Health and Care Excellence) has recently updated its referral guidance NG12 Suspected Cancer: recognition and referral. Primary care is advised to request an urgent (within 2 weeks) MRI.
- Referral criteria for MRI included:
  - Sub-acute progressive neurological deficits developing over days to weeks (e.g. weakness, sensory loss, dysphasia, ataxia).
  - New onset of seizures characterised by one or more of the following: focal seizures, prolonged post-ictal focal deficit (greater than one hour), status epilepticus, associated into ictal focal deficit.
  - Patients with headache, vomiting and papilledema.
  - Cranial nerve palsy (e.g. diplopia, visual failure including optician defining visual field loss, unilateral sensory neural deafness).

- Considering urgent referral for patients with non-migrainous headaches of recent onset, present for at least one month and accompanied by features suggestive of raised intracranial pressure (e.g. woken by headache, vomiting, drowsiness).
- The validity of the referral criteria has been debated extensively, especially in relation to the ability to lead to earlier diagnosis of brain and CNS tumours and to improve the outcome. Nevertheless at this time they remain relevant criteria for consideration of referral to a specialist centre.
- It is expected that GP's will have counselled patients appropriately in relation to their referral under the "Two Week Rule".

### **Referral guidance for secondary care**

- The diagnosis of a brain or other CNS tumour is most commonly made in the secondary care setting after patients have presented to the acute medical or oncology teams.
- Emergency referral to the on call neurosurgical team is warranted in the following:
  - Patients with scan appearances suggestive of high grade malignant primary brain tumour where abscess is also being considered.
  - Tumour associated with hydrocephalus.
  - Posterior fossa or midline third ventricular tumour.
  - Intratumoural haemorrhage, intradural tumour causing spinal cord compression.
- Patients requiring emergency referral must have the following initial management:
  - Contrast enhanced scan of brain, preferably MRI
  - Chest x-ray, full blood count, electrolytes, clotting screen.
  - Anti-coagulant treatment (Warfarin, Heparin, Apixaban, DOACs) and anti-platelet treatment (e.g. Aspirin, Clopidogrel, Dipyridamol, Ticagrelor etc) must be stopped.
  - Treatment with Dexamethasone up to 16 mg daily and a PPI should be commenced following discussion with the neurosurgical team unless
    - ~ there is a high index suspicion of cerebral abscess
    - ~ there is a high suspicion of primary cerebral lymphoma
- The majority of patients with newly diagnosed brain or other CNS tumour require urgent, rather than emergency, referral to the Neurosciences MDT.

- Patients requiring urgent referral should have baseline assessments prior to referral as follows:
  - Full clinical examination.
  - Full neurological examination.
  - Pre and post contrast MRI scan of brain.
  - If metastatic disease is suspected the patient should have CT scan chest/abdomen/pelvis and tumour markers.
  - If spinal tumour is suspected the patient should have a whole neuro axis MRI scan.
  - Full blood count, urea and electrolytes, liver function tests, clotting screen.
  - If a patient is on anti-platelet medication (e.g. Aspirin, Clopidogrel, Dipyridamol, Ticagrelor etc) these must be stopped. If patient is on Warfarin anti-coagulant therapy this should be stopped unless there is a high risk of thrombotic complication (recent DVT, recent pulmonary embolus) in which case the patient should be converted to Heparin anti-coagulation.
  - The patient should be commenced on Dexamethasone (up to maximum dose of 16mg daily) and a PPI, unless cerebral abscess or primary cerebral lymphoma is the suspected diagnosis.
  - An assessment of functional status using the WHO Performance score or the Karnofsky score.
- Urgent referrals to the Neurosciences MDT should have comprehensive referral documentation which includes presenting history, co-morbidities, routine medications, the outcome of assessments/interventions described above and an indication of the level of information which has been provided to the patient and their carers.

### **Minimum information requirements in referral letter for primary and secondary care referrals**

- Name, date of birth, address, contact number.
- NHS Number.
- Name of General Practitioner.
- For referrals from secondary care: name of referring consultant.
- Current location of patient (home/ward/community hospital).
- Brief history of presenting complaint.

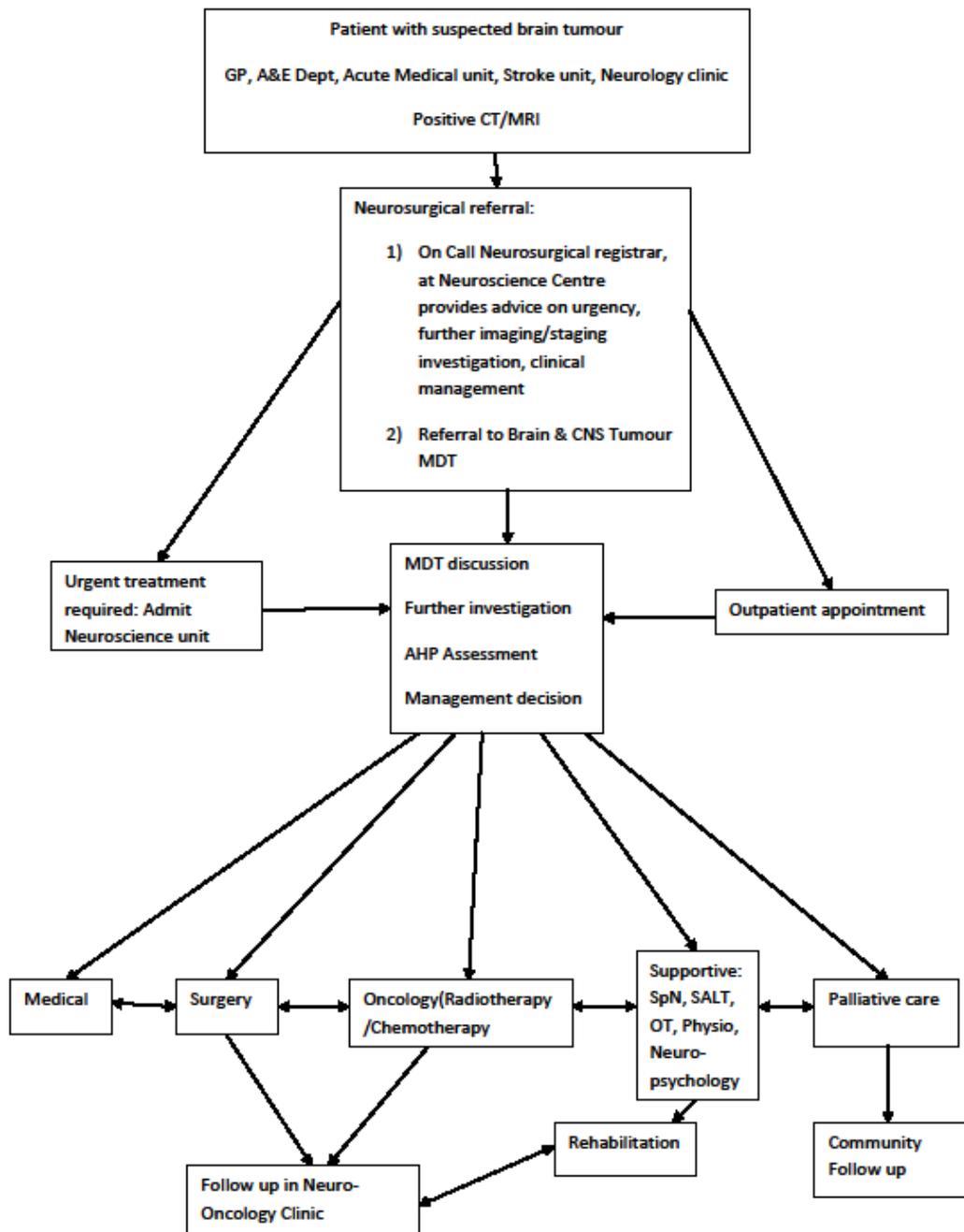
- Brief description of physical signs.
- List of significant co-morbidities.
- Relevant past medical history.
- Medications, importantly anti-platelet drugs and anti-coagulants should be reported and whether these have been discontinued/altered.
- Allergies.
- Level of social support.
- Current functional status (WHO / ECOG or Karnofsky score).
- Response to initial treatment if steroids have been started.

### **Incidental tumours**

- Incidental findings on brain imaging are defined as previously undetected abnormalities of potential clinical relevance that are unexpectedly discovered and unrelated to the purpose of imaging.
- Incidental findings are increasingly detected in clinical practice as the access to cranial CT and MRI scanning has improved. Data on the prevalence of incidental findings are scarce.
- The prevalence of incidental tumours (mostly meningioma and pituitary adenoma) is suggested as being 1%. The available literature suggests that the likelihood of detecting malignant incidental tumour is extremely small.
- It is possible that the detection of incidental tumours will increase with the passage of time as MR imaging becomes more widespread.
- Commonly detected lesions include meningioma, pituitary adenoma, low grade Glioma, pineal region cysts, colloid cysts and intradural spinal neurofibroma. These radiological diagnoses are not “suspected cancers” and therefore do not fall under the remit of the two week rule referral system. However, it is understood that these diagnoses can cause profound anxiety for patients and their families and referral for outpatient assessment and review by the relevant MDT should be made.
- It is most likely that a conservative approach to management with "watchful waiting" will be implemented in most cases.

## Patient Pathway for Brain and Other Rare CNS Tumours

### Generic referral pathway for patients with suspected brain tumour



## High-grade malignant primary brain tumour

- Routes of referral and relevant contact details are shown below:

CCG Referral Pathways		Trust	Designated MDT	Named MDT Lead/ Contact/Tel/Fax
Area	Pop*			
Newcastle/ Gateshead	503		Brain and CNS tumours Royal Victoria Infirmary	Mr D Holliman Tel: 0191 2826206
Northumberland	320			
North Tyneside	206			
South Tyneside	150			
Sunderland	277		Spinal Royal Victoria Infirmary	Mr J Nissan Tel: 0191 2823019
North Durham	252			
North Cumbria	319		Skull base Royal Victoria Infirmary	Mr John Crossman Tel: 0191 2825677
			Pituitary Royal Victoria Infirmary	Dr Yaasir Mamoojee Tel: 0191 2820114
South Tees	277	South Tees Hospitals NHS FT	Brain and CNS tumours James Cook University Hospital (JCUH)	Mr A Varma Tel: 01642 835706
Hartlepool & Stockton	290			
Durham Dales, Easington & Sedgefield	275			
Darlington	107		Spinal (JCUH)	Mr S Tizzard Tel: 01642 854435
Hambleton, Richmondshire & Whitby	153		Skull base (JCUH)	Mr M Prasad Tel: 01642 835717
			Pituitary (JCUH)	Mr A Varma Tel: 01642 835706

Source - Mid-2018 Population Estimates for Clinical Commissioning Groups (CCGs) in England - ONS.gov.uk

- All patients with a radiological diagnosis of a high grade malignant primary brain tumour (Glioblastoma, anaplastic astrocytoma, Oligodendroglioma, ependymoma, lymphoma) will be reviewed by the neurosciences MDT and consideration of treatment options given.
- The MDT will advise as to whether further imaging is required:

- additional MRI sequences may be indicated if there is concern regarding a diagnosis of abscess.
  - functional MRI sequences that the indicated for tumours in close approximation to eloquent areas of brain.
  - MR Spectroscopy to assist diagnosis
  - MR angiography or venography in relevant cases
  - nuclear medicine scans (e.g. thallium SPECT) may be required in some cases in order to support a radiological diagnosis of high-grade tumour.
  - the MDT will agree to review the case again when the relevant additional imaging is available.
- The radiological appearances of High Grade Tumour and cerebral abscess can be very similar: If MDT review raises a high index of suspicion of cerebral abscess the referring team will be alerted to this by telephone immediately following the MDT meeting. Contact will be made by the MDT lead or a designated deputy (recorded in the MDT minutes) and advice on urgent neurosurgical referral given.
    - The MDT will advise on medical management of the tumour and tumour related conditions:
      - the use of high-dose steroids in relation to the control of peritumoural oedema.
      - the management of tumour related epilepsy and the requirement for review by a neurologist.
  - Tissue diagnosis is of fundamental importance in determining specific treatment plan and prognosis and obtaining tissue diagnosis should be considered in all patients. If obtaining tissue diagnosis is not felt to be appropriate the reasons for this should be documented in the outcomes of the MDT discussion.
  - Options for surgical intervention should be considered including:
    - Image guided biopsy (frameless or frame based). “Free hand” biopsy should be avoided because of the associated increased risk of complication and risk of non-diagnostic procedure.
    - Feasibility of craniotomy and debulking of the tumour should be considered in all suspected highgrade glioma patients due to the reported improvement in outcome in patients who have undergone maximal surgical resection. Patients deemed suitable for radical surgical resection should also be considered for their suitability for the use of implantable carmustine wafers (Gliadel) at the time of operation.

- Where available the use of intra-operative ultrasound should be considered.
  - Where available, the use of fluorescein (ALA) guided tumours section should be considered if the imaging suggests that the tumour is well circumscribed and is suitable for macroscopic resection.
- As a consequence of the advanced nature of their tumour, extensive neurological signs and poor functional status, some patients may be unsuitable for neurosurgical intervention.
  - The MDT will recommend arrangements to be made to review the patient in an outpatient setting if appropriate, and advise on the outcome of the MDT discussion. If the patient is unfit to travel to the outpatient clinic due to the effects of their tumour and the effects of travel would cause undue distress, the MDT would provide comprehensive descriptions of the discussions that have taken place to fully brief the referring doctor and permit informed local discussion with the patient.
  - All patients will be allocated a key worker (clinical nurse specialist) at the time of their initial discussion at the MDT and documented in the MDT outcomes.
  - The MDT will advise on the need for pre-treatment assessment by Allied Health Professionals (AHP) including physiotherapist, occupational therapist, speech and language therapist and neuropsychologist.
  - All patients undergoing biopsy or craniotomy will have their case reviewed by the MDT at the next available meeting after the histology results are available. Histology will be reviewed and recommendations regarding further treatment given. Consideration will be made with regards to;
    - Radiotherapy (radical / palliative).
    - Concomitant / adjuvant chemotherapy.
    - Medical management with best supportive care.
  - Further management will be transferred to the Network MDT who will arrange outpatient assessment in a multi-disciplinary setting to discuss plans for further management in the multidisciplinary team and to consider how best to support patient and their carers. The Network MDT will oversee the oncological management, subsequent follow up and surveillance with interval scanning.
  - All patients reviewed by the MDT will be considered for inclusion in clinical trials, which are relevant to their diagnosis at that stage. The outcome of eligibility screening will be documented in MDT records. A reminder front sheet with current available trials will accompany each MDT patient list.

- At the time of first recurrence of tumour, a patient will be re-discussed at the neuroscience MDT for consideration of further surgical intervention if appropriate. If further surgery is not indicated, this will be communicated to the network MDT who will continue to oversee further management.
- The network MDT will consider the use of adjuvant chemotherapy or retreat radiotherapy for recurrent disease including:
  - Temozolamide.
  - PCV (procarbazine, lomustine, vincristine).
- The key worker will continue to monitor a patient's progress throughout the course of their treatment and follow-up. The key worker will liaise with specialist neuro-oncology allied health professionals (AHP)'s to provide support and care for patients as needed. The specialist neuro-oncology AHPs will liaise directly with the rehabilitation team according to patient's needs.
- Following completion of conventional treatments for recurrent tumour, each patient will be considered for inclusion in clinical trial if available. If no trials are available, or the patient is not wishing to pursue this or the patient has a poor functional status preventing trial entry, then referral to the palliative care team for ongoing care should be initiated.

## Low-grade primary brain tumour

- Routes of referral and relevant contact details are shown below:

CCG Referral Pathways		Trust	Designated MDT	Named MDT Lead/ Contact/Tel/Fax
Area	Pop*			
Newcastle Northumberland North Tyneside Gateshead South Tyneside Sunderland North Durham Cumbria	289 315 202 205 149 277 246 328	Newcastle Upon Tyne Hospitals NHS FT	Brain and CNS tumours Royal Victoria Infirmary  Spinal Royal Victoria Infirmary  Skull base Royal Victoria Infirmary  Pituitary Royal Victoria Infirmary	Mr D Holliman Tel: 0191 2826206  Mr J Nissan Tel: 0191 2823019  Mr John Crossman Tel: 0191 2825677  Dr Yaasir Mamoojee Tel: 0191 2820114
South Tees Hartlepool & Stockton Durham Dales, Easington & Sedgfield Darlington Hambleton, Richmondshire & Whitby	275 287 274 105 152	South Tees Hospitals NHS FT	Brain and CNS tumours James Cook University Hospital (JCUH)  Spinal (JCUH)  Skull base (JCUH)  Pituitary (JCUH)	Mr A Varma Tel: 01642 835706  Mr S Tizzard Tel: 01642 854435  Mr M Prasad Tel: 01642 835717  Mr A Varma Tel: 01642 835706

- All patients with a radiological diagnosis of low-grade primary brain tumour (astrocytoma, oligodendroglioma) will be reviewed by the neuroscience MDT and consideration of treatment options given.
- The MDT will advise as to whether further imaging is required:
  - Additional MRI sequences to define position and configuration of the tumour.
  - Functional MRI sequences to define the relationship of the tumour to eloquent speech and language areas of the brain.

- MR Spectroscopy to assist diagnosis
- Nuclear medicine scans (e.g. thallium SPECT) support the diagnosis of low-grade tumour.
- The MDT will agree a date to review the case again when the results of additional imaging are available.
- The MDT will advise on the medical management of the tumour and tumour related conditions:
  - The management of tumour related epilepsy and the requirement for specialist neurology input.
- The MDT will advise on the need for further clinical assessments including:
  - Speech and language assessment.
  - Occupational therapy assessment.
  - Physiotherapy assessment.
  - Cognitive assessment by neuropsychologist.
- The MDT will consider the need to obtain a tissue diagnosis to assist in planning future management. If obtaining a tissue diagnosis is not felt to be appropriate the reasons for this will be documented in the outcomes of the MDT discussion.
- Options for surgical intervention should be considered including:
  - Image guided biopsy (frameless or frame based). "Free hand" biopsy should be avoided because of the associated increased risk of complication and risk of non diagnostic procedure.
  - Craniotomy and debulking of the tumour should be considered in all patients due to the reported improvement in outcome in patients who have undergone maximal surgical resection. Patients with tumours adjacent to eloquent speech and motor areas of the brain should be considered for "awake craniotomy" or cortical / subcortical stimulation guided resection.
  - Some patients, as a consequence of the configuration of the tumour on MRI scan and the known diffusely infiltrative nature of low-grade tumours may be unsuitable for neurosurgical intervention.
- The MDT will make arrangements to review the patient in an outpatient setting and advise on the outcome of the MDT discussion and options for management including observation as opposed to intervention.
- All patients will be allocated a key worker (clinical nurse specialist) at the time of their initial discussion at the MDT and documented in the MDT outcomes.

- All patients undergoing biopsy or craniotomy will have their case reviewed by the MDT at the next available meeting after the histology results are available. Histology will be reviewed and recommendations regarding further treatment given. Consideration will be made with regards to;
  - If the histology suggests an unsuspected high-grade primary tumour, the patient will be considered for appropriate treatment as described above.
  - If the histology confirms the diagnosis of low-grade tumour, the MDT will make arrangements for the patient's case to be discussed by the Network MDT in relation to the need for any adjuvant treatment.
  - Close liaison is required between the Neuroscience and Network MDTs regarding the best course of management for a patient. In many cases the patient will enter into a period of "watchful waiting" with serial MRI scanning as an outpatient. In some cases there may be a need for radiotherapy (eg if the patient has progressive neurology or significant tumour mass) as part of first line treatment. Alternatively patients may elect to proceed with "upfront" radiotherapy having discussed in length the options for first line approach to treatment.
- All patients reviewed by the MDT will be considered for inclusion in clinical trials, which are relevant to their diagnosis at that stage. The outcome will be documented in MDT records.
- At the time of first recurrence of tumour, a patient will be re-discussed at the neuroscience MDT for consideration of further surgical intervention if appropriate. If further surgery is not indicated, this will be communicated to the network MDT and advice taken regarding the role of adjuvant therapy.
- The network MDT will consider the use of adjuvant radiotherapy.
- The key worker will continue to monitor a patient's progress throughout the course of their treatment and follow-up. The key worker will liaise with specialist neuro-oncology AHPs to provide support and care for patients as needed. The specialist neuro-oncology AHPs will liaise directly with the rehabilitation team according to patient's needs.

## Meningioma

- Routes of referral and relevant contact details are shown below:

CCG Referral Pathways		Trust	Designated MDT	Named MDT Lead/ Contact/Tel/Fax
Area	Pop*			
Newcastle	289	Newcastle Upon Tyne Hospitals NHS FT	Brain and CNS tumours Royal Victoria Infirmary	Mr D Holliman Tel: 0191 2826206
Northumberland	315			
North Tyneside	202			
Gateshead	205			
South Tyneside	149			
Sunderland	277			
North Durham	246			
Cumbria	328			
South Tees	275	South Tees Hospitals NHS FT	Brain and CNS tumours James Cook University Hospital (JCUH)	Mr A Varma Tel: 01642 835706
Hartlepool & Stockton	287			
Durham Dales, Easington & Sedgefield	274			
Darlington	105			
Hambleton, Richmondshire & Whitby	152			
			Spinal (JCUH)	Mr S Tizzard Tel: 01642 854435
			Skull base (JCUH)	Mr M Prasad Tel: 01642 835717
			Pituitary (JCUH)	Mr A Varma Tel: 01642 835706

Source - Mid-2014 Population Estimates for Clinical Commissioning Groups (CCGs) in England - ONS.gov.uk

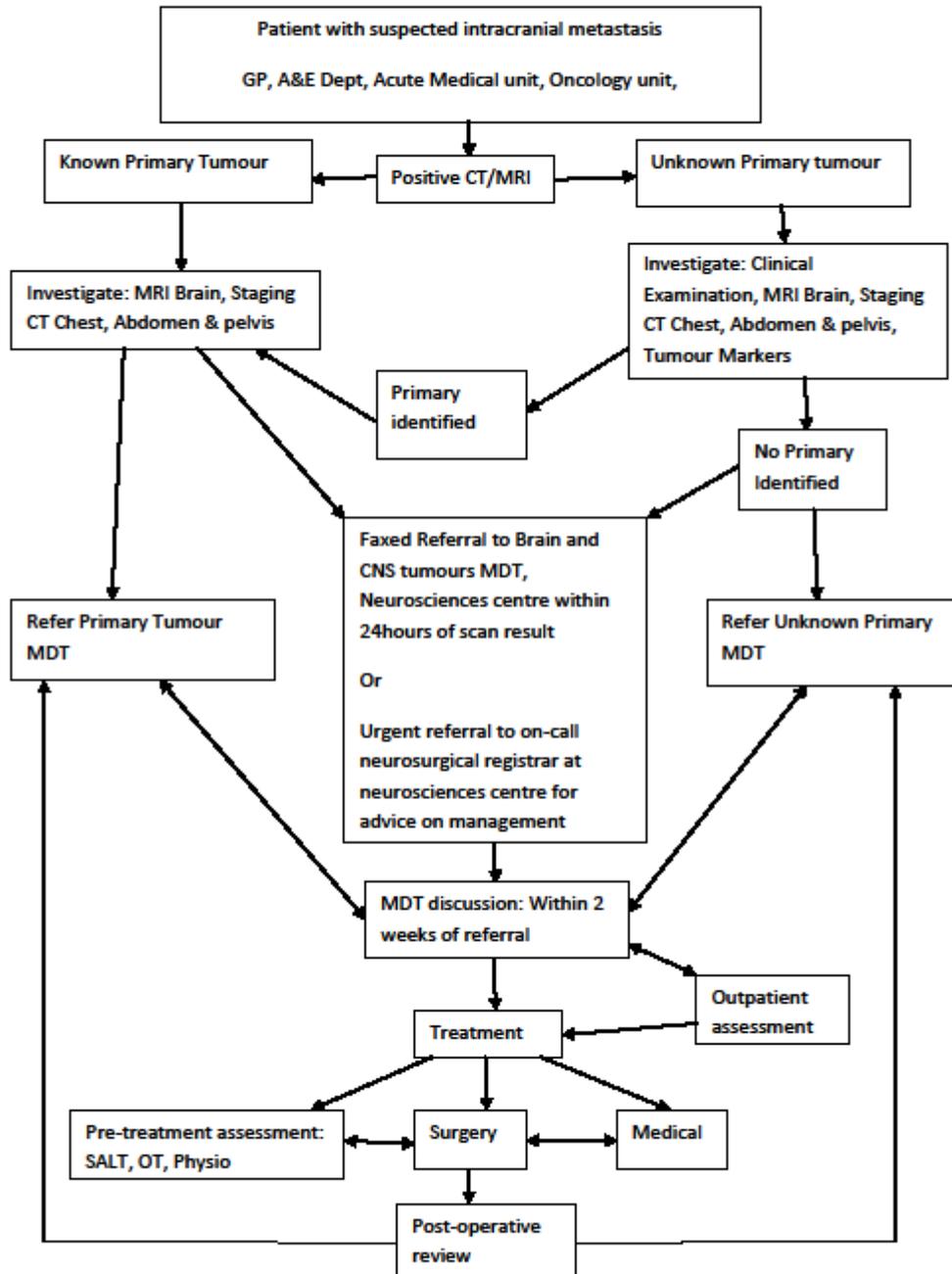
- All patients with a radiological diagnosis of meningioma will be reviewed by the neurosciences MDT and consideration of treatment options given.
- The MDT will advise as to whether further imaging is required:
  - Additional MRI sequences including MR angiography and venography may be indicated if the tumour is in close approximation to the venous sinuses and to assess relationship to major arteries and its vascularity.

- Functional MRI sequences that the indicated for tumours in close approximation to eloquent areas of brain.
  - If the MRI scan suggests the tumour is highly vascular then consideration of the need for formal angiography to assess the vascular supply and suitability for embolisation merely needed.
  - The MDT will agree to review the case again when the relevant additional imaging is available.
- the MDT will advise on medical management of the tumour and tumour related conditions:
    - The use of high-dose steroids in relation to the control of peritumoural oedema.
    - The management of tumour related epilepsy and the requirement for specialist neurology input.
- The MDT will advise on the need for further clinical assessments including:
    - Speech and language assessment.
    - Occupational therapy assessment.
    - Physiotherapy assessment.
    - Cognitive assessment by neuropsychologist.
- Surgical excision is the mainstay of meningioma treatment and should be considered in all cases of symptomatic meningioma. Special consideration be given to:
    - The need for preoperative embolisation of highly vascular tumours.
    - Meningiomas involving the CP angle, clivus and foramen Magnum region should be referred to the skull base MDT for management by a specialist skull base neurosurgeon.
    - Small meningiomas involving the skull base and paracavernous regions may be considered unsuitable for surgical treatment because of an unacceptable risk/benefit ratio. In this situation, consideration of referral for stereotactic radiosurgery / gamma knife surgery should be made.
- It is accepted that the prevalence of meningioma is higher than previously anticipated. An increasing number of incidental meningiomas are referred to the MDT. The MDT will carefully consider the presenting history in relation to the position of the meningioma and in many cases may recommend a conservative approach to treatment with a "watchful waiting" approach using serial monitoring with MRI.

- The MDT will recommend arrangements to review the patient in an outpatient setting and advise on the outcome of the MDT discussion.
- All patients will be allocated a key worker (clinical nurse specialist) at the time of their initial discussion at the MDT and documented in the MDT outcomes.
- All patients undergoing excision of their meningioma will have their case reviewed by the MDT at the next available meeting after the histology results are available. Histology will be reviewed and recommendations regarding further treatment given. Consideration will be made with regards to:
  - Grade 1 tumours: no adjuvant treatment will be required. Patient will remain under regular follow-up in the outpatient clinic of the operating surgeon with serial scanning. If there is residual disease in eloquent location, adjuvant radiotherapy should be considered.
  - Grade 2 tumours: patients will be referred to the network MDT for consideration of the option of adjuvant radiotherapy treatment. In fully resected grade 2 meningioma, trials are open to look at role of adjuvant radiotherapy – if residual disease that is non resectable a consultation to consider radiotherapy will be recommended
  - Grade 3 tumours: patients will be referred to the network MDT as recurrence rates are very high and adjuvant radiotherapy is very likely to be recommended in all cases and Oncology referral will be advised.
- All patients reviewed by the MDT will be considered for inclusion in clinical trials, which are relevant to their diagnosis at that stage. The outcome will be documented in MDT records.
- At the time of first recurrence of tumour, a patient will be re-discussed at the neuroscience MDT for consideration of further surgical intervention if appropriate. If further surgery is not indicated this will be communicated to the network MDT who will continue to oversee further management.
- The network MDT will consider the use of adjuvant treatment including:
  - Radiotherapy.
  - Stereotactic radiosurgery / gamma knife surgery
  - Systemic therapy.
- The key worker will continue to monitor a patient's progress throughout the course of their treatment and follow-up. The key worker will liaise with specialist neuro-oncology AHPs to provide support and care for patients as needed. The specialist

neuro-oncology AHPs will liaise directly with the rehabilitation team according to patient's needs.

**Generic referral pathway for patients with suspected intracranial metastasis**



## Intracranial metastases

- Routes of referral and relevant contact details are shown below:

CCG Referral Pathways		Trust	Designated MDT	Named MDT Lead/ Contact/Tel/Fax
Area	Pop*			
Newcastle Northumberland North Tyneside Gateshead South Tyneside Sunderland North Durham Cumbria	289 315 202 205 149 277 246 328	Newcastle Upon Tyne Hospitals NHS FT	Brain and CNS tumours Royal Victoria Infirmary  Spinal Royal Victoria Infirmary  Skull base Royal Victoria Infirmary  Pituitary Royal Victoria Infirmary	Mr D Holliman Tel: 0191 2826206  Mr J Nissan Tel: 0191 2823019  Mr John Crossman Tel: 0191 2825677  Dr Yaasir Mamoojee Tel: 0191 2820114
South Tees Hartlepool & Stockton Durham Dales, Easington & Sedgfield Darlington Hambleton, Richmondshire & Whitby	275 287 274 105 152	South Tees Hospitals NHS FT	Brain and CNS tumours James Cook University Hospital (JCUH)  Spinal (JCUH)  Skull base (JCUH)  Pituitary (JCUH)	Mr A Varma Tel: 01642 835706  Mr S Tizzard Tel: 01642 854435  Mr M Prasad Tel: 01642 835717  Mr A Varma Tel: 01642 835706

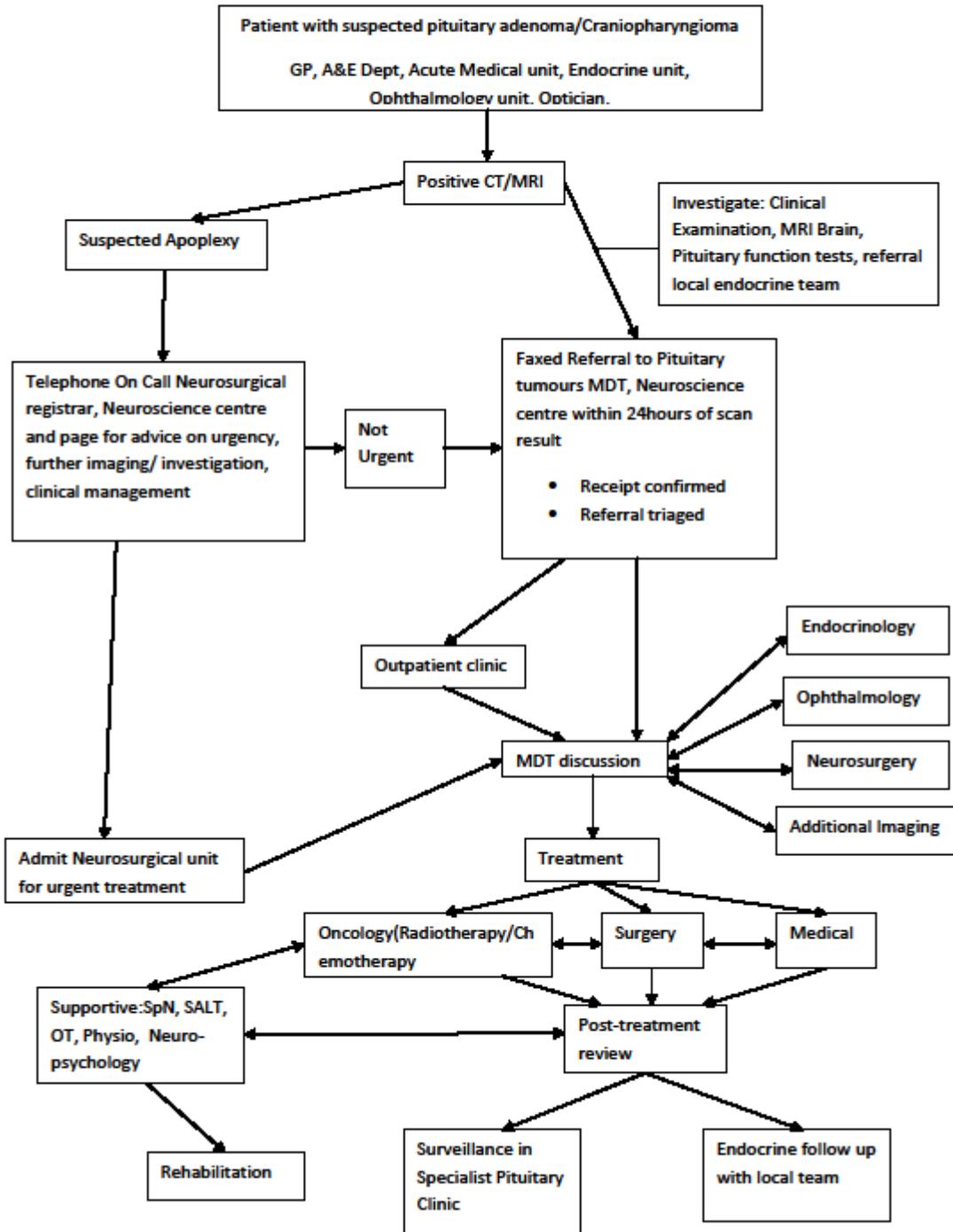
- Patients with a radiological diagnosis of intracranial metastasis will be reviewed by the neurosciences MDT and consideration of treatment options given. It is anticipated that referrals to the neuroscience MDT would be adequately screened for appropriateness by the primary tumour MDT overseeing the patients care. Patients with multiple intracranial metastases and widespread systemic cancer are unlikely to benefit from the involvement of the Neuroscience MDT.

- The frequency of intracranial metastasis is such that this patient group will constitute a significant proportion of the workload of the brain and other CNS tumours neuroscience MDT.
- The role of the neurosciences MDT will be to determine the suitability of the patient for neurosurgical or radiosurgical intervention and provide options for this.
- It is not the role of the neuroscience MDT to advise on the overall treatment of the primary tumour leading to the metastasis.
- In order to facilitate the decision-making process it will be essential that the patient has undergone comprehensive preliminary assessment by the referring team as described in the pathway diagram above. This screening is facilitated by the proforma for MDT referral in place.
- In patients who have known primary cancer, the initial imaging should be complemented with pre-/post contrast MRI scan and a staging CT scan of chest/abdomen/pelvis. At the time of referral to the neurosciences MDT, the patient should also be referred to the MDT dealing with the primary tumour and these referrals confirmed with both MDTs. Effective communication should exist between the neuroscience MDT and the primary tumour MDT to ensure that decisions made by the neuroscience MDT are in the context of expert advice regarding the extent of the primary tumour and the underlying prognosis.
- In patients who do not have a known primary cancer initial imaging should be complemented with pre-/post contrast MRI scan, staging CT scan of chest/abdomen/pelvis, tumour markers and a comprehensive clinical examination for primary tumour site. If these investigations lead to the diagnosis of primary tumour, the patient should be referred to the relevant MDT for appropriate assessment and advice on investigation and management. If no primary tumour is detected the patient should be referred to the acute oncology service or the MDT for "metastases of unknown primary" for advice on investigation and management. Referral to either of these MDTs should occur in parallel with referral to the neuroscience MDT. Effective communication should exist between the neuroscience MDT and the acute oncology service/MDT for metastases of unknown primary to ensure that decisions made by the neuroscience MDT on made in the context of expert advice regarding prognosis and the appropriateness of neurosurgical intervention. It is likely that in the absence of primary despite full investigation that surgery to obtain histology +/- remove the metastases will be considered.

- The radiological appearances of isolated cerebral metastasis and cerebral abscess can be very similar: If MDT review raises a high index of suspicion of cerebral abscess, the referring team will be alerted to this by telephone immediately following the MDT meeting. Contact will be made by the MDT lead or a designated deputy (recorded in the MDT minutes) and advice on urgent neurosurgical referral given.
- The MDT will advise on the need for surgical or radiosurgical treatment including:
  - Image guided/stereotactic biopsy.
  - Craniotomy and tumour resection.
  - SRS in patients with 1-3 lesions
  - No surgical intervention considered appropriate.
- For those patients will require neurosurgical intervention, the MDT will recommend arrangements be made with the receiving surgeon to review the patient in an outpatient setting and advise on treatment.
- For those patients where no neurosurgical intervention is considered appropriate, this information will be fed back to the primary tumour MDT/ referrer or the acute oncology/metastasis of unknown primary MDT and no neuroscience MDT follow-up will be arranged.
- In those patients where there is a recommendation for radiosurgery, referral to SRS MDT based at Freeman Hospital will be made by the primary team on recommendation from the brain and CNS MDT for review of imaging and planning for out-patient discussion for presentation of the appropriate treatment choices in accordance with NHS England policy and urgent timeframe
- All patients who require neurosurgical intervention will be allocated a key worker (clinical nurse specialist) at the time of their initial discussion at the MDT and documented in the MDT outcomes. The key worker will monitor the patient's progress during the course of their treatment under the care of the neurosciences MDT.
- All patients undergoing surgery for suspected for metastasis will have their case reviewed by the MDT at the next available meeting after the histology results are available. Histology will be reviewed and arrangements made to discuss these with the patient in an outpatient setting and assess post-operative recovery. Advice will be given to referring oncology team with respect to post operative imaging and indications for adjuvant SRS.
- For patients where the primary tumour is known, referral back to the primary tumour MDT will be made at this stage.

- For those patients where no primary tumour site is known or can be identified, referral back to the acute oncology MDT or the metastasis of unknown primary MDT should be made.
- Patient will be discharged from the care of the neuroscience MDT at this stage with no further follow-up arranged.

**Referral pathway for patients with suspected pituitary adenoma/craniopharyngioma**



## Pituitary adenoma (PitNET – Pituitary Neuroendocrine tumour)

- Routes of referral and relevant contact details are shown below:

CCG Referral Pathways		Trust	Designated MDT	Named MDT Lead/ Contact/Tel/Fax
Area	Pop*			
Newcastle West	144	Newcastle Upon Tyne Hospitals NHS FT	Royal Victoria Infirmary	Dr Yaasir Mamoojee Tel: 0191 2820114
Newcastle North & East	146			
Northumberland	316			
North Tyneside	203			
Gateshead	201			
South Tyneside	149			
Sunderland	277			
North Durham	244			
Cumbria	328			
South Tees	274	South Tees Hospitals NHS FT	James Cook University Hospital	Mr A Varma Tel: 01642 835706
Hartlepool & Stockton	287			
Durham Dales, Easington & Sedgefield	273			
Darlington	105			
Hambleton,	152			
Richmondshire & Whitby				

Source - Mid-2014 Population Estimates for Clinical Commissioning Groups (CCGs) in England - ONS.gov.uk

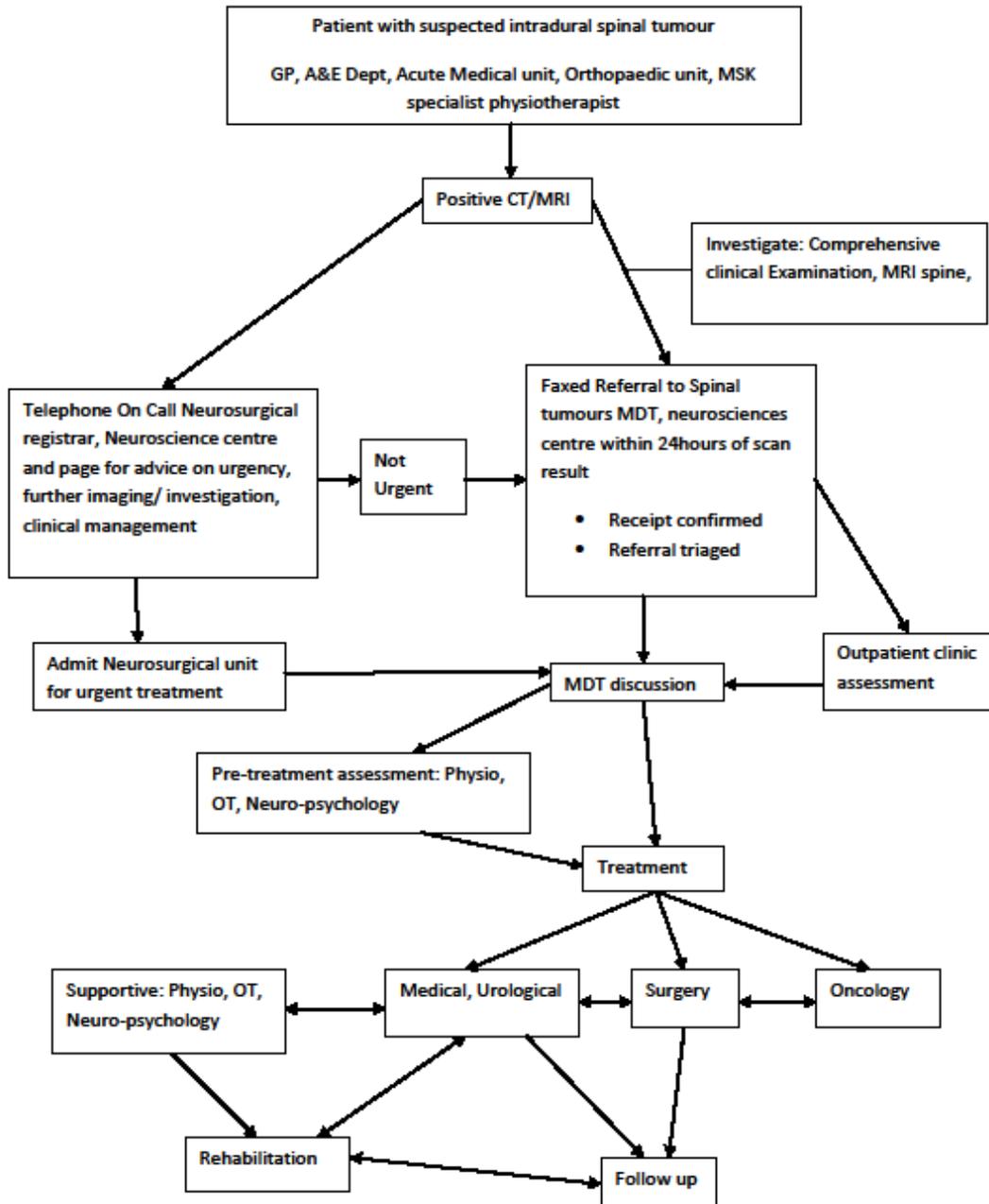
- All patients with a radiological diagnosis of pituitary tumour (including craniopharyngioma) will be reviewed by the neurosciences MDT (South Network) and pituitary MDT (North Network) and consideration of treatment options given. The MDT will review the results of any endocrine studies which accompany the referral.
- The MDT will advise as to whether further imaging is required:
  - Additional MRI sequences which permit more accurate anatomical localisation.
  - Additional CT imaging which permits more accurate radiological diagnosis (e.g. calcification within a craniopharyngioma) or for surgical planning purposes.
  - Additional CT imaging if there is suspicion that the pituitary lesion is a metastasis or if there is uncertain that the pituitary lesion may constitute part of the multiple endocrine neoplasia syndrome.
  - Additional MR imaging if there is suspicion that a pituitary adenoma has undergone apoplexy and may be undergoing spontaneous involution.
  - The MDT will agree to review the case again when the relevant additional imaging is available.

- the MDT will advise on the endocrine management and the need for further investigation of the tumour:
  - Additional investigation including the need for dynamic studies of pituitary function (including the need to consider invasive investigation with inferior petrosal sinus sampling).
  - The need for pituitary hormone replacement.
  - The requirement for medical treatment (blockade) of pituitary tumours which present as hormonal excess (Cushing's, acromegaly, TSHoma, prolactinoma).
- the MDT will advise on the need for further clinical assessments including:
  - Ophthalmic assessment in patients with evidence of optic nerve/optic chiasm compression on initial imaging. Assessment to include visual acuity and visual field assessment with perimetry.
  - SALT assessment.
  - Occupational therapy assessment.
  - Physiotherapy assessment.
  - Cognitive assessment by neuropsychologist.
- the MDT will advise on the need for surgical and radiotherapy treatment including:
  - Trans-sphenoidal surgery.
  - Trans-cranial surgery
  - External beam radiotherapy
  - Stereotactic radiosurgery / gamma knife surgery
- It is accepted that the prevalence of pituitary adenoma is higher than previously anticipated. An increasing number of incidental pituitary adenomas are referred to the MDT. The MDT will carefully consider the presenting history in relation to the configuration of the pituitary adenoma and in many cases may recommend a conservative approach to treatment with a "watchful waiting" approach using serial monitoring with MRI.
- The MDT will make recommendation to review the patient in an outpatient setting and advise on the outcome of the MDT discussion.
- All patients will be allocated a key worker (clinical nurse specialist) at the time of their initial discussion at the MDT and documented in the MDT outcomes.
- All patients undergoing surgery for suspected pituitary adenoma or craniopharyngioma will have their case reviewed by the MDT at the next available meeting after the histology results are available. Histology will be reviewed and

recommendations regarding further treatment given. Consideration will be made with regards to:

- The need for repeat assessment of pituitary function (including dynamic studies).
  - The need for ongoing pituitary hormone replacement.
  - The need for continued pituitary hormone blockade (acromegaly, Cushing's, Prolactinoma).
  - The need for adjuvant radiotherapy.
- Further management will be transferred to the relevant Network MDT who may recommend outpatient assessment in a multi-disciplinary clinic setting to discuss plans for further management with the patient and their carers. The Network MDT (South Tees) and the pituitary joint clinic (North and West Network) will oversee the oncological management, subsequent follow up and surveillance with interval scanning according to local protocol.
  - It would be anticipated that the patients long-term endocrine management would be transferred to the endocrine team at their local hospital as this would clearly be more convenient for the patient in view of the geography of the North of England Cancer network and the site of the specialist MDTs. The local endocrine team must ensure that relevant information is fed back to the multidisciplinary pituitary team.
  - All patients reviewed by the MDT will be considered for inclusion in clinical trials, which are relevant to their diagnosis at that stage. The outcome will be documented in MDT records.
  - The key worker will continue to monitor a patient's progress throughout the course of their treatment and follow-up. The key worker will liaise with specialist neuro-oncology AHPs to provide support and care for patients as needed. The specialist neuro-oncology AHPs will liaise directly with the rehabilitation team according to patient's needs.
  - At the time of first recurrence of tumour a patient will be re-discussed at the Pituitary MDT for consideration of further surgical intervention if appropriate. If further surgery is not indicated this will be communicated to the network MDT (South Tees) and to the pituitary joint clinic (North Network) who will continue to oversee further management.

**Referral pathway for patients with suspected intradural spinal tumour**



## Intradural spinal tumour

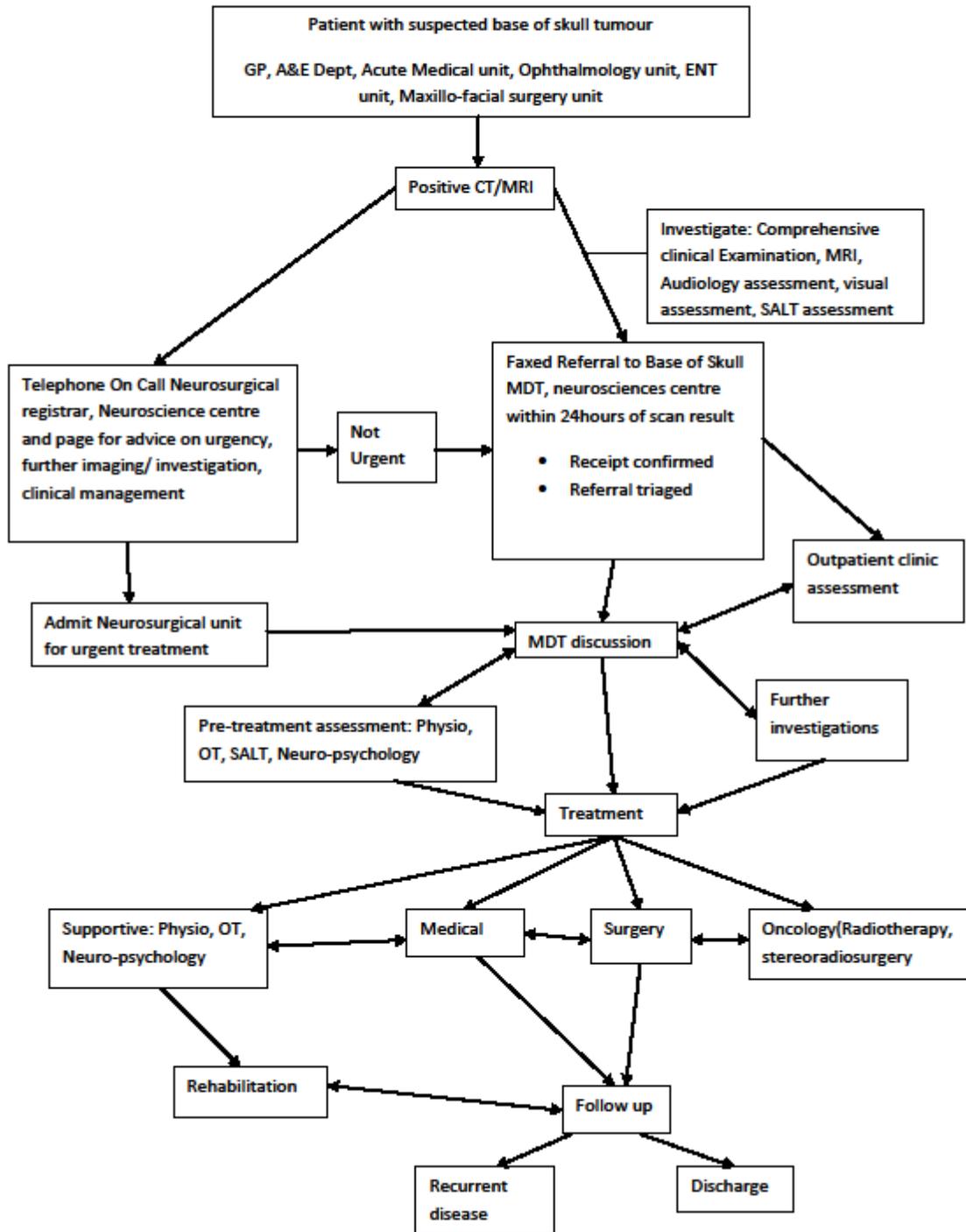
- Routes of referral and relevant contact details are shown below:

CCG Referral Pathways		Trust	Designated MDT	Named MDT Lead/ Contact/Tel/Fax
Area	Pop*			
Newcastle West	144	Newcastle Upon Tyne Hospitals NHS FT	Royal Victoria Infirmary	Mr J Nissen Tel:0191 2823019
Newcastle North & East	146			
Northumberland	316			
North Tyneside	203			
Gateshead	201			
South Tyneside	149			
Sunderland	277			
North Durham	244			
Cumbria	328			
South Tees	274	South Tees Hospitals NHS FT	James Cook University Hospital	Mr S Tizzard Tel: 01642854435
Hartlepool & Stockton	287			
Durham Dales, Easington & Sedgefield	273			
Darlington	105			
Hambleton,	152			
Richmondshire & Whitby				

- Source - Mid-2014 Population Estimates for Clinical Commissioning Groups (CCGs) in England - ONS.gov.uk
- All patients with a radiological diagnosis of intradural spinal tumour (astrocytoma, ependymoma, meningioma, schwannoma) will be reviewed by the neurosciences MDT and consideration of treatment options given.
- The MDT will advise as to whether further imaging is required:
  - Additional MRI sequences which permit more accurate anatomical localisation of the tumour.
  - Additional MRI sequences which permit more accurate assessment of the extent of any tumour related syrinx.
  - Additional CT imaging to assess the bony anatomy and assist with surgical planning purposes.
  - The MDT will agree to review the case again when the relevant additional imaging is available.
- The MDT will advise on the need for further clinical assessments including:
  - Urological assessment for any reported/documented sphincter disturbance. Subsequent advice from continence advisor may be required.
  - Assessment by spinal rehabilitation service.
  - Occupational therapy assessment.
  - Physiotherapy assessment.
- the MDT will advise on the need for surgical or radiotherapy treatment including:

- Biopsy to obtain tissue diagnosis.
  - Tumour resection.
  - The appropriateness of radiotherapy at times this will be on the basis of a radiological diagnosis in others post biopsy
  - The potential need for spinal stabilisation.
- The MDT will recommend arrangements to review the patient in an outpatient setting and advise on the outcome of the MDT discussion.
  - All patients will be allocated a key worker (clinical nurse specialist) at the time of their initial discussion at the MDT and documented in the MDT outcomes.
  - All patients undergoing surgery for suspected intradural spinal tumour will have their case reviewed by the MDT at the next available meeting after the histology results are available. Histology will be reviewed and recommendations regarding further treatment given. Consideration will be made with regards to:
    - The need for adjuvant treatment (radiotherapy and/or chemotherapy).
    - The need for serial monitoring.
  - For those patients requiring adjuvant treatment further management will be transferred to the Network MDT who will recommend outpatient assessment in a multi-disciplinary clinic setting to discuss plans for further management with the patient and their carers. The Network MDT will oversee the oncological management, subsequent follow up and surveillance with interval scanning according to local protocol.
  - The key worker will continue to monitor a patient's progress throughout the course of their treatment and follow-up. The key worker will liaise with specialist neuro-oncology AHPs to provide support and care for patients as needed. The specialist neuro-oncology AHPs will liaise directly with the rehabilitation team according to patient's needs.
    - All patients reviewed by the MDT will be considered for inclusion in clinical trials, which are relevant to their diagnosis at that stage. The outcome will be documented in MDT records.
    - At the time of first recurrence of tumour, a patient will be re-discussed at the neuroscience MDT for consideration of further surgical intervention if appropriate. If further surgery is not indicated this will be communicated to the network MDT who will continue to oversee further management.

**Base of skull tumour pathway**



## Base of skull tumour

- Routes of referral and relevant contact details are shown below:

CCG Referral Pathways		Trust	Designated MDT	Named MDT Lead/ Contact/Tel/Fax
Area	Pop*			
Newcastle West	144	Newcastle Upon Tyne Hospitals NHS FT	Royal Victoria Infirmary	Mr John Crossman Tel: 0191 2825677
Newcastle North & East	146			
Northumberland	316			
North Tyneside	203			
Gateshead	201			
South Tyneside	149			
Sunderland	277			
North Durham	244			
Cumbria	328			
South Tees	274	South Tees Hospitals NHS FT	James Cook University Hospital	Mr M Prasad Tel: 01642 835717
Hartlepool & Stockton	287			
Durham Dales, Easington & Sedgefield	273			
Darlington	105			
Hambleton,	152			
Richmondshire & Whitby				

- Source - Mid-2014 Population Estimates for Clinical Commissioning Groups (CCGs) in England - ONS.gov.uk
  - All patients with a radiological diagnosis of base of skull tumour (acoustic neuroma, cerebello-pontine angle meningioma, foramen magnum meningioma, orbital apex meningioma, glomus tumour chordoma, 'sarcoma') will be reviewed by the skull baseMDT and consideration of treatment options given.
  - The MDT will advise as to whether further imaging is required:
    - Additional CT/MRI sequences which permit more accurate anatomical localisation or which assist in treatment planning.
    - MR angiography/conventional angiography if the tumour involves vascular structures or if there is clinical suspicion that the tumour may be amenable to embolisation.
  - the MDT will advise on the need for further clinical assessments including:
    - Ophthalmic assessment in patients with orbital apex tumours.
    - ENT/audiology assessment in patients with CP angle tumours.
    - SALT assessment.
    - Occupational therapy assessment.
    - Physiotherapy assessment.
    - Cognitive assessment by neuropsychologist.
  - the MDT will advise on the need for surgical treatment including:
    - Tumour biopsy.
    - Tumour resection.

- Referral for radiosurgery consideration – pathway can be the SRS MDT based at the Freeman Hospital (acoustic neuroma) / gamma knife in Sheffield depending on patient choice
- Referral for external beam fractionated radiotherapy
- The MDT will recommend arrangements to review the patient in an outpatient setting and advise on the outcome of the MDT discussion.
- All patients will be allocated a key worker (clinical nurse specialist) at the time of their initial discussion at the MDT and documented in the MDT outcomes.
- All patients undergoing surgery for base of skull tumour will have their case reviewed by the MDT at the next available meeting after the histology results are available. Histology will be reviewed and recommendations regarding further treatment given. Consideration will be made with regards to:
  - The need for adjuvant oncology treatment.
  - The need for SALT involvement in relation to ongoing bulbar dysfunction.
  - The involvement of ophthalmic surgeon in relation to eye closure difficulties.
  - The involvement of plastic surgeon for management of facial palsy.
- For patients requiring oncology treatment, management will be transferred to the Network MDT or SRS MDT as appropriate, who will recommend outpatient assessment in a multi-disciplinary clinic setting to discuss plans for further management with the patient and their carers.
- Patients who do not require oncology treatment will undergo long-term follow-up in the specialist base of skull clinic.
- All patients reviewed by the MDT will be considered for inclusion in clinical trials, which are relevant to their diagnosis at that stage. The outcome will be documented in MDT records.
- The key worker will continue to monitor a patient's progress throughout the course of their treatment and follow-up. The key worker will liaise with specialist neuro-oncology AHPs to provide support and care for patients as needed. The specialist neuro-oncology AHPs will liaise directly with the rehabilitation team according to patient's needs.
- At the time of first recurrence of tumour, a patient will be re-discussed at the neuroscience MDT for consideration of further surgical intervention if appropriate. If further surgery is not indicated this will be communicated to the network MDT who will continue to oversee further management.

## **Emergency surgical management of brain and other CNS tumours**

- The IOG for brain and other CNS tumours recognises that patients affected by these conditions may present to the on call neurosurgical team with effects of their tumour which require emergency neuro surgical intervention. In many instances this surgery is life-saving. Commonly it will prevent neurological deterioration and subsequent morbidity.
- Conditions that may be encountered include:
  - Haemorrhage into a tumour.
  - Hydrocephalus secondary to obstruction of flow of CSF by tumour.
  - Pituitary apoplexy.
  - Spinal-cord compression by tumour.
- Where such emergency surgery is indicated it should be carried out without delay, ideally by the relevant designated tumour surgeon. However the designated surgeon may not be available and if the on-call neurosurgeon feels competent to undertake the procedure it should be performed.
- Where possible the need for emergency surgery should be discussed with the designated surgeon.
- Following surgery the patient should be referred to the relevant MDT and the case discussed within one week.
- Other than the specific indications for emergency surgical intervention tumour surgery should not be performed "out of hours" by non-specialist clinicians in accordance with guidance described in the IOG and also the recommendations of NCEPOD regarding good clinical practice for "out of hours" surgery.

## **Rehabilitation-Allied health professionals**

- The IOG for brain and other CNS tumours recognises the profound effects that such tumours can have on patient's lives and those of their families or carers. The diagnosis of a brain or other CNS tumour can lead to significant changes in the patient's lifestyle function and cognition. The configuration of the MDTs acknowledges this with the inclusion of specialist allied health professional support included in each MDT.
- The specialist AHP's attached to each MDT provide essential input to affected patients during the diagnostic, treatment and long-term management elements of the treatment pathway.

- The specialist AHP's provide a direct link with the NCA neuro rehabilitation pathway and a network of linkages to community support services.
- The rehabilitation guidelines for the NCA can be found in Appendix 4.
- It is not possible in this guidance to provide a comprehensive description of the role of each AHP but general themes relating to their involvement in patient care are as follows:
  - Speech and language therapist (SALT)
    - ~ Assessment and management of slurred speech (dysarthria).
    - ~ Assessment and management of dysphasia.
    - ~ Assessment and management of swallowing difficulties.
    - ~ Assessment and management of patients who are "nil by mouth" but who want to eat and drink for pleasure/comfort.
  - Physiotherapist
    - ~ Assessment and management of motor deficits (ie limb weakness, proprioception, inattention).
    - ~ Assessment and management of reduced mobility/balance problems.
    - ~ Assessment and management of pre-existing chest problems.
    - ~ Assessment and management of spinal pain/referred pain.
    - ~ Assessment and management of spasticity.
    - ~ Highlight problems and refer to appropriate facility for ongoing rehabilitation.
    - ~ Start rehabilitation process prior to transfer to the rehabilitation facility.
    - ~ Take part in discharge planning meetings
    - ~ Provide family support and education (ie safe moving and handling).
    - ~ Refer to community rehabilitation teams during discharge process.
  - Occupational therapist
    - ~ Assessment and management of reduced functional status caused by motor / perceptual deficits.
    - ~ Assessment and management of cognitive deficits ie memory deficit, confusion, disorientation Assessment and management of fatigue.

- ~ Start rehabilitation process prior to transfer to rehabilitation facility
- ~ Take part in discharge planning meetings
- ~ Provide family support and education (ie home visit / safe use of equipment).
- ~ Refer to community rehabilitation teams during discharge process.
- ~
- Dietetics
  - ~ Assessment and management of significant weight gain arising as a side-effect of treatment with steroids (weight loss arising from a primary brain or other CNS tumour is very rare).
  - ~ Assessment and management of anorexia or altered sense of taste following adjuvant oncology treatment.
- Neuropsychology
  - ~ Assessment and management of changes in cognitive processing, personality and / or behaviour arising from brain tumours with the aim of ensuring the patient has mental capacity to support informed decision making, promote independent functioning, and participation in valued activities at any stage of the patients journey.
  - ~ Adjustment and management of psychological distress arising from diagnosis and / or adjustment to reduced functional status of a CNS tumour.
- the AHP's will liaise with specialist rehabilitation services, the patient's general practitioner, community support services, social services, palliative care services (including hospice) and the specialist nurses in neuro oncology to ensure coordinated patient care.

## Rehabilitation-neuro rehabilitation units

- Routes of referral and relevant contact details are shown below:

CCG Referral Pathways		Trust	Designated MDT	Named MDT Lead/ Contact/Tel/Fax
Area	Pop*			
Newcastle West	144	Newcastle Upon Tyne Hospitals NHS FT	Royal Victoria Infirmary	Dr L Graham Tel: 0191 2875121
Newcastle North & East	146			
Northumberland	316			
North Tyneside	203			
Gateshead	201			
South Tyneside	149			
Sunderland	277			
North Durham Cumbria	244 328			
South Tees	274	South Tees Hospitals NHS FT	James Cook University Hospital	Dr S Hameed Dr Stephan Tel: 01642 282816
Hartlepool & Stockton	287			
Durham Dales, Easington & Sedgfield	273			
Darlington	105			
Hambleton, Richmondshire & Whitby	152			

- Source - Mid-2014 Population Estimates for Clinical Commissioning Groups (CCGs) in England - ONS.gov.uk
- Within the NCA a range of facilities are available for patients who have rehabilitation needs arising directly from the effects of their tumour or its treatment. The IOG recognises that patients may have rehabilitation needs which will improve their quality-of-life and that the availability of rehabilitation services should not be contingent upon their prognosis; the IOG indicates that patients will not be excluded from the scope of practice of rehabilitation facilities on the grounds alone of the diagnosis of tumour.
- Rehabilitation facilities are available within the NCA as follows:
  - Walkergate Park Hospital, Newcastle upon Tyne: region-wide tertiary complex specialised rehabilitation to patients with all neurological disease including brain and CNS tumours. The unit also provides a service for specialist "out of area" referrals. (Level 1 Cover)
  - City Hospitals, Sunderland: level 2 cover.
  - Cumberland Infirmary, Carlisle: level 2 cover.
  - The James Cook University Hospital, Middlesbrough: level 2 cover.
  - Golden Jubilee Spinal Injuries Centre, The James Cook University Hospital, Middlesbrough: regional referral centre for spinal cord injury and the rehabilitation of affected patients. (Level 1 Cover)
  - Friarage, Rutson Ward: level 2
  - Bishop Auckland: level 2

- As described previously the AHP's associated with the MDTs are pivotal in both assessment for, and liaison with, the neuro-rehabilitation facilities. The AHPs can liaise directly with the neuro rehabilitation facilities to advise whether in-patient or community is required.
- It is the role of the AHP's to ensure that patients affected by primary brain tumour or other CNS tumours have equitable access to rehabilitation facilities.
- It is accepted that local variation in clinical practice will affect the process for accessing neuro rehabilitation facilities for inpatients:
  - At the Royal Victoria infirmary, Newcastle, patients are reviewed during the neuro-rehabilitation ward round which takes place every Tuesday morning. Patients are also reviewed by the Neuro-oncology physiotherapist. Appropriate liaison takes place with the community and specialist rehabilitation centres.
  - At the James Cook University Hospital, Middlesbrough, the neuro-science ward and the neuro-rehabilitation wards are on the same hospital site and can be accessed by AHP's according to need. All patients are screened / assessed by the specialist Neuro-oncology physiotherapist/Occupational therapist and/or SALT. The care pathway is discussed by the MDT and the AHP lead liaises with the appropriate rehabilitation services, including community services. If in-patient care is required, a referral is made directly to the Neuro-rehabilitation consultant. The MDT has strong links with rehabilitation and social services.

## **Supportive care and Palliative care**

- In addition to their role in identifying the rehabilitation needs of patients affected by brain and other CNS tumours, the specialists neuro-oncology AHPs together with the neuro-oncology nurse specialists, play a crucial role in symptom and disability management.
- Many patients will require specialist input from the palliative care team for symptom control; the need for this input will be identified by the neuro oncology nurse specialists and the AHP's who will arrange the appropriate referrals. Referrals can also be made by ward doctors and nurses.
- Patients with high-grade malignant primary brain tumours whose initial treatment is "best supportive care" should be notified to the palliative care team at the time the treatment decision is made.

- Management of symptoms including the management of the end of life care pathway will be in accordance with NCA clinical guidelines for palliative care.

## **End of life care and bereavement support**

- Patients affected by primary brain tumours are at risk of acute deterioration in their condition. Malignant primary brain tumours can undergo rapid progression whilst low-grade primary brain tumours are a risk of transformation to high-grade tumour with associated progression. In both situations the affected patient may show rapid deterioration in their neurological status, conscious level and cognitive function.
- At the time of acute deterioration, it is not uncommon for patients to be admitted to an acute hospital bed under the care of the local acute care consultant or their consultant oncologist or consultant neurosurgeon. The clinical and radiological picture may indicate that the patient is in a terminal phase of their illness and no further specific neuro oncological or surgical care is appropriate.
- Best supportive care will be given in this situation. Full discussion with the patient and their family/carers should take place regarding prognosis, planned treatment and the patient's preference for the place for end of life care. If the patient requests transfer to a community setting or discharge home, this should be facilitated as far as is possible.
- The patient's condition may prevent transfer/discharge from acute hospital setting. Further clinical deterioration may indicate the need to develop and individualised care plan using local hospital guidelines and documentation
- Following death of the patient, bereavement support should be offered in accordance with NCA guidelines, taking into account local factors and hospital protocols.

## **Audit**

- The EAG will agree a network audit each year which will be presented during a meeting of the group and the results included in the EAG annual report.
- In addition to their involvement in the network audit it is expected that all MDTs will undertake local clinical audit as part of their work programme each year and the results included in their annual report.
- Ideally the results of local audits should be disseminated more widely at the NCA annual conference each autumn.

## Research

- All MDTs are expected to be involved in clinical research studies and to recruit to them.
- The availability of a study to patients will be recorded at MDT for each patient discussed
- The EAG in collaboration with the CRN NENC will disseminate a list of available research studies to all MDTs on an annual basis and advise the MDTs of changes (new studies opening, previous studies closing) as they arise.
- The MDTs will record the outcome of discussion regarding involvement in clinical trials in the patients' records.
- Trials open at Newcastle Site will be offered to Tees patients if logistics are possible

## Rare tumours

- The Improving Outcomes Guidance for Brain and Other CNS Tumours encompasses a wide variety of tumour types. Many of the tumours are rare with individual Neuroscience MDT's treating only a very small number of patients with these tumour types each year. Similarly, a number of the tumour types involve collaboration with MDT's in other areas, such as Lymphoma MDT and Teenage and Young Adult MDT together with the access to the expertise of the extended membership of these MDT's. Recently the British Neuro Oncology Society, in collaboration with the National Cancer Action Team has issued guidance on the management of the following rare tumours:
  - Adult pineal area tumours.
  - Optic pathway Glioma.
  - Primary CNS and intra-ocular Lymphoma.
  - PNET in adult patients
- These guidelines provide detailed advice on the management of these conditions. They will be reviewed by the EAG to assess the implications and incorporated in future clinical guidance.
- In the interim these rare tumour types should be referred according to the pathway for suspected brain tumour
- If radiological or histopathology report suggest the diagnosis of sarcoma, the patient should be referred for discussion in the regional sarcoma MDT in Freeman

Hospital. The current sarcoma MDT lead is Mr Mani Ragbir, Consultant plastic surgeon based in Freeman Hospital.

- Patients with Neurofibromatosis (NF) need referral to a geneticist and needs referral and discussion in the NF MDT in Manchester.

## **Pathology Guidelines for the Examination and Reporting of Brain Tumour Specimens**

- histopathological examination of tumour specimens obtained at stereotactic biopsy or craniotomy will be performed in accordance with the joint guidance agreed by the neuro pathologists within the Northern Cancer Alliance who support the neuroscience MDTs at the Royal Victoria infirmary Newcastle and the James Cook University Hospital Middlesbrough.
- Reporting of histopathology specimens will also be in accordance with these guidelines.
- The full guidelines are described in Appendix 1.

Sources of information for patients and carers :

Brain Tumour UK

Telephone 0845 4500 386

[www.braintumouruk.org.uk](http://www.braintumouruk.org.uk)

The Pituitary Foundation

Telephone 0845 450 0375

[www.pituitary.org.uk](http://www.pituitary.org.uk)

Brain's Trust

Telephone 0983 292 405

[www.brainstrust.org.uk](http://www.brainstrust.org.uk)

Meningioma UK

Telephone 01787 374 084

[www.meningiomauk.org](http://www.meningiomauk.org)

Samantha Dickson Brain Tumour Trust

Telephone 0845 130 9733

[www.braintumourtrust.co.uk](http://www.braintumourtrust.co.uk)

Macmillan Cancer Support

Telephone 0808 808 0000

[www.macmillan.org.uk](http://www.macmillan.org.uk)

Cancer Research UK

[www.cancerresearchuk.org](http://www.cancerresearchuk.org)

Marie Curie Cancer Care

Telephone

[www.mariecurie.org.uk](http://www.mariecurie.org.uk)

British Neuro Oncology Society

Multiple links to brain tumour charities

[www.bnos.org.uk](http://www.bnos.org.uk)



## **Microbiology**

Sampling for microbiological studies is best carried out by the neurosurgeon in the operating theatre where sterile facilities are available and there is less risk of specimen contamination. This may require pre- or intra-operative discussion with the surgeon (eg if imaging or intraoperative report suggests abscess or encephalitis).

If microbiological sampling is deemed necessary on the specimen, adopt aseptic techniques and sample appropriate tissue.

### **FROM CLINICAL DETAILS ON REQUEST FORM:**

- Consider requirement for intraoperative report by smear or frozen section technique according to clinical details and nature of specimen.
- Consider requirement for sampling for electron microscopy, or freezing of tissue sample for possible molecular biological/genetic studies according to clinical scenario and nature of specimen and intraoperative report findings. Examples where this may be appropriate include tumours which may prove difficult to classify as judged on the basis of the intra-operative report, rare or unusual tumours, tumours in the under 18s.
- All paediatric cases: keep frozen tissue if biopsy sufficient size.
- Consider requirement for photography - eg to indicate sites of block sampling, macroscopic features, for publication or teaching purposes.
- Consider requirement for decalcification - before or after specimen dissection and block sampling.

## **Macroscopic analysis**

- Specimens should be measured and described, and weighed if appropriate - eg lobectomy, large meningioma. Medium and larger sized tumour specimens should be weighed (for neuro-oncology trial purposes).
- Fix remaining tissue in formalin according to nature and size of specimen. (Small biopsies may be placed directly into nets/cassettes for overnight processing while larger specimens will need overnight fixation and a longer processing schedule).
- For most smaller or medium sized (not exceeding 4g) specimens, all remaining tissue should be processed for histological examination.
- Consider requesting special stains/immunostains (guided by intraoperative report findings) at time of specimen dissection so that appropriate spare sections can be cut at the same time as a section for H&E staining, saving time/work and avoiding waste of tissue.

- For larger specimens, dissect and sample as appropriate in the judgement of the pathologist. An evidence base to guide this does not exist, but (for example) at least six blocks from a large meningioma would be appropriate to look for atypical features. Meningioma specimens should be examined for the presence of cerebral cortex/brain tissue on the surface of the specimen and dura/bone involvement.
- Orientation of the specimen may be appropriate - eg temporal lobectomy, requiring slicing at thin intervals in the coronal plane. Sample according to macroscopic appearances, eg areas suggestive of necrosis in meningiomas or gliomas should be sampled as well as areas appearing viable, areas of adjacent brain to look for invasion or circumscription of the tumour.
- Large blocks may be appropriate for lobectomy specimens. Resection margins are not usually assessable in glial tumours, but inking of dural margins prior to sampling may be indicated in some meningioma specimens. The origin of the blocks may need to be recorded in writing or on a photograph. On large specimens eg cortical gyri, freshly cut grey and white matter surfaces should be covered with glove paper prior to formalin immersion.

## **TISSUE FIXATION AND PROCESSING**

Fix remaining tissue in formalin according to nature and size of specimen (small biopsies may be placed directly into nets/cassettes for overnight processing while larger specimens will need overnight fixation and possibly a longer processing schedule).

### **Intraoperative Reporting**

This is carried out on some neuropathology tumour specimens to guide the operative procedure and post-operative management of patients. Within normal working hours smear and frozen section preparations are available, by prior arrangement; outside normal working hours the technique is limited in some centres to smear preparation and is subject to the availability of the Consultant Neuropathologist or an on-call pathologist prepared to carry out this procedure.

- Intra-operative reporting is not appropriate for heavily calcified lesions – eg bone.
- Discussion with the surgeon regarding the indication for intraoperative reporting may be appropriate if only a small amount of tissue is available, as fixation and processing for paraffin sections may be more appropriate.
- Care should be taken that sufficient representative material remains for paraffin sections; occasionally all of a small sample may be used if the pathologist is aware that more tissue is to be sent for paraffin sections.

- Consideration should be given to any increased risk of infectious hazard; specimens should be handled according to the appropriate laboratory protocols.

### **Retention of frozen tissue**

In all paediatric and some adult cases consideration should be given to keeping frozen tissue for molecular diagnostic purposes – this may be by keeping the frozen tissue block used in the intra-operative report or if sufficient tissue is available, by sampling the fresh tissue.

### **Contact with Neurotheatre**

The intraoperative neuropathology assessment should be communicated to the operating theatre by a telephone message, either directly to the surgeon or via an appropriate intermediary (anaesthetist, junior medical staff, nursing staff) if the surgeon cannot come to the theatre telephone. Advice on the need for further specimens and their handling can be given at this time.

### **PARAFFIN SECTION REPORTING**

Tumour classification and typing and grading should be in accordance with WHO Classification of Tumours of the CNS (2016), as modified by cIMPACT- NOW guidance, and future revisions of the WHO classification. Glial and embryonal neoplasms will be investigated with an integrated diagnostic approach combining histological assessment, IHC and appropriate molecular and genetic studies including glioma panel sequencing and DNA methylation profiling using EPIC array. When such studies are uninformative or not possible for technical reasons, terminology such as “not otherwise specified” or “not elsewhere classified” can be used, as indicated in the WHO classification.

If the specimen is non-diagnostic, eg non-specific reactive change at the edge of a lesion, the neurosurgical team should be informed and the possibility of a further biopsy considered.

Non-tumour diagnoses should be based on Greenfield's Neuropathology (ninth edition, 2015) and appropriate literature.

Soft tissue, bone and lymphoma tumour diagnosis is likely to require consultation with or referral to the relevant specialist reporting teams.

### **Metastatic disease**

As guided by clinical, radiological and morphological findings, and as per protocols for diagnosis of primary of unknown origin.

### **Multidisciplinary Team Meetings**

Cases are to be discussed as appropriate at multidisciplinary meetings involving Neurosurgeons, Neuro-oncologists, Neuropathologists, Neuroradiologists and others involved in the care of the patient.

## **EAG Guidelines for Teenage and Young Adults**

### **Teenage and Young Adults Peer Review Measures Topic 11-1C (Functions of the Network Site Specific Groups for TYA)**

#### **1. Teenage and Young Adult Pathway for initial Management**

The EAG has received the document named 'NCA Teenage and Young Adult Cancer Pathway Guidance Paper' and agrees to follow the generic TYA Pathway with any site specific variations to be documented. Please see Appendix 1 for pathway.

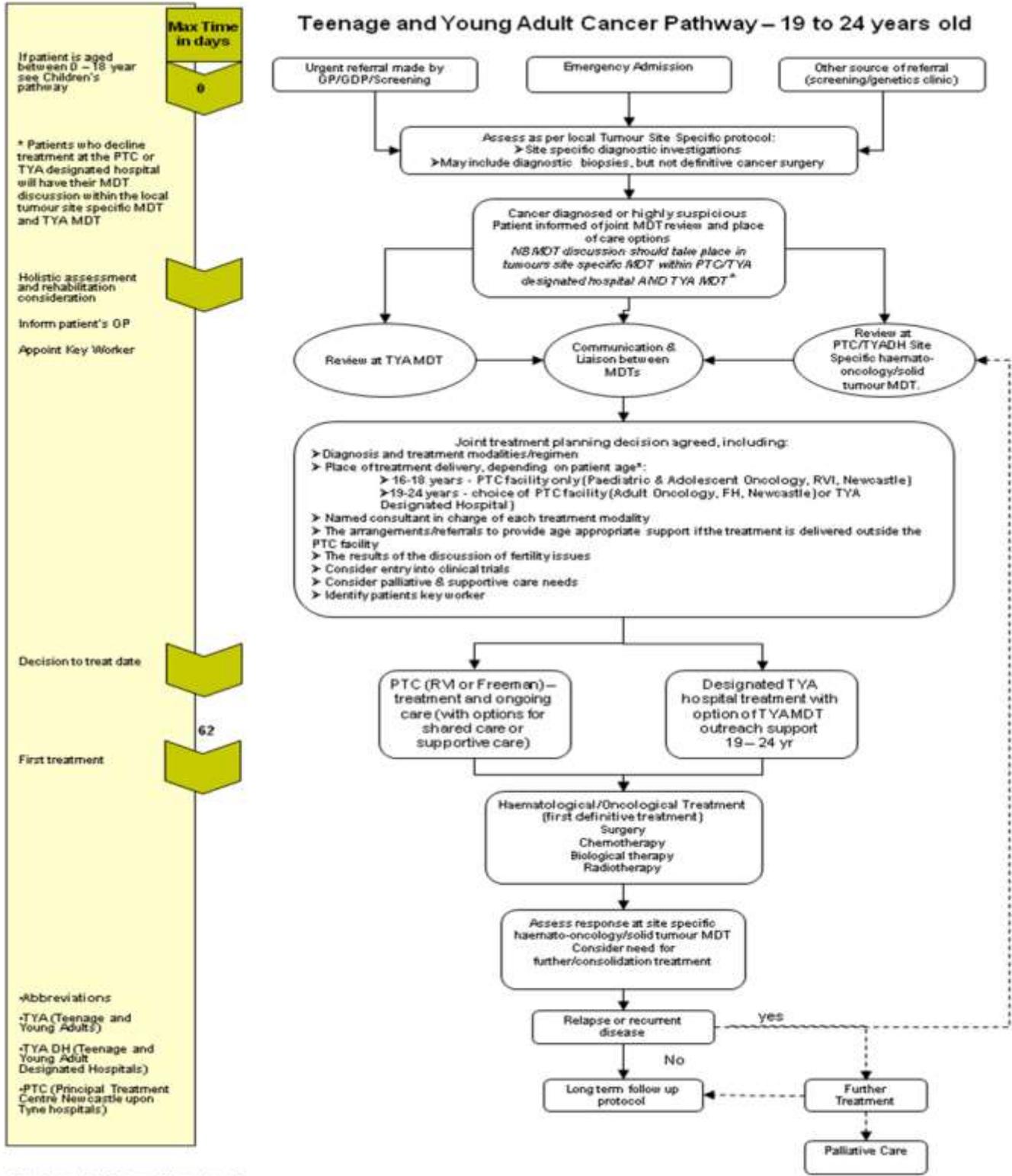
#### **2. Teenage and Young Adult Pathway for Follow up on completion of first line treatment**

The EAG has received the document NCA Teenage and Young Adult Cancer Follow up on completion of first line treatment and agreed to follow this pathway. Please see appendix 1 for pathway

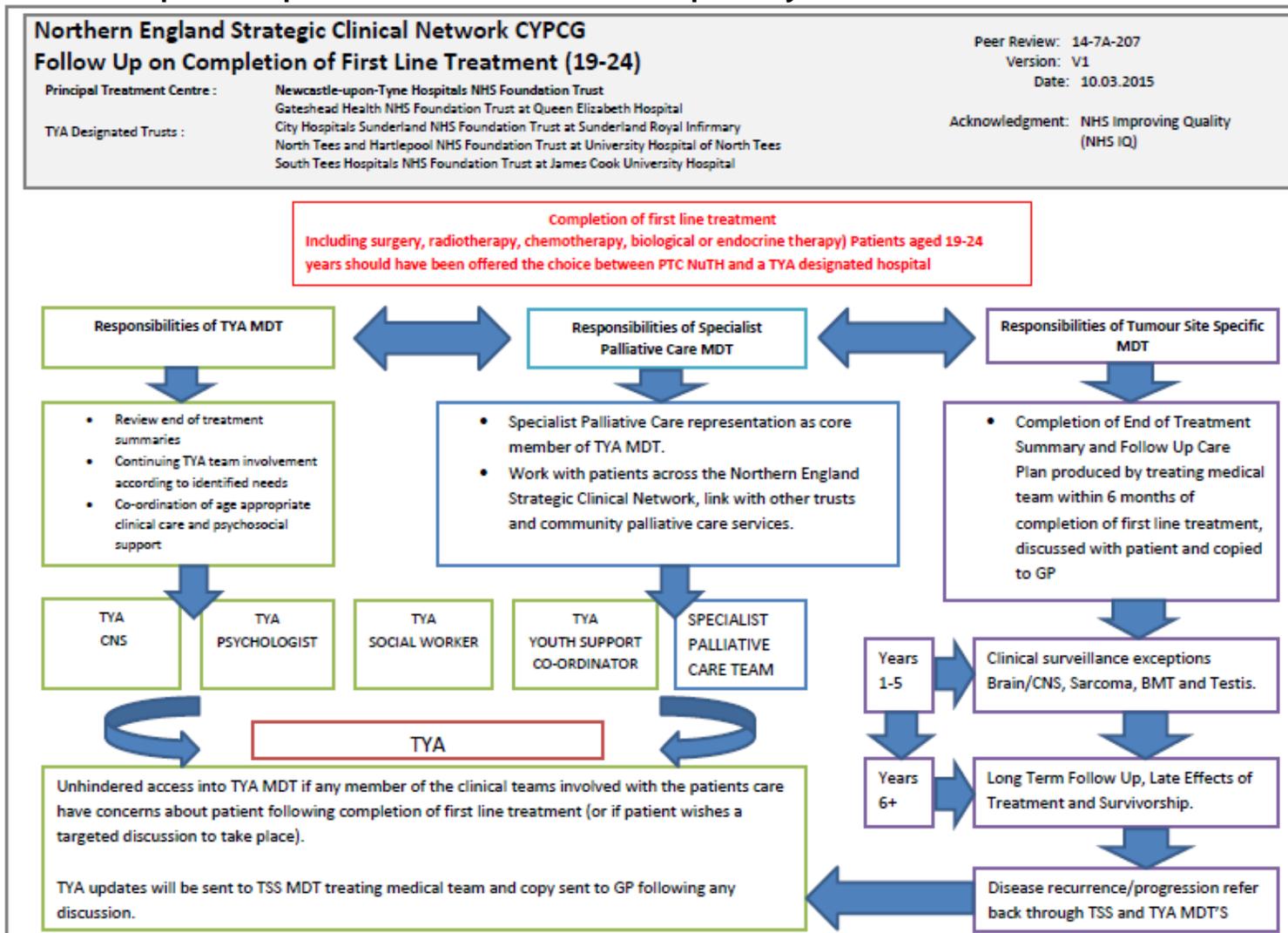
#### **3. Pathways for cases involving Specialised NHS services (Only Gynae and Sarcoma)**

The Gynae EAG and SAG reviewed and agreed the Specialised NHS Service pathway for patient's age 16-24 years. This is attached in Appendix 3.

# Appendix 1 – Teenage and Young Adult Pathway for initial Management and Follow up on completion of first line treatment



# TYA follow up on completion of First Line Treatment pathway



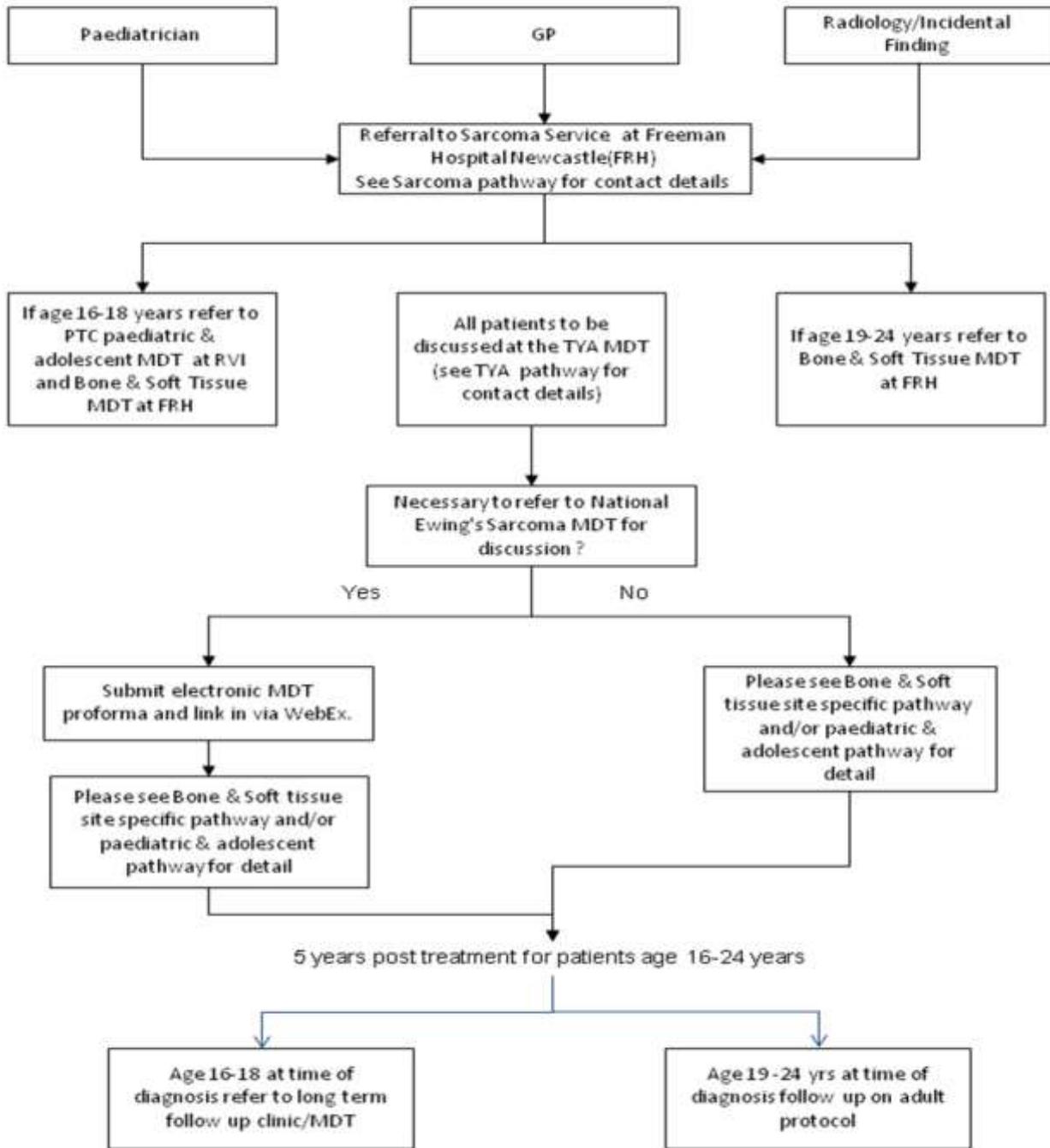
Contact Information	MDT RESPONSIBILITIES			Transition to TYA Transition to Adult
	TYA MDT	SPECIALIST PALLIATIVE CARE MDT	TUMOUR SITE SPECIFIC MDT	
<p>These are the trusts that are designated to treat TYA patients within the Northern Region Strategic Clinical Network:</p> <p>PTC: Newcastle-upon-Tyne Hospitals NHS Foundation Trust</p> <p>16-18 Great North Children's Hospital. 19-24 Freeman Hospital</p> <p>Switchboard 0191 2336161</p> <p>DH: City Hospitals Sunderland Foundation Trust Sunderland Royal Infirmary</p> <p>19-24 only Switchboard 0191 5656256</p> <p>DH: Gateshead Health NHS Hospitals Trust Queen Elizabeth Hospital</p> <p>19-24 only Switchboard 0191 4820000</p> <p>DH: North Tees and Hartlepool NHS Foundation Trust University Hospital of North Tees</p> <p>19-24 only Switchboard 01642 617617</p> <p>DH:South Tees Hospitals NHS Foundation Trust James Cook University Hospital</p> <p>19-24 only Switchboard 01642 850850</p>	<p>Location: NUTH Time: Thursdays, 12:00-14:00 Lead Clinician: Dr Emma Lethbridge Lead Nurse: Mr David Short Coordinator: Sharon Buckley Phone: 0191 233 6161 email: <a href="mailto:tnu.tr.tyamdt@nhs.net">tnu.tr.tyamdt@nhs.net</a></p> <p><b>TYA MDT</b> Review end of treatment summary</p> <p><b>TYA CNS</b></p> <ul style="list-style-type: none"> <li>Co-ordination of clinical care.</li> <li>Acts as point of contact/reference</li> </ul> <p><b>TYA Psychologist</b></p> <ul style="list-style-type: none"> <li>Continue to provide level 3+4 support according to need.</li> <li>Involvement in end of treatment/ Survivorship clinic/event.</li> </ul> <p><b>TYA Social Worker</b></p> <ul style="list-style-type: none"> <li>Continue to provide support according to need</li> <li>Introductory letter sent with information and offer of grant at time of diagnosis and relapse</li> <li>More in depth service offered based on assessed need</li> </ul> <p><b>TYA Youth Support Co-ordinator</b></p> <ul style="list-style-type: none"> <li>Continue to invite patients to support activities for up to 2 years post first line treatment</li> <li>Involvement in end of treatment/ Survivorship clinic/event</li> </ul>	<p>Location: NCCC Freeman Hospital Time: Wednesdays, 09:30-11:30 Lead Clinician: Dr M. Comiskey Coordinator: Kerry Halliday Phone: 0191 2138606 email: <a href="mailto:kerry.halliday@nuth.nhs.uk">kerry.halliday@nuth.nhs.uk</a></p> <ol style="list-style-type: none"> <li>Specialist Palliative Care representation as core member of TYA MDT.</li> <li>All site specific MDT outcomes notified to palliative care lead clinician.</li> <li>Patients reviewed at any point along the pathway (diagnosis, relapse, long term follow up, end of life care).</li> <li>Holistic needs assessment to include family/carers.</li> <li>Work with patients across the Northern England Strategic Clinical Network, link with other trusts and community palliative care services.</li> <li>MDT outcomes documented on Somerset.</li> </ol>	<ul style="list-style-type: none"> <li>Completion of end of treatment summary and follow up care plan produced by treating medical team within 6 months of completion of first line treatment, discussed with patient and copy to GP Treatment Summaries should be assigned a level of care.</li> <li>Level 1: Supported self-management with contact info about how to reconnect back into LTFU.</li> <li>Level 2: Planned coordinated care with support from the primary treatment centre and local services. Low level care required such as monitoring with echocardiograms.</li> <li>Level 3: Complex care requiring follow-up in the long-term follow up clinic usually requiring input from the multi-disciplinary team.</li> </ul> <p><b>YEARS 1-5</b></p> <ul style="list-style-type: none"> <li>Clinical surveillance for disease recurrence and treatment toxicity monitoring (including history, clinical examination, laboratory investigations, imaging studies and invasive procedures where indicated according to tumour site specific follow up protocols)</li> </ul> <p><b>YEARS 6+</b></p> <ul style="list-style-type: none"> <li>Long term follow up for late effects of treatment, consider survivorship issues</li> <li>Consider referral to long term follow up/late effects MDT if disease free after 5 years from completion of first line treatment</li> <li>Consider extended clinical follow up to 10 years+ in selected patient groups as defined by the TSS MDT's (e.g. brain/CNS, sarcoma, BMT, testis)</li> </ul>	<p>Transition into adult services is planned for and discussed with patients well in advance. Transition at a time of crisis e.g. relapse, intensive chemotherapy will be avoided wherever possible. Transition will be facilitated by the keyworkers</p>

## Appendix 2 – Contact Details

Name of NHS Trust and designated hospital site	Name of MDT	TYA Lead Clinician	TYA Lead Nurse	Contact Number
Principal Treatment Centre	<b>All MDTs:</b>	Dr Emma Lethbridge	David Short david.short@nuth.nhs.uk	0191 2448858 (Dect48858)
	Breast			
	Colorectal			
	Gynaecology (diagnostic)			
	Haematology			
	Head & Neck			
	Lung			
	Neurooncology (Brain/Spinal, Pituitary, Skull Base)			
	Sarcoma			
	Specialist Skin			
	Specialist pancreatic			
	Supra T-cell Lymphoma			
	Teenage and Young Adult MDT			
	Testicular			
Thyroid				
Specialist Upper GI				
Specialist Urology				
Gateshead Health NHS Foundation Trust - at Queen Elizabeth Hospital	Specialist Gynaecology	Ms Christine Ang	rachel.mugnai@ghnt.nhs.uk	0191 4456148
City Hospitals Sunderland NHS Foundation Trust - at Sunderland Royal Hospital	Haematology	Dr Scott Marshall	Faye Laverick faye.armstrong@chsft.nhs.uk	0191 5656256
	Specialist Urology ( <i>testicular only</i> )			
North Tees and Hartlepool NHS Foundation Trust - at University Hospital of North Tees	<b>All MDTs:</b>	Dr Padmaja Lokireddy	Kat Dawson Katherine.Dawson@nth.nhs.uk	01642 617617 ext 24697
	Haematology			
	Local Urology			
	Thyroid			
	Breast			
	Colorectal			
	Lung			
Local Upper GI				
South Tees Hospital NHS Foundation Trust - at James Cook University Hospital	<b>All MDTs:</b>	Dr Dianne Plews	Jill Linton jill.linton@stees.nhs.uk	01642 854381
	Specialist Gynaecology			
	Breast			
	Colorectal			
	Haematology			
	Head & Neck			
	Lung			
	Neurooncology			
	Specialist Skin			
	Thyroid			
Specialist Upper GI				
Specialist Urology				

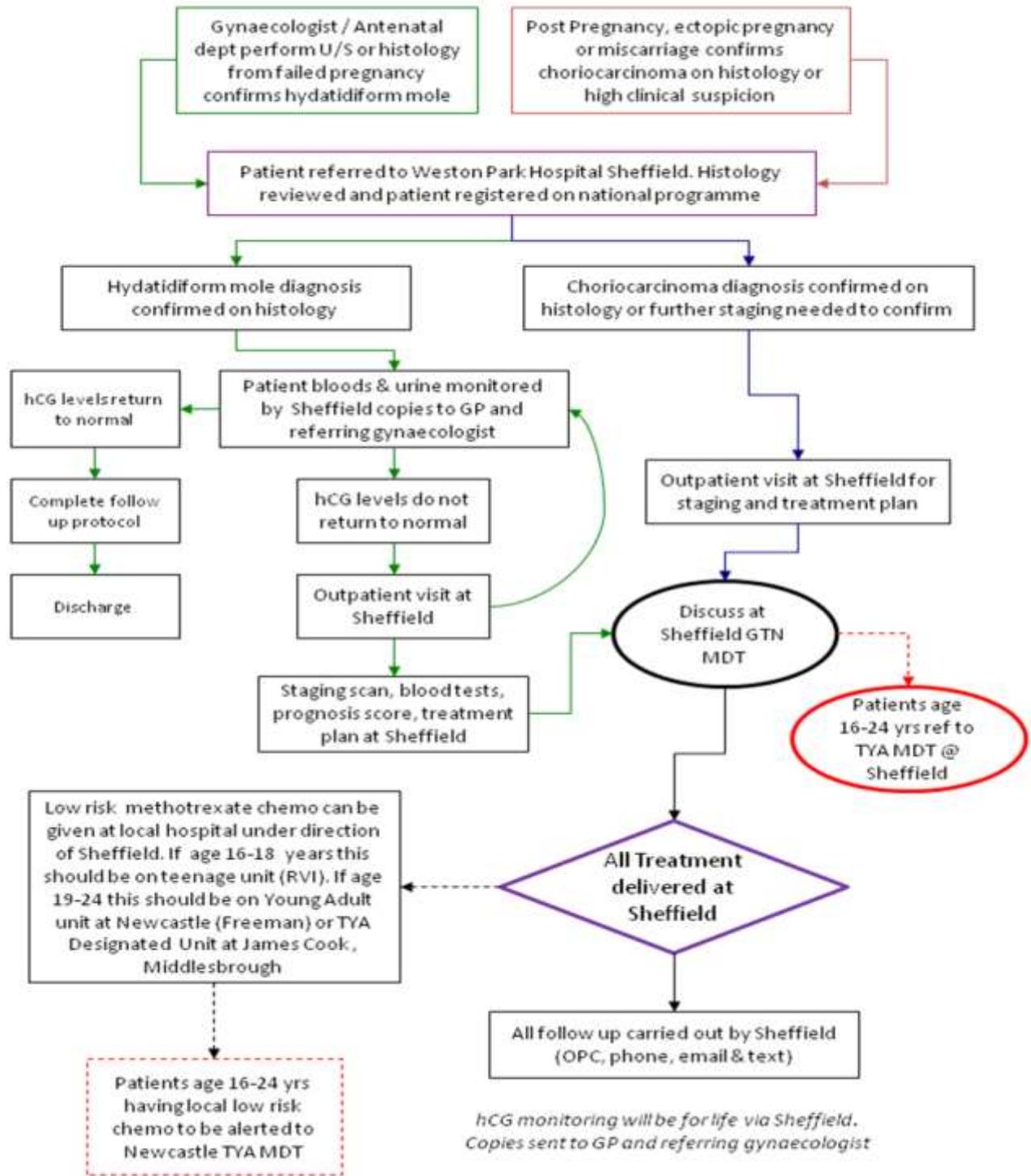
### Appendix 3 – NHS Specialised Services Pathway

#### NHS Specialised Services - Referral Pathway for Primary Malignant Bone Cancer for patients age 16-24 years within the North of England



# NHS Specialised Services

Referral Pathway for Hydatidiform Mole / Gestational Trophoblastic Neoplasm / Choriocarcinoma  
Weston Park Hospital, Sheffield



## Appendix 3 – Chemotherapy Algorithm

# NCA CHEMOTHERAPY TREATMENT ALGORITHM FOR BRAIN & CNS

*“Quality and safety for every patient every time”*

### Document Control

Prepared By	Issue Date	Approved By	Review Date	Version	Contributors	Comments/ Amendment
EAG		Chemotherapy group		1.0	Network Pharmacists	
EAG	4.2014	Brain and CNS	4.2016	1.1		Chemotherapy algorithms update
EAG	5.2016	Brain & CNS	5.2018			

For more information regarding this document, please contact:

EAG Chair: A Varma

## **INTRODUCTION**

The 2011 Peer Review Chemotherapy Measures require each Network Site Specific group (EAG) to agree in consultation with the Network Chemotherapy Group (NCG) a set of site specific chemotherapy treatment algorithms for the Network.

### ***Peer Review Definitions***

#### ***Chemotherapy treatment algorithm***

A guideline which specifies the acceptable ranges of regimen options for named steps on the patient pathway. Treatment algorithms are cancer site-specific. Thus, the treatment algorithm for the Brain and CNS EAG includes a statement of the range of regimens agreed as acceptable

#### ***Chemotherapy***

The term 'chemotherapy' refers to the use of those cytotoxic agents commonly understood and accepted as being covered by this term and includes other agents such as, biological therapy and small molecule tyrosine kinase inhibitors used for the systemic treatment of cancer.

In NCA Treatment Algorithms are included in each EAG's Clinical Guidelines which can be found under the tumour specific page of the guidelines section of the website, e.g. for Lung Cancer

[www.necn.nhs.uk](http://www.necn.nhs.uk)

## **SUPPORTING DOCUMENTS**

As new regimens are approved by NICE / NECDAG protocols for use of the new treatment will be uploaded to the chemotherapy site specific pages. The EAG will be asked to update their algorithm with each new treatment approval.

The availability of the Cancer Drug Fund (CDF) has increased the number of treatments potentially available to patients. CDF funded drugs may not be included in the EAG clinical guidelines due to the dynamic nature of CDF funding (i.e. treatments can be removed as well as added).

Any deviation from the algorithm should be recorded by the local Trust clinical chemotherapy service and brought to the NCG for discussion. The Network Policy on managing deviations from approved protocols/ algorithms is on the website: [www.necn.nhs.uk](http://www.necn.nhs.uk)

## **LIST OF APPROVED REGIMENS**

The NCA website provides the most up to date list of approved regimens and should be regularly checked. Appendix One below summarises the Brain and CNS regimens on the website.

## **BRAIN & CNS ALGORITHM**

### **High-grade malignant primary brain tumour**

- All patients with a radiological diagnosis of a high grade malignant primary brain tumour (Glioblastoma, anaplastic astrocytoma, Oligodendroglioma, ependymoma, lymphoma) will be reviewed by the neurosciences MDT and consideration of treatment options given.
- The MDT will advise on medical management of the tumour and tumour related conditions:
  - the use of high-dose steroids in relation to the control of peritumoural oedema.
  - the management of tumour related epilepsy and the requirement for review by a neurologist.
- All patients undergoing biopsy or craniotomy will have their case reviewed by the MDT at the next available meeting after the histology results are available. Histology will be reviewed and recommendations regarding further treatment given. Consideration will be made with regards to;
  - Radiotherapy (radical/palliative).
  - Concomitant/adjuvant chemotherapy.
  - Medical management with best supportive care.
- The network MDT will consider the use of adjuvant chemotherapy as per table 1 below (the algorithm is to be regarded as a guide only and is not devised as a replacement for individual case consideration by specialist neuro-oncology team);

Table1

Adjuvant Chemotherapy	Stupp protocol	Indication - PS 0/1 GBM Plan: Includes RT week days with 1. Concurrent temozolomide with RT 75mg/m sq max 42 days 2. Adjuvant Phase 28 days after RT Cycle 1 150mg/m sq; Cycles 2-6 200mg/m sq; cycle length 28 days
	Post Radiotherapy PCV	Indication - Double deletion 1p 19q Anaplastic Oligodendroglioma post radical radiotherapy Plan: 28 days post radiotherapy; 6 cycles of PCV cycle length 42 days
	PNET High Risk Patients	Indication - PNET High risk Sup PNET post radical CSRT Plan: Packer regimen 6 cycles as per BNOS rare tumour guidelines Or NCCC protocol 4-6 cycles Cyclo/Cisplatin/Etoposide 21 day cycle
	CATNON adjuvant Chemo for grade 3 astrocytoma	Indication – grade 3 non deleted astrocytoma Plan: Adj temo as per Stupp adjuvant cycles temozolomide 5/28 200mg/meter sq
	Low Grade astro	Individual consideration of post RT PCV or temo as per std Protocol. Evidenced as per draft IOG guidance 2018
Palliative Chemotherapy	PCV	Indication - progressed glioma; any grade 1 <sup>st</sup> line relapse standard Treatment with PS 0-1 Plan: Cycle number depends upon response assessment up to 12 cycles. Also in selected relapsed cerebral NHL (not 1 <sup>st</sup> line) 42 day cycle length Protocol summary attached
	Temozolomide	Indication - progressed glioma any grade 2 <sup>nd</sup> line relapse as per NICE guidance Pt should be PS 0-2, have prognosis 3 months, have high grade Pathology; ? not had adj temozolomide Plan: 28 day cycle length Chemoniave cycle 1 200mg/m sq otherwise 150mg/m sq and subsequent cycles increase to 200mg/m sq No of cycles depends on response status
	Carboplatin	Indication - 3 <sup>rd</sup> line relapse glioma Plan: AUC 4-5 rising to 7 if tolerated Cockroft GFR satisfactory 21 day cycle Cycle number depends on response
	Cyclo/Cisplat/Etop	Indication - relapsed PNET Relapsed Ependymoma Relapsed Pineal Paranchymal Tumour Plan: Cycle length 21 days Number cycles depends on response – max 6
	Carbo/Etop/Vinc	Indication – alternative regimen relapsed PNET, Pineal Paranchymal Tumour Plan: Cycle length 21 days Number of cycles depends on response – max 6 cycles

**APPENDIX ONE: NCA APPROVED LIST OF REGIMENS FOR BRAIN & CNS**

<b>Doc No.</b>	<b>Brain and CNS Cancers</b>
CRP-08-CNS002	<b>Protocol for Temozolomide (Adjuvant)</b>
CRP-08-CNS001	<b>Protocol for Temozolomide (Metastatic)</b>

**Appendix 4 Operational Policy for Neuro- Rehabilitation**

# **Brain and CNS EAG**

## **Operational Policy for Neuro-Rehabilitation**

**Document Control**

<b>Version</b>	<b>Date</b>	<b>Summary</b>	<b>Review Date</b>
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V1.2	03.05.18	Updated	4.2020
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## 1. Introduction

The purpose of this document is to provide operational and service details in relation to in-patient, out-patient and community rehabilitation facilities for patients with brain and central nervous system (CNS) tumours within the Northern Cancer Alliance (NCA) of the North Eastern Clinical Network (NECN). The NCA Network is a partnership of primary, secondary and palliative care services across three strategic health authorities of the North East of England, which serves a population of about 3 million.

There are two designated teams for the care of Brain and CNS tumour patients within the NCA. One is operational within The James Cook University Hospital, Middlesbrough (JCUH), South Tees Hospitals NHS Foundation Trust providing services to the southern part of the region and the other based in Newcastle Upon Tyne Hospitals NHS Foundation Trust (NUTH), Newcastle upon Tyne, providing services to the Northern part of the region.

Brain and CNS tumours include primary malignant, non-malignant and secondary tumours that are being managed by the neuro-oncology team.

Primary drivers are provided by the Brain and CNS and Base of Skull tumour quality indicators produced by NHS England. The policy is in line with the intent and purposes of the following supporting documentation:

- NICE Improving Supportive and Palliative Care for Adults with Cancer, 2004
- NICE Improving Outcomes Guidance for People with Brain and CNS Tumours, 2006
- Cancer Reform Strategy, 2007
- National Cancer Action Team Supporting and Improving Commissioning of Cancer Rehabilitation Services: Guidelines and Review of Evidence, 2009
- National Cancer Action Team Cancer Rehabilitation Pathway, 2013
- NICE Guidance – Brain tumours (primary) and brain metastases in adults, July 2018.

## 2. Background

Primary brain tumours account for less than 2% of cancer diagnoses in the UK (CRUK 2008) but more people under 40 die from a brain tumour than from any other cancer.

Brain and CNS tumours can result in significant physical, psychological, functional and cognitive disabilities, both as a result of the disease and the treatment regimens of surgery, radiotherapy and chemotherapy. These morbidities may be further

complicated by poor prognoses, and the potential for rapid progression and changing needs of the patient. It is essential that consideration is given to the impact that such a diagnosis has and the wide-ranging needs and support required throughout this period of care for both the patient and their support network. This requires a skilled and specialist allied health professional (AHP) workforce to provide services within multi-disciplinary teams, in a variety of settings, to ensure appropriate care provision that is high quality, needs-based, flexible, timely and accessible.

Cancer rehabilitation supports the patient and contributes to the process of adaptation to their condition, with the intention of maximising function, independence and quality of life (NICE 2004), regardless of the overall life expectancy of the patient.

Studies have demonstrated that rehabilitation in brain and CNS tumour patients is effective in producing significant functional improvements, and that these improvements are comparable to those seen in rehabilitation programmes for stroke and traumatic brain injury patients (NICE, 2006).

Four stages of cancer rehabilitation may be identified (Dietz, 1980)

Preventative – to reduce impact of expected issues, and provide coping strategies.

Restorative – to return the patient to pre-illness levels of function.

Supportive – limiting functional loss and providing support when disease persists, and further treatment intervention is required.

Palliative – to eliminate or reduce complications and provide support.

Rehabilitation in oncology should be offered at all key stages from diagnosis through to end of life. Rehabilitation and palliative care practitioners are also key workers in the discharge planning of patients from acute care and care planning. Discharge preparation should commence at the point of admission and be a pro-active, multi-disciplinary and a joined up process.

The transition from secondary or tertiary into primary or community care and to the home setting should be supported with appropriate interventions based upon need, rehabilitative potential and patient goals, rather than neurological aetiology and prognosis.

Rehabilitation should be provided in the best location for the patient, whether that is an in-patient, out-patient, community or domiciliary setting. Specialist rehabilitation units should be considered if appropriate. Currently there are gaps and delays in provision of some rehabilitation services within the NECN. Commissioners should work

collaboratively with all providers and social services to ensure that rehabilitation pathways are properly financed to meet patient needs in a timely manner.

Patients with spinal cord tumours should have the opportunity to undergo intensive rehabilitation in a specially adapted unit such as a spinal injuries unit, in order for them to achieve their maximum functional potential. Commissioners should ensure that patients with spinal tumours have the opportunity to be admitted to such units and that the treatment programme is appropriate to their needs (NICE, 2006).

### **3. Description of Service**

#### **3.1 Aims and Objectives**

- For the Brain and CNS EAG to advocate that appropriate rehabilitation services are open and accessible to patients whose rehabilitation needs are caused by their tumour or its treatment.
- For the Brain and CNS EAG to promote equality of rehabilitation services across the North of England Cancer Network for people with brain and central nervous system tumours.
- For the Brain and CNS EAG to facilitate that all patients diagnosed with brain and CNS tumours are managed within an appropriate multidisciplinary care pathway as described in this document and in the complementary Operating Policy of the EAG.
- All patients will be assessed for their rehabilitation needs and referred or signposted to appropriate services, regardless of location and stage on the cancer pathway.
- To improve outcomes and rehabilitative service delivery for patients with brain and CNS tumours within the NCA region.
- To provide clear lines of communication and signposting to rehabilitation services for brain and CNS patients.
- To provide an evidenced based resource and educational support of rehabilitation needs to other therapists/health professionals working with Brain and CNS within the North Of England Cancer Network

### **3.2 Service Users**

This policy covers all patients with primary or secondary tumours of the brain and central nervous system, and is inclusive of skull base, pituitary and spinal cord tumours who are being managed by the neuro-oncology teams.

All grades of tumours are included within this operational policy, as people with low grade and high grade tumours may require rehabilitation for any neurological deficits caused by the tumour and/or treatments given.

All stages of the cancer pathway are covered by this policy, as patients may require intervention from diagnosis, through treatment and into the survivorship stage, or palliative pathway, and through to end of life.

### **3.3 Equality and Accessibility**

All patients with rehabilitation potential and identified rehabilitation goals should be offered referral to appropriate rehabilitation services (NICE, 2006).

Neurological rehabilitation facilities should be accessible to patients whose rehabilitation needs are caused by their tumour or its treatment. Patients should not be excluded on account of age and patients should not be excluded from a facility's scope of practice on the grounds alone of the diagnosis of a brain tumour.

### **3.4 Service Provision**

Patients with brain and CNS tumours should have rapid access to AHP assessment and rehabilitation services. There should be provision of inpatient, outpatient, community and domiciliary rehabilitation which should include specialist neuro-rehabilitation. Specialist palliative rehabilitation should be available where appropriate, as a patient's condition changes.

There is a directory of rehabilitation services for the area served by the Southern region of the NCA and is accessible via the JCUH internet for ease of access. A similar directory is under development in the Northern region.

Service provision should include the immediate access to, or provision of, specialist equipment as necessary (NICE, 2006).

The following health and social care professionals have an integral role in rehabilitation:

Neuro-rehabilitation consultants

Physiotherapists including vestibular rehabilitation and facial function

Occupational Therapists (OT)

Speech and Language Therapists (SLT)

Dieticians

Specialist Nurses

Neuropsychology, neuropsychiatry and psychological therapy

Primary healthcare teams

Social services

Wheelchair/equipment services

Sensory loss services

The NICE (2004) guidance 'Improving supportive and palliative care for adults with cancer' describes a four-level model of rehabilitation, assessment and support services with the range of healthcare professionals involved at each level. Level four specialist AHPs should be available in each locality of the Network for patients and health professionals to access as and when appropriate (NICE, 2006).

Service providers should focus the rehabilitation of patients with brain and CNS tumours on their goals and desired outcomes, including promoting functional independence, participation in normal activities of daily life and aspects related to quality of life. This should include vocational and work related rehabilitation where appropriate.

Service providers should offer admission to a specialist inpatient neuro-rehabilitation unit to those patients with brain/CNS tumours who are most likely to benefit, including those with a high activity tolerance, strong rehabilitation potential and a good prognosis with a life expectancy greater than 6 months.

Service providers should recognise the importance of the psychological needs of this patient group and their carers and ensure that appropriate services are available and accessible.

#### **4. Operational Service Details**

The NCA covers the largest geographical area of any cancer network in the UK and oversees cancer services for a population of just over 3 million. Due to the geography and population distribution of the NCA the National Cancer Action Team (NCAT) recommended the formation of two cancer network MDT's which are located with the two neurosciences sites in the NCA.

In the northern region of the NCA the neuroscience MDT (NSMDT) is based in the Newcastle Upon Tyne Hospitals NHS Foundation Trust (NUTH). There are separate MDT's for brain and CNS tumours, intradural spinal cord tumour, pituitary tumour and base of skull which feed patients into the rehabilitation and non-surgical MDT (RNSMDT).

In the southern region of the NCA the neuroscience MDT is based at the South Tees Hospitals Foundation Trust. This MDT functions as a combined NSMDT and RNSMDT for brain and CNS tumours, intradural spinal tumour, pituitary tumour and base of skull tumours.

The Brain and CNS quality indicators state that the NSMDT should have an AHP agreed as having responsibility for liaison with neuro-rehabilitation services in attendance as a core member. This should be specified in the job plan of the person designated to cover this meeting, and they should have a named representative to cover when they are not able to attend. This person is responsible for ensuring that rehabilitation needs are discussed in the NSMDT meeting with appropriate referral/signposting to AHP services or via the RNSMDT.

The Brain and CNS quality indicators state that there should be an occupational therapist, speech and language therapist and a physiotherapist with specified time in their job plan for the care of patients with a CNS tumour as part of the RNSMDT.

The RNSMDT is responsible for nominating and recording 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.

The MDT's may utilise the NCAT Cancer Rehabilitation Pathway (2013) for a list of triggers to referrals to the main rehabilitation AHP groups (Physiotherapy, Occupational Therapy, Speech and Language Therapy, Dietetics) to ensure that patients are referred to the appropriate services.

#### **4.1 Referral**

Service users should be assessed for their rehabilitation needs at each key stage of the cancer pathway and at any point where there is a change in their condition.

Referrals can be made direct to rehabilitation services for advice, screening, assessment and intervention as required, or via the RNSMDT.

All neuro-oncology patients on each neuro-surgical unit will have a screening assessment of their AHP needs prior to discharge.

There should be AHP input at NSMDT and RNSMDT meetings to ensure rehabilitation needs are discussed, and to ensure referral and signposting to appropriate services. Decisions made at the meeting should be recorded in the NSMDT and RNSMDT outcomes form, with referrals made within one working day of the meeting and a copy of the referral/outcomes placed in the patient's notes in accordance with national guidance (NICE 2006). If a patient is assessed as needing onward referral before the NSMDT/RNSMDT is due to meet, it is made without delay and before the next MDT meeting.

Patients requiring specialist neurological rehabilitation as an in-patient in the northern region of the NCA should be referred to the neuro-rehabilitation services shown below. The pathway for referral is shown in Appendix 2.

<b>Neuro-rehabilitation services serving the Northern region of the NCA</b>		
<b>Name of facility</b>	<b>Contact</b>	<b>Contact Number</b>
Walkergate Park (level 1 facility) Newcastle Upon Tyne	Dr L Graham	0191 287 5000
Neuro-rehabilitation Unit Bishop Auckland University Hospital	Dr Baliga	01388 455000
Neuro-rehabilitation Unit Sunderland Royal Hospital	Dr D Mitchell	0191 5656256
Neuro-rehabilitation ward Cumberland Infirmary	Dr Y Jagatsinh	01228 523444
Spinal Injuries Unit James Cook University Hospital	Mr M Mecci	01642 282644 Ext 52647

In the southern region of the NCA specialist rehabilitation is available at the facilities described below. The pathway for referral is shown in Appendix 3.

<b>Neuro-rehabilitation services serving the Southern region of NCA</b>		
<b>Name of facility</b>	<b>Contact</b>	<b>Contact Number</b>
Neuro-rehabilitation Unit Wd 26 James Cook University Hospital.	Dr Hameed Dr Stephan	01642 852816
Neuro-rehabilitation Unit Bishop Auckland University Hospital	Dr Bagida	01388 455000
Neuro-rehabilitation Unit Rutson Ward Friarage Hospital	Dr T Jayasuriya	01609 779911
Spinal Injuries Unit James Cook University Hospital	Mr M Mecci	01642 282644 Ext 52647
Walkergate Park (level 1 facility) Newcastle Upon Tyne	Dr L Graham	0191 287 5000

For out-patients, patients should be referred to appropriate community rehabilitation services. For complex physical needs, this should be a neuro-rehabilitation team. For patients with general rehabilitation needs it may be more appropriate to use general rehabilitation teams, who would be able to access specialist advice from practitioners in neuro-rehabilitation, neuro-oncology or specialist palliative care services if required. Patients should be able to have expedited access or re-access to neuro-rehabilitation and/or specialist palliative care services due to the nature of the disease and potential for rapid changes in condition. This will contribute towards avoidable hospital/hospice admissions and enable patients to remain at home for as long as possible.

Referrals should be made to the appropriate teams and responded to within an appropriate timescale as per local policy.

Due to the complexity of neurological and cognitive deficits, patients should be offered domiciliary visits where required.

Discharge/end of treatment summaries should be sent to referrers, patients and GPs within 7 working days of the end of an episode of care. Rapid re-access to rehabilitation services should be available and clearly signposted through appropriate contact information.

## **4.2 Equipment**

Holistic assessment at all key stages of the cancer pathway, and particularly in respect of discharge planning, should highlight any functional problems which may require referral for further specialist assessment for equipment needs.

Providers should ensure suitable facilities and ready access to equipment to support effective and safe rehabilitation. They should ensure equipment is available to enable patients to continue their rehabilitation plan at home. Priority should be given to those patients who are at the end of life, with recommendations that appropriate equipment is available within 24 hours of the request.

Providers and commissioners must ensure that equipment required for discharge is organised and delivered in a timely manner to facilitate a timely and safe discharge. This will include carrying out any access visits required locally.

## **5. Neuro- Rehabilitation Pathway**

Patient pathways for rehabilitation access/referral are detailed as below; recognising that referral to rehabilitation services should take place as part of holistic assessment at key stages of the pathway and, as a result of any changes in condition that would indicate the need for rehabilitative intervention.

Appendix 1: shows pathway for the whole NCA

Appendix 2: shows local pathways for north region of NCA

Appendix 3: shows local pathways for south region of NCA

## 6. References

Department of Health (2007) Cancer Reform Strategy

Dietz JH (1980). Adaptive rehabilitation in cancer. *Postgraduate Medicine*, 68 (1), 145-153

NICE (2004). Improving supportive and palliative care for adults with cancer (NICE guideline). *Guidance on Cancer Services*. National Institute for Health and Clinical Excellence.

NICE (2006). Improving Outcomes for People with Brain and other CNS Tumours. (NICE Guideline). *Guidance on Cancer Services*. National Institute for Health and Clinical Excellence.

National Cancer Action Team (2009). *Supporting and Improving Commissioning of Cancer Rehabilitation Services: Guidelines and Review of Evidence*.

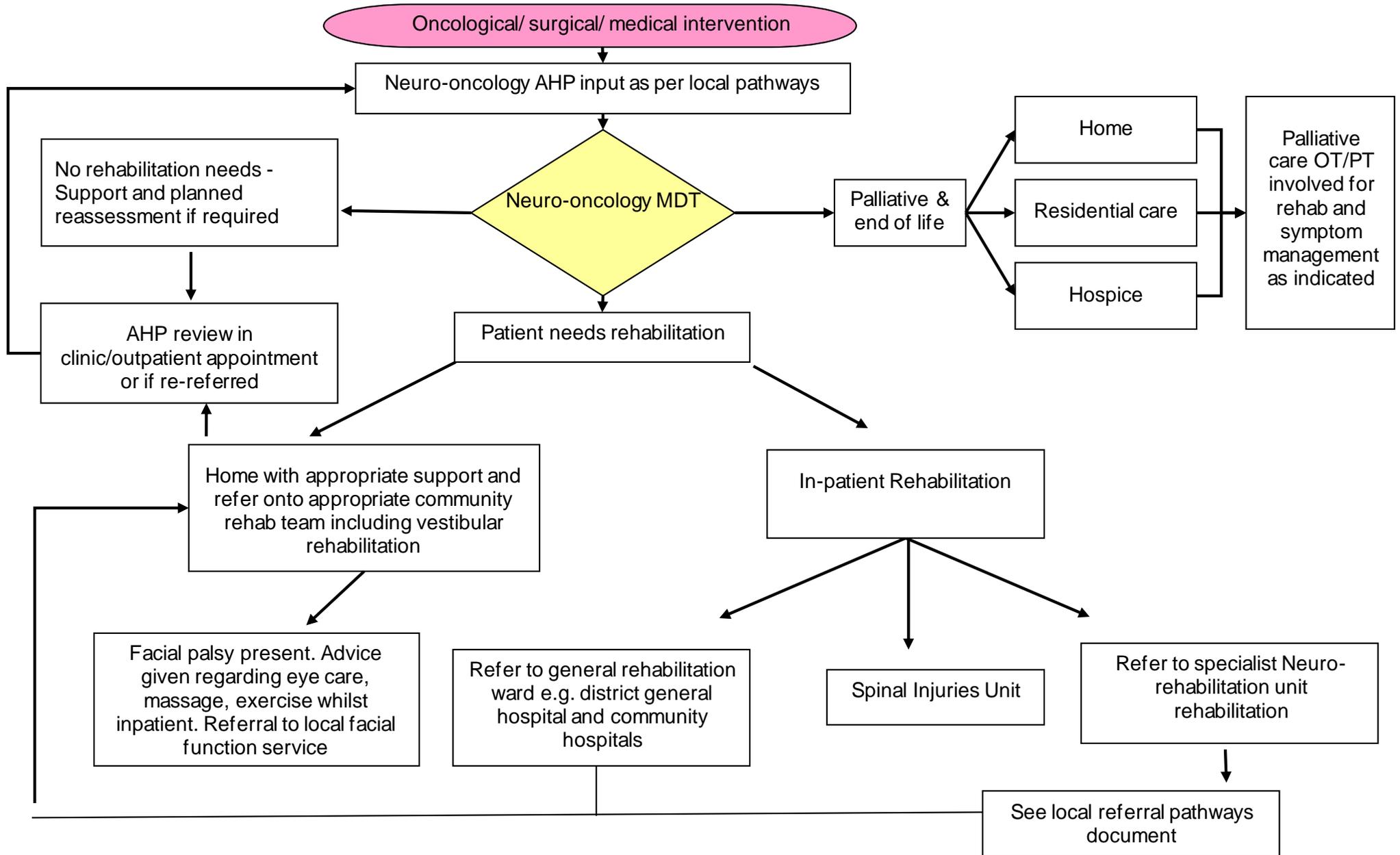
National Cancer Action Team (2013). *Cancer Rehabilitation Common Pathway*.

NICE Guidance – Brain tumours (primary) and brain metastases in adults, July 2018.



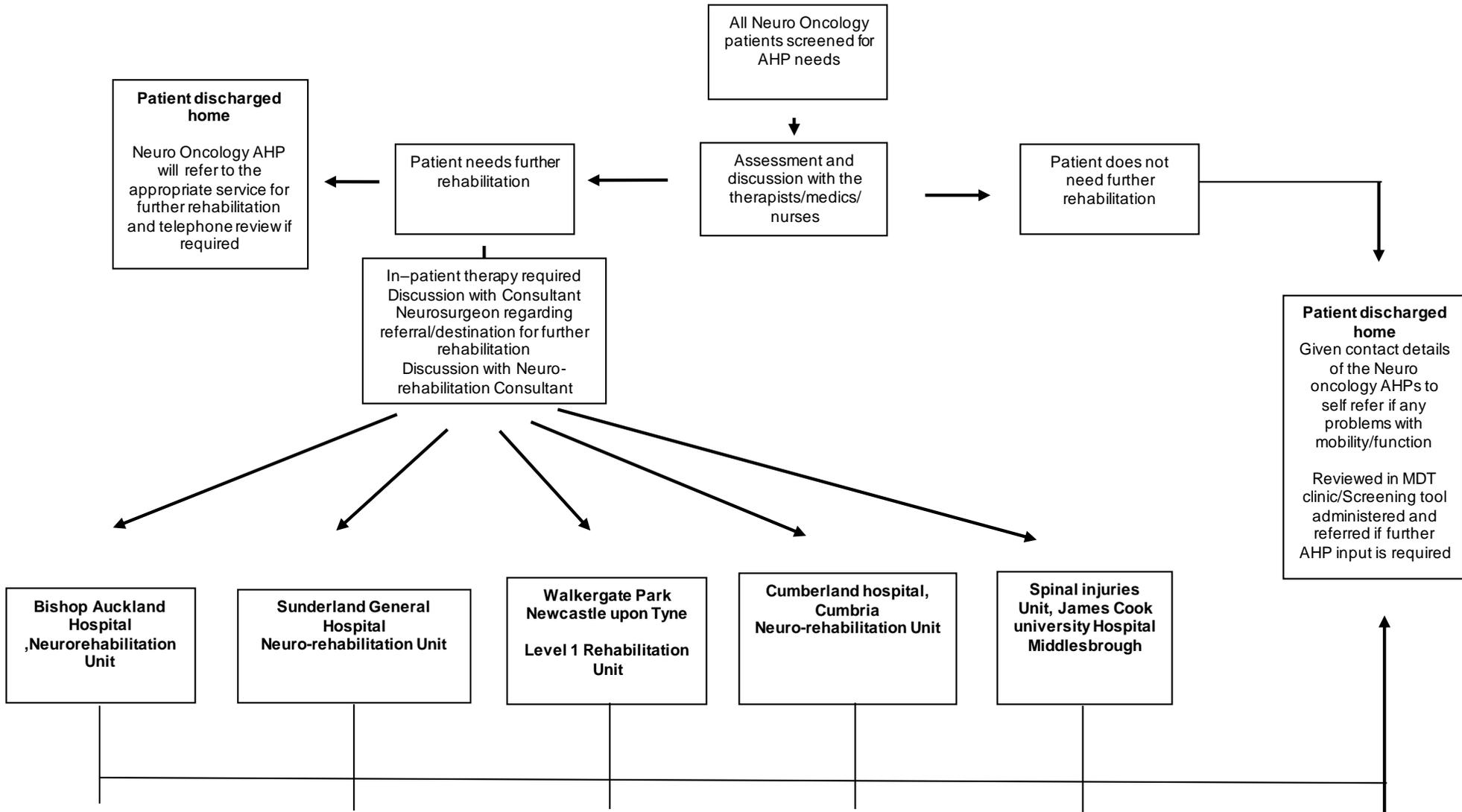
Appendix 1

Rehabilitation Pathway for Neuro Oncology patients accessing services in Northern Cancer Alliance



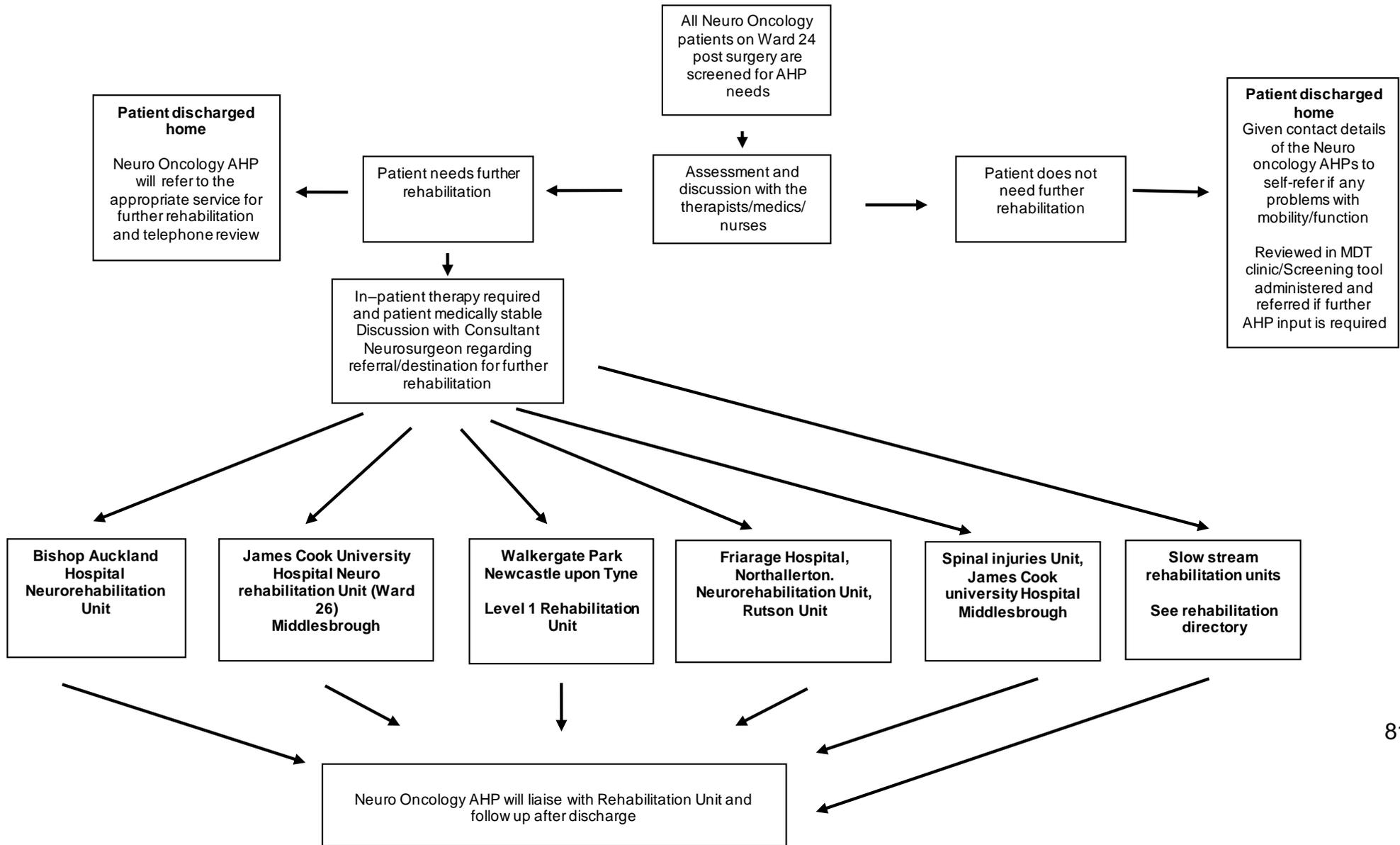
Appendix 2

Rehabilitation Pathway for Neuro Oncology patients following surgical intervention at Royal Victoria Infirmary, Newcastle upon Tyne Hospitals NHS Foundation Trust



Appendix 3

**Rehabilitation Pathway for Neuro Oncology patients following surgical intervention at James Cook University Hospital, Middlesbrough, South Tees Foundation NHS Trust**

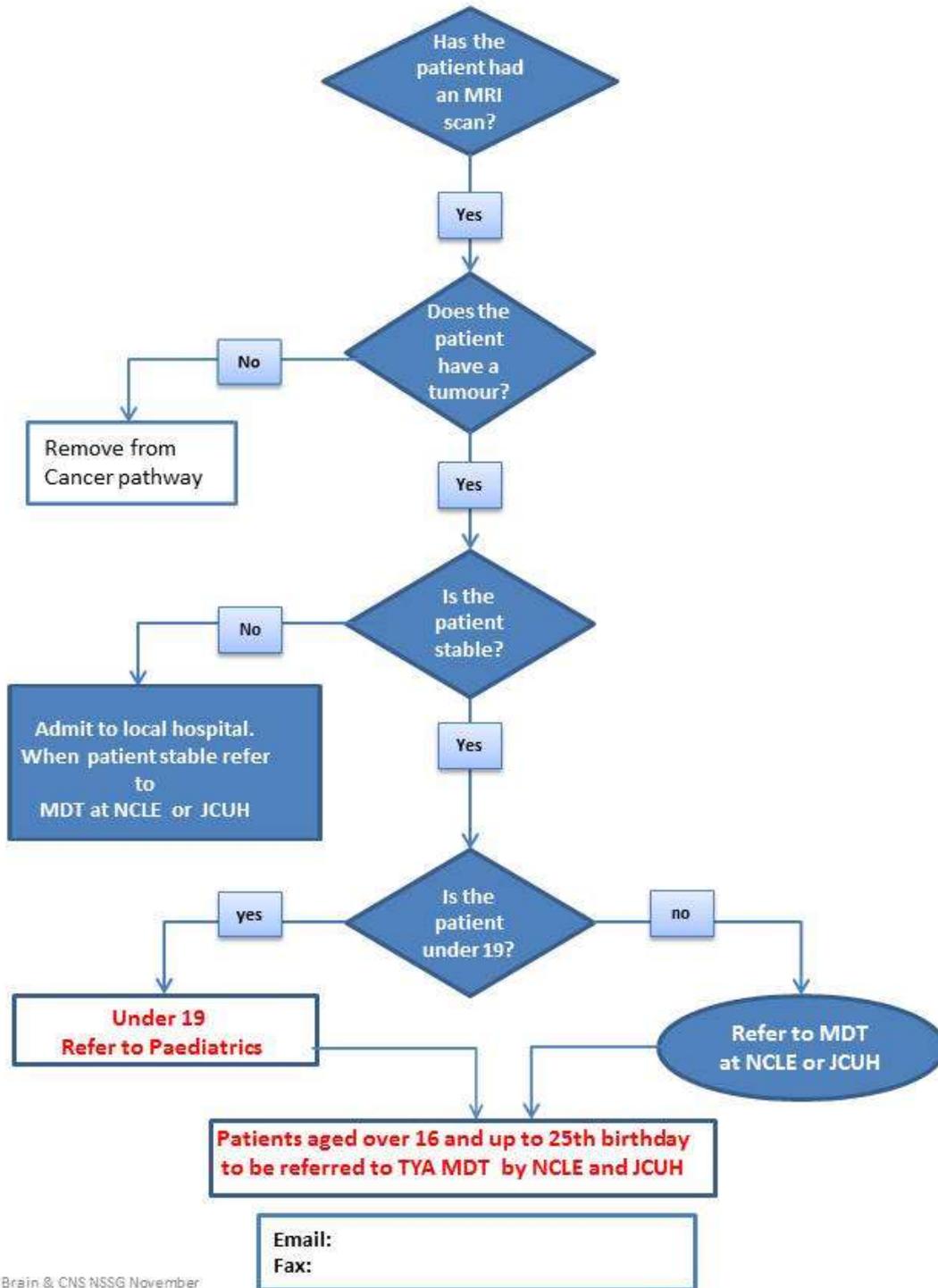


Meningioma and complex low grade/high grade patients have pre-operative multi-disciplinary assessment (Physio, OT, SALT and Neuro-psychology) and 6 month follow up MDT assessment.

Rehabilitation Directory accessible at: <https://www.southtees.nhs.uk/services/neuro-rehabilitation/directory>

# Appendix 5 Brain and CNS Patient pathway – post MRI

## Brain and CNS Patient Pathway - post MRI



# Appendix 6 – Patient Pathway

Pathway for ADULT patients (aged 19 and above) with suspected primary cancer of the Brain and Central Nervous System

