King’s College Hospital NHS Foundation Trust

Neuro-oncology MDT

Operational Policy

2023

The MDT’s Operational Policy has been agreed by:

MDT lead Prof Ashkan

Date 12/11/23

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# Introduction / Background

The Neuro-oncology Service at King’s Health Partners (KHP) consists of three specialist Neuroscience services with local neuroscience MDTs for each specialty. This document refers to the main Neuro-oncology service. There are separate policies for the Skull Base and Pituitary services.

The growth of the Neuro-oncology service led to the development of sub-specialties. The individual MDTs are all continuing to grow year on year, this structure has created the necessary capacity for this increase as well as providing patients with access to an expert service dedicated to their rare tumour type. Patients attending all the KHP Neuroscience services receive outstanding individualised care.

Specialist Neuro-oncology surgery has been a key service provided by the department of neurosurgery at King’s College Hospital (KCH) ever since its establishment in 1995 following the merger of the neurosciences units at the Brook and Maudsley Hospitals. Prior to the merger, high quality Neuro-oncology service was a well-recognised feature of both the latter hospitals. King’s College Hospital NHS Foundation Trust is part of King’s Heath Partners working in partnership with Guy’s and St Thomas’s NHS Foundation Trust (GSTFT), King’s College London and South London and Maudsley NHS Foundation Trust.

King’s Health Partners was designated as a supra stroke centre and is also a designated trauma centre for Neurosciences. The Improving Outcomes Guidance for People with brain tumours and other CNS tumours (2006 and 2018) has been implemented and adhered to along with the more recent recommendations.

Consultant neurosurgeons work in partnership with a comprehensive multi-disciplinary team (as defined by Improving Outcomes Guidance). The infrastructure within which the Neuro-oncology service is providedincludes 62 neuroscience adult and 10 paediatric ward beds, an 11-beded neurosurgical high dependency unit and four operating theatres equipped with Neuro-navigational, image guidance and stereotactic equipment necessary for optimal neuro-oncological surgery. Extensive neuroradiology services and expertise are available on site including two 1.5 Tesla MRI scanners and dedicated CT scanner for neurosurgery. The oncology services are located at the closely linked Guys Cancer Centre which is a state-of-the-art facility opened in 2016 and Kent Cancer Centre based in Maidstone.

The Trust’s commitment to the ongoing growth and development of Neuro-oncology services has been demonstrated by the employment of further neurosurgeons with subspecialty interest in Neuro-oncology; expanding the Neuro-oncology Clinical Nurse Specialist team; expanding the dedicated Neuro-oncology research team, and investment in stereotactic and surgical equipment has also been made. The benefit of this has been realised by South East London demonstrating the best survival data for neuro-oncology patients in the country.

The vision of King’s Health Partners is to work with specialist clinical teams to support local diagnosis, treatment and care, through providing ready access to the very highest level of clinical expertise and quality. We believe that patient care should be delivered locally wherever possible and we are working with our partners in South East London and Kent and Medway to further establish the communication, technology and outreach services that will enable us to minimise journeys to the centre and maximise use of local resources.

King’s is committed to improving patients’ experiences of care and providing the highest quality, personalised support to patients and their families (4.1 million catchment area). Experienced Clinical Nurse Specialists are central to the MDT and the holistic care of our patients. There are separate compliant MDTs for Paediatric and Teenage and Young Adult patients which are well established and supported by Oncologists from the Royal Marsden Hospital with dedicated sessions. King’s works in collaboration with the Royal Marsden Hospital as the principal treatment centre for children and young people for South East London and Kent and Medway. There is an ongoing service development strategy that includes gathering feedback from patients on all aspects of their journeys through our care. For outpatient attendances and inpatient admission, King’s is compliant with all cancer waiting time targets.

Children and Young Persons are managed according to the South London children and young person’s groups’ pathway. There is a dedicated teenage and young adult clinic ran on a monthly basis. Our principal treatment centre for children, and teenagers aged between 16 and 19 is the Royal Marsden Hospital. The teenagers and young adults aged between 19 and 24 are offered the choice of treatment at the Royal Marsden or Guys and St Thomas’ Hospital.

KHP have an established metastatic spinal cord compression service for the population of South East London and Kent and Medway. This service is in addition to the Trusts Acute Oncology Service. There is a co-ordinator for the metastatic spinal cord compression service who is part of the acute oncology team. All cases of suspected MSCC are discussed in the specialist MDT.

The services for Brain and Central Nervous System at King’s Health Partners consist of the main Neuro-oncology service and subspecialties in Pituitary and Skull base services. The spinal tumour cases that are non-metastatic cord compression are also dealt with by the main Neuro-oncology service.

Each area has a specialist MDT that links together via internal referral as required. The main Neuro-oncology MDT occurs weekly on a Friday. The Skull Base MDT takes place weekly on Mondays. The Pituitary MDT operates weekly on a Wednesday. The timings of the MDT’s ensure any onward referral amongst the specialties is done so without delay.

The local Neuroscience MDT takes place twice a month on the 2nd and 4th Mondays of the month before the combined Neuro-oncology clinic. Where required patients from the pituitary and skull base services will be noted at this meeting.

# Neuro-oncology Catchment Population

King’s College Hospital serves a large geographical area for its Neuro-oncology services, including the natural catchment area of south London and Kent. A significant volume of work is also received from the rest of London and across the country.

For Neuro-oncology in particular, the service currently receives referrals from:

South East London:

* Guy’s and St Thomas’ NHS Foundation Trust – Neuroscience and combined local MDM
* South London Health Care Trust.
* University Hospital Lewisham
* Royal Marsden Hospital (paediatric and young adults)

Kent and Medway:

* Medway Foundation NHS Trust, Medway Maritime Hospital
* Dartford and Gravesham NHS Trust, Darenth Valley Hospital
* East Kent Hospitals University Foundation Trust: -

 - William Harvey Hospital

 - Queen Elizabeth the Queen Mother Hospital

 - Kent and Canterbury Hospital

* Maidstone & Tunbridge Wells NHS Trust: -

 - Tunbridge Wells Hospital (Pembury)

 - Maidstone Hospital –local MDT to be established

**Catchment Population**

King’s is the referral centre for Neuro-oncology for the South East London and the Kent and Medway. We also take a proportion of patients from South West London as well as other parts of London and Surrey.

Surgery rates for Neuro-oncology vary, although the national figure is suggested as being in the region of 10-15%. The number of patients that are not operated on has increased year on year as has the outpatient activity figures.

The number of patients referred for discussion in the Neuro-oncology MDT is also continuing to grow, as a result of this the MDT is now 2 hours in duration to facilitate appropriate discussion for the increased numbers referred to the service.

# Membership of the Multidisciplinary Team

## Lead Clinician

The Lead Clinician Professor Keyoumars Ashkan is the chairperson of the MDT meeting who has responsibility for making sure that the meeting runs efficiently and that the appropriate conclusions of each case are summarised so that they can be recorded by the MDT co-coordinator.

The principal responsibility of this role is to ensure high quality services and clinical management for **all** patients suspected of having a neurological malignancy, in line with the objectives as laid out in the Manual of Cancer Service Standards and as documented in the Trust MDT role description and confirmed in the letter from the Trust Lead Cancer Clinician to the Neuro-oncology MDT lead

That is:

* To ensure that designated specialists work effectively together in teams such that decisions regarding all aspects of diagnosis, treatment and care of individual patients and decisions regarding the team’s operational policies are multidisciplinary decisions.
* To ensure that care is given according to recognised guidelines (including guidelines for onward referrals) with appropriate information being collected to inform clinical decision-making and to support clinical governance/audit.
* To ensure that mechanisms are in place to support entry of eligible patients into clinical trials, subject to patients giving fully informed consent.
* To ensure that the MDT coordinator will ensure that minimum data is collected as per the national cancer dataset.
* Chairs quarterly service improvement meeting which annually reviews and updates operational policies.

## Core Members

|  |  |  |
| --- | --- | --- |
| Core member | Role | Cover |
| Prof K Ashkan | Service Lead. Neurosurgeon with subspecialist interest in Neuro-oncology | Neuro-oncology fellow/SPR |
| Mr R Bhangoo | Neurosurgeon with subspecialist interest in Neuro-oncology | Neuro-oncology fellow/SPR |
| Mr Vergani | Neurosurgeon with subspecialist interest in Neuro-oncology | Neuro-oncology fellow/SPR |
| Mr Gullan | Neurosurgeon with subspecialist interest in Neuro-oncology and spinal  | Mr Gullan SPR |
| Mr Jose Lavrador | Neurosurgeon with subspecialist interest in Neuro-oncology | Neuro-oncology fellow/SPR |
| Dr Brazil | Consultant Neuro-oncologist GSTFT | SPR/Dr Swampillai/ Dr Al-Salihi |
| Dr Swampillai | Consultant Neuro-oncologist GSTFT | SPR/Dr Brazil/ Dr Al-Salihi |
| Dr Al-Salihi | Consultant Neuro-oncologist GSTFT  | SPR/Dr Swampillai/ Dr Brazil |
| Dr K Chia | Consultant neuro-oncologist GSTT | Dr Al-salihi/Dr Brazil |
| Dr J Glendenning | Consultant Neuro-oncologist Maidstone | SPR/Dr Forner |
| Dr S Forner | Consultant Neuro-oncologistMaidstone | SPR/Dr Glendenning |
| Dr Sibtain | Consultant Neuro-radiologist. Lead. | Dr Dudau/ Dr Deasy/ Dr Ederle |
| Dr Deasy | Consultant Neuro-radiologist | Dr Ederle/ Dr Sibtain / Dr Dudau |
| Dr Ederle | Consultant Neuro-radiologist | Dr Sibtan/ Dr Deasy / Dr Dudau |
| Dr Dudau | Consultant Neuro-radiologist | Dr Sibtan/ Dr Deasy / Dr Ederle |
| Prof Al-Sarraj | Consultant Neuro-pathologist | Dr Bodi/SPR |
| Dr I bodi | Consultant Neuro-pathologist | Prof Al-Sarraj/SPR |
| Dr K Cikurel | Consultant Neurologist with subspecialist interest in neuro-oncology | Dr Joe Cons neurologist |
| Mrs V Hurwitz | Nurse Consultant **Responsible for users and carers issues and information.** | CNS team |
| Mr A Suarez | Specialist genomics Neuro-oncology Clinical Nurse Specialist. | CNS team |
| Ms L Mullens | Neuro-oncology Clinical Nurse Specialist. | CNS team |
| Ms J La | Neuro-oncology Clinical Nurse Specialist. | CNS team |
| Ms C Robinson | Low grade glioma Neuro-oncology Clinical Nurse Specialist. | CNS team |
| Ms E Kostick  | Neuro-oncology Clinical Nurse Specialist. | CNS team |
| Ms N Harding | Neuro-oncology CNS | CNS team |
| Ms S Hedges | TYA Neuro-oncology CNS | CNS team |
| Mrs E Kennaird | Neuro-oncology Clinical Nurse Specialist Kent Cancer Centre Maidstone | AOS |
| Mrs A Jones | Lead Physiotherapist For Neuro-oncology | AHP rotational attendance/ SLT/OT |
| Ms C Tooher | Lead Occupational Therapist for Neuro-oncology  | AHP rotational attendance/ SLT/PT |
| Mrs H Wren | Lead Speech and Language Therapist for Neuro-oncology | AHP rotational attendance/ OT/PT |
| Dr C Butler | Consultant Neuropsychologist  | Attends Low Grade MDT |
| Dr Burman | Consultant In Palliative care | SPR. Liaises via CNS team |
| Sherifat Adedeji | Neuro-oncology Co-ordinator | Neuro-oncology admin assistant for outcomes. Assistant service delivery manager for MDT meeting |

## Extended Team

Rhiannon Davies Advanced Practitioner Radiographer GSTFT

Mr N Thomas Consultant Neurosurgeon sub-specialising in Skull base and Spine

Mr S Barazi Consultant Neurosurgeon sub-specialising in Skull base.

Mr R Selway Consultant Neurosurgeon sub-specialising in epilepsy surgery

Dr D Bell Consultant Neurosurgeon sub-specialising in Spine and MSCC Lead

Ms C Bleil Consultant Neurosurgeon sub-specialising in Paediatric and Young adult Neuro-oncology

Mr B Zebian Consultant Neurosurgeon sub-specialising in Paediatric and Young adult Neuro-oncology

Mr S Bassi Consultant Neurosurgeon sub-specialising in Paediatric and Young adult Neuro-oncology

Mr Tolias Consultant Neurosurgeon sub-specialising in Neurovascular

Dr G Shields Clinical Psychiatrist

Ms A Rogers Macmillan Information Centre Manager

Mr A Barry Database manager

Mr G Maynard-Wyatt Lead CNS for Teenage and Young adults

Mr C Bayliss Research Lead Research Nurse GSTFT

Ms N Peat Lead Neuro-oncology Physiotherapist GSTFT

Ms R Marshall Lead Neuro-oncology Occupational Therapist GSTFT

Mrs S Hassan Project Radiographer –Intracranial Stereotactic Radiotherapy

## MDT Operational Meeting

Core team members or their cover attend the meeting on a weekly basis. Weekly MDT attendance is recorded by the MDT co-ordinator, there is a sign in sheet which is translated to the database. The co-ordinator is responsible for recording the attendance of anyone linking in via video conference,

The MDM has identified representation at the Service Improvement Meetings. In addition, the specialist MDT welcomes attendance from the unit hospitals although it is recognised that it is not possible for them to attend every week. However, video conferencing is available to enable this to happen.

The Lead Clinician for service improvement is Mr R Bhangoo who is the person responsible for ensuring that service improvement is integrated into the functioning of the MDT.

# 3. Operational Policy of MDMs for discussion and referral of patients suspected of having cancer

## 3.1 Attendance, Frequency, Location, Dates and Time

### 3.1.1 MDM schedule

The Neuro-oncology MDT runs weekly on a Friday from 1pm until 4pm. The oncology centres video-link in to the meeting from GSTFT and Maidstone. It is held virtually via TEAMs. There are 52 meetings per year. Referrers to the MDT are encouraged to attend the MDT to present and discuss their patient’s. The MDT benefits from IT presence within the meeting.

### 3.1.2 MDM attendance

Attendance is recorded via a database kept by the MDT Co-ordinator using the Teams attendance log. The meeting is recorded. There is designated cover in place for all core MDT members. This is presented in the annual report and reviewed at the Service Improvement meetings. If in extreme circumstance it was not possible to make a decision at MDT meeting due to the absence of a core member this will be documented and discussed outside of the meeting at the earliest opportunity. The patient would be added to the following week for formal re-discussion.

### 3.1.3 Quorate Meetings

In the rare occasion the MDT meeting is not quorate a decision will be made in the meeting by the Lead clinician or their deputy as to how to proceed. Given the volume of patients discussed at each weeks meeting all possible would be done to find cover so that the meeting could proceed. For any individual cases where a decision could not be reached they would be discussed outside of the meeting for an immediate plan and would then be re-discussed to confirm this.

There is a pre-clinic MDT meeting on the 1st, 2nd and 4th Mondays of the month where all patients attending clinic that day are discussed. These patients will be new patients referred from the MDT, patients on follow up with surveillance imaging and patients referred back to the joint clinic following completion of their oncology treatments. Patients who have become clinically unwell whilst on follow up can also be seen here.

This is an excellent model of joint working ensuring patients who are found to have recurrence have a proposed management plan formulated when they attend clinic that afternoon following the meeting. As the clinic is multi-disciplinary they will also see the most relevant person to that point of their pathway. This “King’s model” is now rolled out nationally and is featured in the NHS plan.

## 3.2 Patients discussed at MDT meetings

### 3.2.1 Referrals – internal

Internal referrals are made electronically via EPIC to the neuro-oncology co-ordintor. The referral is automatically on the patient record and they are added to the MDT list. This is recorded on their visit history as neuro-oncology MDT. Referrals are to be received by 5pm on Wednesdays for discussion on a Friday. The outcome is feedback via email to the referrer and added to the patient’s electronic record that day. The outcome is also sent to the GP that day electronically.

### 3.2.2 Referrals from external Trusts

Referrals are made following discussion with the on call neurosurgeon either via the PCS referral system or the oncall phone. All images must be transferred as soon as possible, ideally prior to referral or at the time of referring. Results are feedback directly to the referrer who is responsible for carrying out the MDT recommendations that are requested and discussing the outcome with the referrer.

For some patients it may not be appropriate to travel to the specialist centre as there may be clear contraindications to surgery due to co-morbidity or widespread metastatic disease. The details of such patients and the proposed MDT treatment plan (palliative care/supportive care, radiotherapy and chemotherapy) are collected and entered in to the data base for audit purposes but their care is managed locally. The referrers are welcome to attend meetings. GP and external referrers must use ERS to refer.

### 3.2.3 Any decisions made outside of MDT meeting

All patients admitted to King’s College Hospital with a suspected or confirmed diagnosis of neurological tumours should have already been discussed in the previous Neuroscience MDT meeting. It is recognised that there will be times when a patient may be admitted and /or operated without previous discussion in the MDT meeting, primarily because of the clinical urgency of the case. In all such situations, the patients will still be discussed in the following MDT meeting in order to formulate further management plan. A member of the admitting neurosurgical team should be present at the MDT meeting to present the clinical details and feedback the recommendations. In the immediate the patient will be discussed with the oncall neurosurgeon who will liaise with the Lead Prof Ashkan or one of his consultant colleagues who is a core MDT member to agree a management plan.

## 3.3 Pathology

*Process of how pathology gets referred in (i.e. slides or blocks, cut off, etc.)*

The biopsies are reported in the Department of Clinical Neuropathology and in most cases a complete diagnosis based on panels of immunohistochemical stains is available within 2 working days. Intra-operative (frozen and smear) diagnoses are available on a 24-hour basis. The reports can be reviewed on the EPR system immediately after authorisation of the report. The Neuropathologists undertake a rigorous audit system to review all cases. Neuropathology participates in all relevant national EQA schemes for both the neuropathologists and laboratory techniques. All relevant team members hold certificates to evidence this. Molecular techniques are available. FISH analyses of 1p19q deletion status and c-myc amplification, which are both prognostic indicators, have been carried out on all relevant samples since 2007 and 2010 respectively. Testing for MGMT methylation, ATRX and IDH status is carried out for all relevant biopsies. This is also now done on historic samples. More recently egfr amplification is being tested for eligibility into clinical trials.

Neuropathology results are reported in line with the Royal College of Pathologists guidelines and protocols.

WGS has been rolled out across neuro-oncology for all glioma patients. Kings is part of the BRAIN MATRIX and as such non-glioma patient will still benefit from WGS.

## Network Pathway Group Attendance

There is not currently a network pathway group for neuro-oncology in the SELACN, nor any other national network pathway group.

# Treatment Pathway

## Diagnostic Pathway

All patients with radiological suspicion of a neurological malignancy should be referred to the Neuro-oncology MDT for discussion on further management within two working days of the date of imaging report.

Neurosurgical Registrar at King’s College hospital on 0203 2994207 (diverted to a mobile if required) acts as a contact for Neurosurgical emergency advice. Refer via PCS so that the SPR can respond directly online to the question once the scans are received and reviewed.

Patients with a scan showing a possible abscess, tumour with associated hydrocephalus, spinal cord compression, posterior fossa or midline or 3rd ventricular tumour, or GCS 13/15 or less warrant emergency referral and must have the following investigations undertaken:

* Brain contrast CT scan or preferably a contrast MRI scan.
* Chest x-ray
* Full blood count/U+E/Clotting screen
* If patient is on Aspirin, Warfarin, Clopidogrel or Dipyridamole, they must be stopped until discussed with neurosurgeons
* Commence patient on Dexamethasone 8mgs bd at 08.00am and 14.00 pm (unless abscess suspected)

All other patients must have the following investigations done prior to referral

* Brain MRI with Gadolinium scan (contrast CT if patient cannot tolerate MRI)
* Chest x-ray
* If metastatic disease suspected: Chest/Abdomen/Pelvis CT scan and tumour markers (directed by results of CT Chest/abdo/pelvis)
* If spinal tumour suspected: whole neural-axis MRI scan
* Full neurological examination
* Full blood count/electrolytes/Clotting screen
* If patient is on Aspirin, Clopidogrel or Dypiridamole they must be stopped
* Stop anticoagulants e.g. warfarin unless high risk such as metallic heart valve, intra-cardiac thrombus or pulmonary embolus in the previous 6 months. In these cases may switch over warfarin to intravenous heparin infusion.

The Neuro-oncology MDT may require the local hospital/ referring team to perform further investigations before a definitive management plan can be formulated or patient transferred to the neurosciences centre. Specialist imaging maybe organised after MDT discussion.

Cross-sectional diagnostic imaging (Computerised Tomography and Magnetic Resonance Imaging) from both King’s College Hospital and the regional district general hospitals is reviewed at the Neuro-oncology MDT by a consultant Neuro-radiologist both pre-operatively and post-operatively. With some difficult cases we have the option of using Magnetic Resonance spectroscopy or functional MRI.

Expertise for CT guided biopsy of spinal and Para-spinal tumours is available. When a conclusive MDT decision is not possible we have the option of following-up patients in the dedicated Neuro-oncology clinic with further interval cross-sectional imaging reported by the Neuro-radiologist.

It is the responsibility of the referrer to feedback the MDT outcome to the patient unless the patient is due to be admitted for surgery within a week, in which case the Neuro oncology CNS team will then call the patient following the MDT meeting and talk through any clinical questions with them. The patient may be offered an appointment in the Neuro-oncology pre-assessment clinic where the role of surgery will be discussed and an admission date confirmed.

Patient’s identified as being suitable for ‘Best Supportive Care’ are offered an appointment with a Neuro-oncology CNS in the nurse-led clinic if they are well enough or a telephone consult for the family if preferred.

Where a patient is reviewed a second or subsequent time by the MDT a new outcome will be generated on their original MDT form to allow the previous discussions to be noted.

Radiology must be electronically transferred. These can then be viewed and discussed at the MDT meeting for specialist opinion. Local hospital PACS systems cannot be shown in the MDT meeting room.

As part of the Neuro-oncology Cancer Centre developments we have an established referral proforma and guidelines which sets out required referral information. We ask always to be advised of existing diagnostic tests and staging so patients are not subject to repeat tests unless clinically indicated.

All patients with a suspected or confirmed neurological malignancy (Brain or CNS tumours) should be notified to the specialist team. The team will agree the treatment options for each patient. The team may also discuss patients diagnosed outside of the Cancer Centre where the agreed management plan may be for the unit to continue the care. All patients will have a referral form filled in by the referring local team and a record of the MDT discussion will be kept. These forms will be subject to audit on an annual basis.

In urgent circumstances, clinical decisions may need to be made outside of the MDT meetings. In such cases, the consultant in charge of the patient will initiate or refer for treatment without delay and the management plan will be presented at the next MDT.

## Outpatients

**Neuro-oncology MDT clinic**

This is held on the 2nd and 4th Mondays of the month on the first floor of the willowfield building at King’s College Hospital. The clinic is attended by the Consultant neurosurgeons with a sub-specialist interest in neuro-oncology, the clinical fellow, the Neuro-surgical trainees rotating in to neuro-oncology at Senior Registrar level, the Oncology consultants from GSTFT, The Consultant Neurologist with a specialist interest in Neuro-oncology and a member of the Neuro-oncology CNS team. The clinical trial team also attend to see patients where applicable.

**Key worker clinic**

All Neuro-oncology patients will be offered a clinic appointment with their designated key worker to receive the results of their histology and to discuss their proposed management plan for further treatment if required. Their case will have been discussed prior to this appointment in the Cancer Network MDT. The clinic appointment is patient choice between video call using TEAMs or in person. Clinic slots are 30 minutes in duration.

**The MDT Neuro-oncology Pre-assessment Clinic**

This is held every Monday morning in the Willowfield Building on the first floor. It is attended on a rotational basis by a Consultant neurosurgeon with a sub-specialist interest in neuro-oncology, the clinical fellow, the Neuro-surgical trainees rotating in to neuro-oncology at Senior Registrar level, Specialist Neuro-oncology AHP representatives on a rotational basis though if a specific discipline such as speech and language is required they will also attend clinic for the identified patient, where possible two members of the Neuro-oncology CNS team attend to ensure all patients have adequate support. The trial team is also present to recruit suitable patients.

**Meningioma Telephone follow up clinic**

This is held on a Wednesday morning on a weekly basis. It is ran by the Neuro-oncology CNS team. The clinic is aimed at patients who have been operated on a Grade I or where appropriate II meningioma and have had one physical follow up appointment with their surgical team. There are ten slots available for this clinic each protocoled for fifteen minutes per patient. This clinic is at or over capacity on a weekly basis therefore this will be subject to review in 2024.

**Low Grade Glioma clinic:**

This is a clinic that has six allocated slots for patients review who have a low grade glioma suspected that is being considered for surgical intervention. It enables the patients to be provided with the time they need to discuss this diagnosis and treatment options. It also allows the team to review all the pre-operative imaging, TMS, neuropsychology assessments and plan their care. The clinic is attended by three neuro-oncology sub specialist neurosurgeons, the low grade glioma CNS and a neurologist with a specialist interest in neuro-oncology. There is a Low grade glioma specific MDT that occurs prior to each clinic. The neuropsychologist attends these MDT meetings alongside the afore mentioned clinicians.

## Treatment Pathways for emergency and non-emergency surgical referrals can be found in appendices 1 and 2.

Once the Neuroscience MDT has decided that neurosurgical input is required for management of a patient, depending on urgency of the case, patient’s may rarely require immediate admission/ transfer to King’s College Hospital or more commonly be booked into either the Neuro-oncology clinic held bi-monthly which includes the following core members:-

* Neuro-surgeon
* Oncologist responsible for radiotherapy
* Oncologist responsible for chemotherapy
* Specialist nurse
* Neurologist

or the Neuro-oncology pre-assessment clinic which is held weekly and attended by a subspecialised neuro-oncology Neurosurgeon, Neuro-oncology CNS, AHP representatives and where appropriate a member of the clinical trials team.

For those patients requiring admission, the Neuro-oncology CNS team will liaise with the surgical team regarding a suitable date. All information and arrangements are fed back to the referring team by the allocated Neuro-oncology CNS and Neuro-oncology co-coordinator. All patients for admission must have MRSA screen results for nose, throat and groin/perineum faxed or emailed to the Neuro-oncology co-coordinator following the outcome.

Neurosurgery for patients with neurological tumours and the immediate post-operative care is performed at King’s College Hospital site. Patients are admitted for biopsy or de-bulking surgery on the day or night before their operation. They are invited back to an outpatient appointment approximately seven days after their surgery where they are seen in the nurse-led histology results clinic.

For those needing post-operative radiotherapy or chemotherapy, referral is then made by the CNS team to either Guys Cancer Centre or The Kent Cancer Centre depending on patient locality, preference or eligibility for any potentially suitable oncology clinical trials that maybe available. Imaging is transferred electronically and all documentation is sent to the accepting consultant.

Patients are generally seen that week or the following week in the oncology clinic. Here they will discuss treatment options and be given written information about the options available. If appropriate they will also see the clinical trial team and be given the patient information sheets. For the duration of their oncology treatment they will remain in the Cancer Centre outpatient clinics. They will be transferred back at the end of their treatment to the multi-disciplinary clinic at Kings College Hospital.

## Palliative Care

There is a well-established Palliative Care Service at King’s. Out of hours nursing care is provided by a number of local providers including

* St Christopher’s hospice
* Trinity Hospice
* Greenwich and Bexley community hospice
* Ellenor Lions Hospice
* Pilgrims Hospice
* Heart of Kent hospice
* Hospice in the weald
* Demelza Hospice for children and young adults
* Lewisham Macmillan Palliative Care Team for inpatients and Lewisham residents in the community

Early referrals for patients on active treatment, given with palliative intent, are encouraged in the local area. In such patients, the prognosis will usually be limited and focus of treatment will have changed from curative to palliative. A demonstrable need for specialist palliative care services must be established. Appropriate reasons for referral include: pain control, control of other symptoms, e.g. vomiting. Psychological distress of patient/family or carer, terminal care/dying (prognosis usually less than two weeks) and complex social needs. The patient and/or their family/carer must be informed and agree to the referral.

The Kings college Hospital Palliative Care team provides a Monday - Friday 9:00am to 5:00pm service. At weekends a SpR is available across Guy's, King's and St Thomas' (GKT) to see patients in King's. A consultant is also available after 5pm and before 9am to offer telephone advice for healthcare professionals with palliative care problems.

All core team members delivering significant news have undertaken the Advanced Communication Course.

## Follow Up

Patients are offered follow up in the multi-disciplinary clinic on the KCH site. Their scans are discussed in the pre-clinic meeting with all members of the MDT present and a provisional management plan will be agreed. The patient will then be seen by the most relevant person in the clinic following the meeting. This allows for joint consultations with the Oncologist and Surgeon as well as specialist advice from the Consultant Neurologist.

For the patients in Kent they may opt to have their follow up locally to save them from the travelling and cost this incurs. If there is any evidence of recurrence on their scans they will be referred back to the MDT for agreement of a management plan.

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# 5. Clinical Guidelines

## 5.1 SELACN Clinical Guidelines

Our service is compliant with the NICE guidance on the treatment of Brain and CNS tumours. Increased awareness and a low threshold of suspicion are probably the most important means of decreasing the delay in diagnosis of brain tumours. Patients with brain tumours usually present with symptoms of raised intracranial pressure such as headaches, nausea and vomiting; focal neurological deficits such as hemiparesis and cranial nerve palsy or epilepsy.

### **King’s College Hospital**

Neurosurgery for patients with neurological tumours and the immediate post-operative care is performed at King’s College Hospital site. These patients are all discussed at the combined Neuroscience and local cancer MDT meeting.  However, the MDT also performs the important function of dealing with Neuro-oncology cases that are inoperable for reasons such as multiple metastases, severe co morbidity, and those referred for palliation.

## **Organisation of Surgical Services:**

All surgery for neurological tumours within the catchment networks is carried out on the King’s College Hospital site by members of the core team.

Following discussion at the combined neuroscience and local cancer MDT meeting and completion of recommended investigations at the local hospital, patients accepted for surgical intervention are admitted to the KCH site, usually a day before the planned surgery. Depending on clinical and technical issues, patients may undergo biopsy, de-bulking or complete resection of tumours. The theatres at KCH are equipped with state of the art stereotactic and image guidance systems to allow localisation and accurate approach to the tumours. Expertise is available for functional mapping, transcranial magnetic stimulation and awake surgery if needed. Following surgery, patients are cared for on the neurosurgical high dependency or post-op bay and then ward beds. The patients are then discussed in the subsequent MDT meeting to correlate the histology, radiology and clinical findings and formulate further management and referral-on aspects.

There are also regular clinics preceded by the combined neuroscience and local cancer MDT meeting for discussion of all patients to be seen in the clinic.

It should be noted that all consultant neurosurgeons at KCH, along with their team, take part in the emergency on call rota. Advice and expertise are therefore always available should a patient require urgent transfer/ intervention.

* Patients undergoing neurosurgery need to fulfill general fitness and anaesthetic criteria.
* Any metabolic, hematological (particularly platelet) and clotting abnormalities should be corrected.
* Non-steroidal anti-inflammatory drugs e.g. Aspirin, Clopidogrel and Dypiridamole should be stopped at time of referral and at least 10 days before surgery.
* Anticoagulants such as warfarin should be stopped except in high risk patients such as those with intra-cardiac thrombus, metallic heart valve or a pulmonary thrombus in the previous six months.
* In such high risk patients warfarin should be switched over to intravenous heparin (if in doubt discuss with the local Haematologist).
* In all patients being transferred under the emergency protocol, anticoagulants should be stopped in preparation for imminent surgery upon admission to KCH.
* Almost all patients with brain tumours undergoing surgery will need to be on Dexamethasone to cover the peri-operative period. The neurosurgical team can be contacted for advice with regard to this.
* Patients with epilepsy will need to be on anti-epileptic medications.
* All patients screened pre-op for incidental DVT.

It is essential that patients are spoken to by the local team responsible for their care regarding the reason for referral to King’s College Hospital and documentation of the discussion must be made in the patients local notes. An open and honest discussion must be undertaken by a person who has completed the connected advanced communication skills course.

**Primary Spinal Tumours Management**

These tumours are relatively rare, some very rare. Most are benign or of ‘low grade’ in nature. Some rare tumours such as chordomas may be difficult to treat because of high local recurrence rates and potential metastatic spread.

Some are malignant and frequently carry a grave prognosis, especially with regard to spinal cord function, for example a malignant astrocytoma of the spinal cord.

Malignant spinal cord compression is managed separately and is due to tumours that have spread to the spine secondarily from a primary and are referred to the malignant spinal cord compression pathway.

The primary tumour arises in either the vertebral column, extradural space or intradural space. In The latter compartment they arise in the spinal cord itself (intramedullary) or within the space between the cord and the dura (intradural, extramedullary).

The patients may have quite lengthy clinical presentation and the diagnosis is radiological (MRI/CT). Many are chronic and pose no immediate threat, but the clinical presentation and radiology are referred to the Neuro-oncology weekly meeting for review. If surgery or further treatment is required an appropriate treatment plan is put forward by the Team. Urgency of surgery largely rests with the nature of the lesion and degree of compromise of the neural structures, rather than any risk of metastatic spread.

The surgery for these lesions as well as oncological and radiotherapy treatments may be complex and specialised, requiring involvement of different specialities with skills in various specialist areas of expertise. This requires appropriate planning and referral, for example management of suspected primary vertebral column tumours such as chordomas or chondrosarcomas may need additional support and guidance from other Units such as The Royal Marsden or National Orthopaedic Hospital.

Policy is that the initial discussion starts with review in the neuro-oncology MDT where core member can make the appropriate referral to specialist spinal surgeons as necessary. Patients with neurofribromas and schwannomas may for example be referred to the specialist Unit at Guy’s Hospital for genetic screening and counselling.

**Metastatic tumour Management**

There are an increasing number of patients referred to the neuro-oncology MDT with suspected metastatic brain tumours. This is acknowledged nationally by the inclusion of metastatic brain tumours in the most recent version of the NICE guidelines published in 2018. We have been pro-active in catering for this and in fact included a section in the MDT dedicated to metastases a year before the NICE publication. The referral process remains the same as all other neuro-oncology referrals. We request all referrers to discuss the patient with their primary oncologist prior to referral to the neuro-oncology MDT to ensure it is appropriate in the context of their systemic disease status and obtain an idea of the prognosis.

As mentioned in the referral guidelines above, it is imperative that these patients have up to date CT chest, abdomen and pelvis scans as well as MRI’s with contrast to show the true nature and extent of their systemic and CNS disease. Brain CT alone is inadequate in this context. Patient management now commonly includes referral for stereotactic radiosurgery at Guys Cancer Centre where there is a weekly MDT to discuss these cases every Wednesday. 2019 will see the introduction of a dedicated MDT clinic for metastases attended by neurosurgeons as well as the clinical oncologists and advanced practitioner radiographer.

**Communication with Patients and Families**

* Patient/ carers are informed of decisions made by both the Neuroscience MDT and the combined neuroscience and local cancer network MDT within 1 working day for inpatients or 5 working days for outpatients.
* Referrals to palliative care or rehabilitation services will happen within 1 working day of decision of combined neuroscience and local cancer MDT
* Any patient requiring onward referral to a member of the CNMDT will be made within two days of the MDT decision.
* All patients will be allocated a Key Worker- see appendix 8 for key worker contact details.
* Information Prescriptions are given at key times
* All patients will be given significant information by members of staff trained in Advanced Communications
* No information will be given by junior doctors

All patients will be offered a copy of clinic letters

Teenage and Young Adults (2018):

The Neuro-oncology cancer team adhere to the Trust's Operational Policy for Teenage and

Young Adults.

The function of the TYA Young Adults Team Meeting (YATM) is to review the presentation, pathways and care of all referred patients aged 16-24 inclusive as defined in the NICE Improving Outcomes Guidance for Children and Young People of 2005.

All TYAs 16-24 will be discussed with the Preferred Treatment Centre (PTC) and will be presented at their TYA MDT regardless of where the 19-24 year olds choose to have their treatment.

Referral of patients to be seen and managed at the designated unit or centre for an informed ‘place of care’ decision:

This refers to patients aged 19-24 inclusive, who will be offered unhindered access to the PTC and will be enabled to make an informed choice of place of care between the local adult cancer service and the PTC. The PTC will be alerted of the patient and informed of the patient’s choice. This choice will then be documented clearly within the notes.

Sending referral and receipt of notification:

The first point in sending a referral is for the cancer site specific team (clinical nurse specialist, consultant or MDT coordinator) to contact the TYA lead cancer nurse, as soon as a TYA with cancer appears likely from radiological or pathological findings. This should not be delayed for confirmation at site-specific MDT (SSMDT), and can be driven by doctor or clinical nurse specialist, including pathology or radiology. The TYA lead cancer nurse’s contact details are: gavin.maynardwyatt@nhs.net or mobile 07833095998. At present the referral can be sent via email.

Once diagnosis is confirmed; referral will be completed and s

ent to the TYA team meeting coordinator (not yet appointed so sent to TYA lead nurse) via email.

Cases to be discussed must be notified to the TYA Coordinator at least two working days prior to the meeting, i.e. by 4pm, Tuesday before. (However telephone discussion of urgent cases is likely often to be essential and can therefore be included on the list for the meeting. Non urgent cases if they miss the 4pm deadline can be discussed at the following meeting); the timing of the respective MDTs must not delay the starting of urgent treatments.

Required information includes:

• Patient demographics

• Date and type of referral to the Unit (2 week wait; Other urgent GP referral; Routine)

• To whom originally referred in the unit

• Details of any internal transfer within the unit

• Date first seen at the Unit and by whom

• Dates and type of any investigations conducted in the Unit

• Date of referral to the Centre

Type of referral to the Centre (pre-op, post-op, relapse, on treatment review)

• Summary of history to date including tumour marker results

• Questions to be addressed by the Centre MDT

• Which specialty opinions are likely to be required

For patients referred for an informed choice decision, a TYA Lead Nurse will identify a suitable clinic appointment with the local team for that discussion, and arrange for the patient to be informed.

RMH do not see low grade brain tumour TYAs that do not need Radiotherapy or Chemotherapy so they are seen at GSTT even if aged 16-18. This is with RMH agreement.

## 5.2 Local implementation of SELACN Guidelines

### 5.2.1 Referrals from Primary Care

Referrals from GP’s are made via ERS the electronic referral system. This has replaced completion of the MDT proforma which is used by all other referrers.

### Referrals within KCH NHSFT

All patients admitted to King’s College Hospital with a suspected or confirmed diagnosis of neurological tumours should have already been discussed in the previous Neuroscience MDT meeting. It is recognised that there will be times when a patient may be admitted and /or operated without previous discussion in the MDT meeting, primarily because of the clinical urgency of the case. In all such situations, the patients will still be discussed in the following MDT meeting in order to formulate further management plan. A member of the admitting neurosurgical team should be present at the MDT meeting to present the clinical details and feedback the recommendations.

# Communication

## MDT Nurse Specialists - Responsibilities/ Key Worker

The Neuro-oncology Clinical Nurse specialist role includes:

* To be the first point of contact for patients accepted under the care of the MDT.
* Act as key-worker or responsible for nominating the key worker for the patient.
* To educate support and counsel patients providing relevant written information as appropriate.
* To lead on patient and carers communication issues for the MDT.
* To co-ordinate the pathway of the patients referred to the Neuro-oncology MDT meeting, ensuring where clinically appropriate that delays are avoided.
* To contribute to the MDT discussion, patient assessment and care planning decisions of the team.
* To carry out the Holistic Needs Assessment at designated points on the patient’s pathway: diagnosis, end of treatment and recurrence.
* To ensure the results of patients holistic needs assessments are taken into account in the decision making process.
* To ensure that patients are able to access members of the MDT for support and advice as appropriate.
* Develop the nurse led services as agreed by the MDT.
* Contribute to the Trust wide development of cancer services as requested and work as a member of the Cancer Nurses Forum.
* Provide teaching and educational input to relevant courses and provide expert nursing advice and support to other health professionals in the area of neurological cancer.
* Ensure effective written communication and verbal communication between the MDT, referring Trusts, GPs and specialist centers.
* Work with the Trust Cancer Data Team supporting the collection of Neuro cancer data and involve in clinical audit.
* To be involved in research/clinical audit in the area of neurological cancer.
* Utilise research to provide evidenced based care in the specialist area.
* To run the Nurse-led meningioma follow-up clinic, ensuring patient consultations are accurately documented and that this is disseminated to all appropriate clinicians in a timely manner.
* To run the Nurse-led results clinic and make all necessary onward referrals.

**Additional responsibilities of Lead CNS Vicky Hurwitz:**

* Responsible for managing the MDT in conjunction with Prof. Ashkan
* Lead Clinical Nurse Specialist for the combined Neuroscience and Local MDT
* Responsible for users and carers’ issues and information
* Responsibility for management, recruitment and retention of the CNS team

## Holistic Needs Assessment

The electronic Holistic Needs Assessment is being introduced in to the Neuro-oncology clinics from February 2019. A weekly virtual clinic has been set up on pims to carry out the care plan with patients who have completed the eHNA either in clinic or at home following their clinic appointment.

## Notification of a Patient’s Diagnosis to their GP

### Notification of General Practitioner/referrer:

General Practitioners will be informed at the following points:

* Within 24 hours of discussion of diagnosis with patient
* Within 24 hours post discussion of referral
* On discharge
* MDT update outcomes
* At any other key points in the patient pathway

As standard practice, clinic letters are sent out within 2-3 days of the appointment. All patients who are registered with a GP in Southwark/ Lambeth clinic letters are now emailed immediately after each patient visit.

Discharge Summaries are sent to general practitioners and referring consultants within one week of discharge. As above those GP surgeries who have the capability now receive these instantly via email as soon as the document is committed to the patient record.

The Neuro-oncology database is an important tool for communication with general practitioners and referring consultants. The database has easy printable summary sheets for communication between clinicians and to place within patient case notes.

The database summary sheet is used as the basis for the fax back information sheet sent to all referring clinicians after discussion of the patient at the MDT meeting. Additional communication to referrers includes outpatient clinic letters and discharge letters.

***Information is provided to the PCT’s on a monthly basis from the Two Week Wait office on the appropriateness and timeliness of the urgent suspected cancer referrals.***

## Patient Survey

The National patient satisfaction survey is carried out annually; the numbers for Neuro-oncology respondents are traditionally low. KHP participates in this and the results are discussed at the next Service improvement meeting and actions are agreed. Due to the poor response rate we carry out local focus groups facilitated by an independent party on an annual basis to look at ways of improving our service from the patient point of view. We also have user representatives as members of the TWG. Our Annual report details the recent audits carried out to ensure we understand our patients experience and continue to strive for improvement. We routinely audit clinic wait times, GP receipt of diagnosis and inpatient satisfaction.

Patients are asked for feedback at the Living Well events as well as the support group and low grade clinic. The response rate for this is high.

Neuro-oncology will be part of the role out of the real time Cancer Patients Experience Survey at KCH.

## Permanent Record of Initial Consultation

Patients receive a copy of all correspondence unless they opt-out. All patients’ notes are electronic and accessible across sites from Kings College Hospital and GSTFT. The GP is notified electronically when the letter is committed to the patient’s notes.

## Treatment Summaries

End of treatment summaries are completed following the initial six weeks of chemo-radiation to ensure effective communication with the GP on symptoms and side effects to expect and advice on how to manage these. A new end of treatment summary will then be completed following each subsequent treatment. If the treatment has to be completed early this will trigger completion of an End of treatment summary to ensure communication on the reasons why the treatment has been stopped are clearly identifiable to all involved in their care. The completion of these is monitored and reported on quarterly.

## Advanced Communication Skills Training

All core members breaking significant news have attended or have a date to attend Advanced Communication skills:

Prof K. Ashkan - Consultant neuro surgeon trust lead for neuro oncology

Mr R. Bhangoo - Consultant neuro surgeon

Mr R. Gullan - Consultant neuro surgeon

Mr F Vergani – Cons neurosurgeon

Mrs V. Hurwitz - Lead clinical nurse specialist

Ms S Hedges - Clinical nurse specialist

Ms E Kostick – clinical nurse specialist

Mr A Suarez – clinical nurse specialist

Ms N Harding – clinical nurse specialist

Ms L Mullens - Clinical nurse specialist

Ms J La - Clinical nurse specialist

Ms C Robinson - Clinical nurse specialist

Dr L. Brazil- Consultant oncologist.

Dr A Swampillai – Consultant Oncologist

Dr J Glendenning - Consultant Oncologist

Dr Al-Salihi – Consultant Oncologist

Level 2 psychological support training has been completed by Vicky Hurwitz, Laura Mullens, Charlotte Robinson and Liz ford. The rest of the CNS team have dates to complete the training. Supervision is provided on a monthly basis as a group.

## 6.8 Psychological Support of Patients

The neuropsychology service is essentially a diagnostic assessment. A detailed neuropsychological assessment is carried out to determine the nature and extent of intellectual and cognitive impairments in these patients. The assessment covers a range of functions including intellectual functions, memory, language, perception and executive functioning.

Referrals come via the neurosurgeons and the Neuro-oncology clinical nurse specialists. Referrals are also received from the oncologists at St Thomas’ Hospital and Maidstone and Kent and Canterbury Hospital who are part of the Joint Neuro-Oncology Clinic at King’s College Hospital. Referrals also come from neurologists.

Patients may be referred for a number of reasons including:

* patient or relative or one of the MDT members is concerned about changes in the patients intellectual or cognitive functioning
* provide a baseline before surgery
* provide baseline prior to radiotherapy treatment
* work related issues
* Post radiotherapy and long term follow-up as appropriate
* For all younger people diagnosed With a low grade brain tumour
* Any patients having awake craniotomies for Low Grade Gliomas

At the present time it is not possible to offer intervention following the assessment due to capacity restraints. Onward referral is required to the Institute of psychiatry or local services.

Level two psychological support is offered by the CNS team to patients. For escalation where level three support is needed referral to the specialist teams at the Richard Dimbleby Centre is made via the electronic referral form and a follow up phone call. Alternatively the patient is referred to the support services at their local Hospice for urgent assessment. When Level four support is required referral is made to the liaison psychiatry team for immediate assessment. Close liaison with the patients mental health teams in the community is kept where relevant.

Cancer Services with Macmillan investment have been successful to appoint to the cancer psychological support team seeing the employment of new psychologists and counsellors in to the Trust. It is envisage that the service will be operational from May 2019 and local population and in patient will have access to psychological support at the KCH.

**Site specific support group**

A site specific support group is available to all patients and their carers, facilitated by one of the Neuro-oncology Clinical Nurse Specialists and a member of the Cancer Information Team at the Ciceley Saunders Institute at King’s College Hospital. The support group runs monthly (1st Monday of the month 2:30pm - 4pm) and offers psychological support to patients in a relaxed informal setting. There is also a newly diagnosed support group running on a quarterly basis.

### **Macmillan information center at Cicely Saunders institute**

On the King’s College Hospital site there is the Macmillan information and support centre, which is open Monday-Friday 10-4pm, to support patients and their carers in a relaxed environment, away from the main hospital building, where there is a range of information available on cancer and long term illness, staffed by an Information manager and trained volunteers.

## **Macmillan Southwark Citizen Advice Bureau (CABx)**

Neuro-oncology patients have access to on site Citizen Advice Bureau clinics provided fortnightly at GSTFT and weekly at the Macmillan Information and Support Centre at KCH Macmillan Information and Support Center. This is a service specifically for cancer patients. Many of the local cab offices now contain Macmillan attachments allowing for patients to gain specialist advice locally.

**Dimbleby cancer care centre**

Patients who go on to have adjuvant treatment at GSTFT have the opportunity to access many services at the Dimbleby cancer centre. A range of holistic treatments, including, massage, aromatherapy, reflexology, counselling and bereavement support are available free to any patient with a diagnosis of cancer.

**Douglas Macmillan Centre**

The Douglas Macmillan Information Centre is based on the Queen Mary’s Sidcup campus which is a part of South London Health Care Trust.

**Maidstone Macmillan information centre**

Patients and their carers who attend Maidstone hospital for follow up treatment have access to a Macmillan information centre on the Maidstone site that is staffed by Macmillan volunteers who are available to offer support and access to range of information

## 6.9 Health and Well Being Events

In 2018 we introduced site specific Health and Wellbeing events on a bi-monthly basis. These are for both patients and their loved ones to attend with an evolving programme of speakers and topics surrounding the three main areas identified by the Brain Tumour Charity in their extensive patient feedback Namely, fatigue, loss of emotional control and fear of recurrence. These events are evaluated and adapted in accordance with feedback. Patients are also invited to attend the Trust Health and Wellbeing events for Cancer patients.

CNSs are part of the Programme to Improve Cancer Patients Experience in the KCH with a focus to improve self-care and support welling.

# Patient Information

## Core Information Pack

Patients are offered written information from the Brain Tumour Charity at diagnosis. This information pack contains information on diagnosis, treatment as well as information on driving regulations, insurance and support services. The Macmillan.org patient information sheets are used for both the chemotherapy and radiotherapy written information. Patients attend the Cicely Saunders Institute for their histology results and are given contact details as well as able to drop in for any advice or support needs. They can also attend the Richard Dimbleby Centre for information and support at Guys Cancer Centre where there are complimentary therapies available for patients and their carers. There are alsobenefits advisors available for one to one appointments.

# 8: Patient Access to Research Trials

## 8.1 Clinical Trials and Studies

All patients referred to the Neuro-oncology MDT are considered for clinical trial entry. This is regardless of their locality. If they are potentially eligible a member of the clinical trial team will attend the clinic appointment to provide clinicians and patients with the support they require. Having clinical trial suitability as a mandatory field on the MDT proforma increases screening and uptake in to clinical trials. The trusts have invested in to this area and provided the Neuro-oncology team with dedicated research support on both the King’s and GSTFT sites. The Annual report details the current trial portfolio with recruitment data. All patients are also given the choice to take part in NHS England’s 100.000 Genome’s Project.

# 9: Data Collection, Audit and Monitoring

The Neuroscience and local cancer MDT has agreed to collect and maintain Cancer waiting Times (including Going Further on Cancer Waits) and Cancer.

## 9.1 Data Collection / MDS

The Neuroscience and local cancer MDT has agreed to collect and maintain Cancer waiting Times (including Going Further on Cancer Waits) and Cancer r Registration Dataset.  The Cancer waiting Times data is collected and uploaded by the MDT co-ordinator for combined neuroscience and local cancer services to the local database used by King’s College Hospital within one week of NSMDT image report.  This information is then uploaded on to the national database Open Exeter on a monthly basis.  The same data is then sent to Thames Cancer Registry, along with Neuro pathology data. The Cancer waits for neuro-oncology are included in the annual report and reviewed annually by the Tumour Working Group (TWG).

King’s College Hospital was amongst the first centres to provide data centrally for a national database. The Trust has invested in this area and there is now a full-time data manager in post dedicated to Neuro-oncology.

Somerset will be introduced at Kings College Hospital from autumn 2018. All the nationally agreed data fields will be collected and this will be audited to ensure all our data needs are met with one single data system. It will be used to run all reports for national databases as well as provide our data reports for the Service improvement meetings.

## 9.2 Network Audit Statement of Agreement

# 10: Service Improvement

Service improvement is a continual process. We review our plans at the bi-annual service improvement meetings formerly the Tumour Working Group meetings. Our annual report is agreed and scrutinised for attendance data. Our work programme is updated throughout the year and progress is reported at the service improvement meetings. The meeting is chaired by Professor Ashkan.

# 11: Education and Training

Education and training is provided and commissioned by the Trust at King’s College London. KHP Staff also have access to courses run by The royal Marsden School of Cancer Nursing and Rehabilitation. All new starters to the above mentioned Neuroscience wards are invited to spend time with the Neuro-oncology CNS team as part of their introduction and ongoing education. The Neuro-oncology CNS team run regular teaching sessions with the ward staff and encourage participation in the Nurse-led ward rounds.

There is access to the Advanced communication skills training courses for all members of the MDT involved in delivering significant news. We have a high uptake with new colleagues enrolled on the first possible dates.

There is access to level 2 psychological skills training which a number of the CNS team have now completed. The CNS team attend group clinic supervision on a monthly basis with an independent supervisor. The CNS posts are adopted by Macmillan and have access to education grants and group grants for service improvement. There are also a wide variety of courses offered by Macmillan which the CNS team can access to enhance their practice and skill set. The Brain tumour Charity also provide an education grant for the Low Grade Glioma post that they have sponsored. They provide regular training session as well as network and research events.

##

## 11.1 Core Pathology Members Participation in EQA

Neuropathology participates in all relevant national EQA schemes for both the neuropathologists and laboratory techniques. Please see the evidence file for certificates.

# 12: Clinical Governance Issues

# Appendices:

Non-emergency surgical referral pathway

Emergency surgical pathway

Rehabilitation policy and assessment tools.

**NON-EMERGENCY REFERRAL TO KING’S COLLEGE HOSPITAL NEUROSURGERY**

Patient presents with symptoms suggestive of space occupying lesion/primary spinal tumour

CT/MRI scan confirms space occupying lesion

If patient on Aspirin, Clopidogrel or Dypiridamole then stop. Change warfarin to IV heparin if anticoagulation is absolutely indicated (see text above) **AND** **unless abscess suspected** commence patient on Dexamethasone 8mgs bd and Omeprazole 20mgs OD

**Scan shows possible abscess, tumour with associated hydrocephalus, Spinal Cord Compression, posterior fossa, midline or 3rd ventricular tumour,** **or** **GCS 13/15 or less**

Undertake neurological examination and further investigations – FBC/U+E/Clotting Screen, MRI+Gadolinium and chest x-ray for all patients.

If metastatic disease suspected perform Chest/Abdo/Pelvis CT and tumour markers

If spinal tumour perform whole neural axis MRI scan

Complete Neuro-Oncology Proforma and refer to local neurologist for opinion

Neurologist organises for patient to be discussed in the Neuro-Oncology MDM meeting at Kings College Hospital

Follow emergency protocol

Send films by image link to Kings **Contact neuro oncology co-ordinator on 020 3299 4151**

Patient discussed in the Neuro-Oncology MDM

Operable

Inoperable

Patient transferred to Kings for biopsy, debulking or excision

Referred by local team to Oncologist or Palliative care

Patient discussed post operatively in Neuro-Oncology MDM and referred to appropriate Oncologist or clinic

**NB:** if family/ patient wishes to discuss decision of best supportive care then can discuss with them at Kings College Neuro-Oncology Clinic. This will not be offer as routine.

Patient unsafe for discharge or needs care package

Patient safe for discharge

Discharge Home

Refer back to local hospital

PROTOCOL FOR REFERRAL OF **EMERGENCY** NEUROSURGICAL PATIENTS TO KING’S COLLEGE HOSPITAL

All patients admitted with suspected space occupying lesion must have:

* Brain contrast CT scan, preferably a contrast MRI scan
* Chest x-ray
* If patient is on Aspirin, Warfarin, Clopidogrel or Dipyridamole, these must be stopped
* Commence patient on Dexamethasone 8mgs bd (**unless abscess suspected)**
* FBC/U+E/Clotting screen

**If scan shows possible abscess, tumour with associated hydrocephalus, spinal cord compression, posterior fossa or midline or 3rd ventricular tumour, or GCS 13/15 or less:**

**(Note: All other cases follow the Non-Emergency referral protocol)**

* Complete Neuro-Oncology Referral Proforma and contact Neurosurgical Registrar at King’s College Hospital on 0203 2994207 – Diverted to a mobile when not in hospital.
* Organise for films to be imaged linked to King’s College Hospital.

If surgically **accessible** patient will be transferred to King’s for biopsy, debulking or excision of tumour.

If surgically **inaccessible** patient to stay in local hospital

All patients will be discussed in the Neuro-Oncology Multidisciplinary Team Meeting on Friday at King’s College Hospital and referred to appropriate Oncologist, Neuro-Oncology Clinic or Palliative care

If patient **safe** for discharge will be discharged home from King’s

If patient **unsafe** for discharge will be transferred back to local hospital for care package to be organised

**EMERGENCY REFERRAL TO KING’S COLLEGE HOSPITAL NEUROSURGERY**

Patient presents with symptoms suggestive of space occupying lesion

CT/MRI scan confirms space occupying lesion

If patient on Aspirin, Warfarin, Clopidogrel, Dipyridamole then stop it **AND** **unless abscess suspected** commence patient on Dexamethasone 8mgs bd

Scan shows possible abscess, tumour with associated hydrocephalus, Spinal Cord Compression, posterior fossa, midline or 3rd ventricular tumour, or GCS 13/15 or less

Scan shows non-emergency tumour

 Scan S

Follow non-emergency protocol

Complete Neuro-Oncology Referral Proforma and contact Neurosurgical Registrar at Kings College hospital on 0203 2994207

Image link scans to Kings College Hospital

**Operable**

**Inoperable** – stay in local hospital

Patient discussed in Neuro-Oncology MDM on Friday at Kings and local team refer to appropriate Oncologist, Neuro-Oncology Clinic or Palliative Care

Patient transferred to Kings and surgery undertaken – biopsy, de-bulking or excision

Patient discussed in Neuro-Oncology MDM on Friday at Kings and referred to appropriate Oncologist, Neuro-Oncology Clinic or Palliative Care. **Contact details for MDT Co-ordinator 020 3299 4151 kch-tr.neuro-oncologymdtreferrals@nhs.net**

Patient not safe for discharge or needs care package

Patient safe for discharge

Discharge Home

Back to local hospital

**** 



**South East London Clinical Network**

**and**

**Kent and Medway Cancer Network**

**Operational Policy for Neuro-oncology Rehabilitation Facilities**

**Brain and Cancer CNS**

**King’s Health Partners Cancer Centre, King’s College Hospital NHS Foundation Trust**

**Bexley, Bromley, Greenwich, Lambeth, Lewisham, Southwark**

**Kent and Medway**

Agreed By:

……………………………………………………….

Date: 24/05/2017

To be reviewed annually. Date of next Review: June 2018

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Appendix 2: Neuro-Oncology Clinic Self-Assessment - Information for before your appointment

Appendix 3: Speech & Language Awake Craniotomy referral form

**1.0 Introduction**

Adult Neuro-oncology patients are admitted to healthcare settings- acute trusts and inpatient or outpatient services- at various stages along their cancer journey- diagnosis, active treatment, post treatment, palliative and end of life. Patients at each of these stages present with differing physical, cognitive and psychosocial needs depending on the particular difficulties they are facing at that time. Therefore rehabilitation services must aim to tailor intervention to the presenting needs of the individual.

The patient’s treatment pathway often necessitates transitional care between King’s College Hospital, Guy’s and St. Thomas’ Hospital and their local cancer services within the South East London Cancer Network. On the emergence of symptoms and/or treatment side effects that impact on functional independence and quality of life, patients will have timely access to rehabilitation services when required, regardless of which stage they are at on the neuro-oncology pathway (see appendix 1).

An Allied Health Professional (AHP) is one of sixteen professions distinct from Medicine and Nursing. AHPs are autonomous and carry individual case loads. For the purpose of cancer rehabilitation and this document, AHP refers to Dietetics, Occupational Therapy, Physiotherapy and Speech and Language Therapy. This reflects the scope of the NCAT (National Cancer Action Team) cancer rehabilitation pathways (2010), the NICE Improving Supportive and Palliative Care rehabilitation chapter (2004) and the LCA Brain/ CNS Cancer Guidelines (2014).

**2.0 Objectives**

* Patients should have access to AHP assessment and intervention whenever required, at any stage in their cancer pathway.
* Patients should have access to comprehensive assessment to identify their health and social care needs, regardless of what stage they are at on their cancer journey.
* Each patient’s potential to derive a benefit from rehabilitation and therapeutic intervention should be assessed, and referral to rehabilitation services made without delay.
* Patients should receive an active and planned approach to rehabilitation including assessment, diagnosis, goal setting, care planning (and evaluation through formal outcome measures when possible).
* Patients should play a central role in setting goals, and should be involved in every stage of care- from referral and assessment through to discharge from rehabilitation services.
* Services provided should be culturally appropriate, designed to suit individual, cultural and language requirements.
* Links should be built between healthcare teams and other agencies in order to develop collaborative working and ensure a seamless transfer of care across the rehabilitation pathway.
* AHPs should be members of site- specific multidisciplinary teams (MDTs) if such MDTs exist in their place of work.
1. **Overview of Service Provided**
* AHPs provide patient assessment, treatment, support, advice and staff training, specialising in the management of cognitive, communicative, perceptual, physical and psychosocial impairments resulting from brain and CNS cancer. AHPs specialise in the provision of neuro-rehabilitation.

Clinical interventions include:

* A therapist attends pre-assessment clinic to help determine baseline function. Patients are asked to fill in self-assessment form to provide further information.
* If tumour is located in language areas, and the patient is being considered for awake craniotomy, a Speech and Language Therapist meets with the patient to discuss surgery and assess baseline language function.
* Speech Therapist attends surgery to assess language function throughout.
* Assessment of cognitive, physical and neurological function with identification and prioritisation of risks.
* Intervention to restore and maintain patient to optimum cognitive and physical function, minimise risk and prevent unnecessary deterioration in cognitive and physical health.
* Monitoring and re-assessment of physical and cognitive/ communicative function of patients who may have progressively deteriorating physical and cognitive presentation.
* Advice and support regarding management of symptoms related to cancer, for example, communication impairment, dysphagia, fatigue, pain, anxiety, reduced motivation.
* Provision without delay of and/or referral for therapeutic equipment including splints and orthoses, adaptive equipment, environmental adaptations, wheelchairs, walking aids and communication aids as indicated.
* Provision of manual handling risk assessment and advice for patients and their carers
* Onward referral to a home enteral nutrition team if indicated.
* Discharge planning from the acute setting and appropriate identification of ongoing clinical risks and rehabilitation needs.
* Provision of generic and neuro-specialist rehabilitation programmes during inpatient stay. Referral onwards to access inpatient or community based rehabilitation services or social services.

**4.0 Patient pathway across SELCN**

4.1 Assessment:

All patients with brain and CNS tumours will have access to AHP assessment to identify their impairments and needs. The following areas should be discussed with the patient/ carer:

* History of presenting condition
* Social support available
* Details of home and/or work environments
* Premorbid function
* Expectations and wishes on discharge

The following areas will be assessed (assessment of specific areas may be completed by a specific AHP discipline- some areas may be assessed jointly).

* Physical presentation- muscle power, tone, range of motion, balance, coordination, dexterity, energy levels, fitness and respiratory status.
* Motor function- transfers, mobility, posture, wheelchair requirements, upper limb function.
* Swallowing function- ability to take normal range of food and drink consistencies or modified consistency textures in quantities to meet nutritional and hydration requirements.
* Communication -ability to communicate functionally within a specific context, at various levels of complexity.
* Cognition and perception- screening for cognitive impairment and in-depth assessment of problems areas including attention, orientation, information processing, sensory processing, perception, memory and executive function.
* Sensory function- for example functional vision, and hearing, touch and pain.
* Assessment of Activities of Daily Living (ADLs) that are relevant and meaningful to the patient including the areas of self care, productivity and leisure (including work, child care, study, volunteer work, driving etc), taking into consideration the environment in which the patient lives/ works.
* Functional Risks - falls risks, environmental risks in home or work environment, manual handling risks.
* The patient will also be supported to identify and discuss problematic symptoms related to cancer such as fatigue, pain, anxiety, stress and reduced motivation
* Patient will be given an opportunity to discuss impact of cancer on physical and emotional relationships.

4.2 Goal-setting

Following completion of initial assessment SMART (Specific, Measurable, Achievable, Realistic and Timely) goals will be set with the patient and their family/ carer if appropriate. Goals may specific to risk reduction, prevention or rehabilitation, or may be orientated towards maintenance and management.

Goals will be appropriately graded to the changing, fluctuating and/or deteriorating needs if the patient.

Goals will be reviewed on a regular basis and short and long term goals communicated between acute and rehabilitation facilities to ensure a seamless transfer of care.

4.3 Intervention:

The specific intervention that is provided to the patient will be a direct result of the assessment findings, taking into consideration the patient’s/carer’s wishes and point in the care pathway. Intervention will be evidence-based where possible. Therapists will provide treatment as indicated including opportunities for the patient to communicate functionally and engage in activities of daily living including personal care, productivity and leisure activities. Therapists will recognise & respond to highly complex physical, emotional & psychological needs and offer specialist treatment and refer for specialist support as necessary.

The aim of rehabilitation for patients with brain and CNS tumours is to reduce risk, optimise function, and maximise quality of life. Therapists will be involved throughout the patient’s pathway and are instrumental in achieving their rehabilitation goals. The specific treatments and interventions will be individual to each patient and will be based on comprehensive assessment, taking into consideration the patient’s own goals.

*Cognition*
Where appropriate patients will receive targeted cognitive rehabilitation to address identified cognitive impairments e.g. cognitive-communication work or training on internal memory strategies. Compensatory approaches will be considered for those patients who are unable to benefit from strategy training. Education about cognitive impairments and specific strategies will be given to the patient and their carers/ employer etc.

*Mental Capacity*

Therapists are skilled in contributing to and fulfilling the assessment of a patient’s mental capacity to make specific decisions. Therapists are trained to facilitate and optimise the patient’s physical, cognitive and communicative functions during the decision-Making Process.

*Communication Skills*

Patients will receive disorder- specific communication rehabilitation focusing on identified impairments and social interactions, aimed at restoring meaningful interactive communication with those in his/her environment. Work will focus on maximising comprehension and expression of speech and language, through verbal and non-verbal channels. Augmentative and assistive communication will be integrated if required.

*Psychological*
Therapists will identify and facilitate the patient and carer’s adjustment to loss and disability which may be associated with brain and CNS cancer related to independence, control of environment, self esteem and quality of life. Advice on anxiety and anger management will also be provided where indicated. Therapists will be considerate of the patient’s and carer’s emotional and social wellbeing and make appropriate referrals to specialist agencies where possible.

*Equipment*
Patients should have access to assessment and provision of equipment for adaptive, supportive or rehabilitative purposes. Therapists must ensure that if equipment is identified as a requirement to facilitate independence in daily living then it arranged without delay.  Risk assessment will be carried out for provision of such equipment and, if required, training offered to the patient and their carers for complex items. Wheelchair and appropriate pressure relieving cushions will be considered for those with mobility and/or breathing difficulties and mobility aids reviewed for appropriateness throughout the rehabilitation process.  Following specialist assessment, if communication aids are required to augment or assist communication skills, appropriate recommendations will be made.

*Exercise and Wellbeing*
Therapists will be considerate of reducing and preventing secondary complications of brain and CNS tumour such as physical skin breakdown , loss of soft tissue range of movement, through advice on medication, postural management and provision of splints where required. Patients will be advised on the benefits of exercise and assisted to increase their levels of activity through exercise prescription. This may be through strengthening exercises and cardiovascular training. The patient will be advised about effective exercise and activity and provided with written support material where required. Mobility and function should be progressed as able with gait re-education and ongoing re-assessment for mobility aids provided.

*Fatigue and Anxiety Management*

Fatigue management will be considered in those patients whom find daily activities including communication difficult to complete due to tiredness. Various management techniques such as relaxation, healthy sleep patterns, energy conservation, environmental adaptations, pacing & compensatory techniques should be considered. Levels of nutrition and hydration will be considered and referral made to the local Dietetics service made if necessary. Patients will be encouraged to undertake exercise programmes aimed at improving strength and stamina. Anxiety & stress management will be considered and onward referral for more specialist services made as required.

*Information and Support*

Therapists will provide advice and education to the patient and their carer throughout the patient’s pathway but also facilitate self-management through enabling patients to make informed choices about their rehabilitation and by providing information and support on all aspects of their cancer care. Therapists can provide specific training for carers e.g. manual handling in the home environment.

*Continence*
Therapists will recognise difficulties that patients may experience with continence and be able to signpost to the specialist services available in their area. They will also offer advice on exercises aimed at muscle strengthening of the pelvic floor and work to improve mobility and transfers to assist with toileting needs. They can also offer advice on adaptive clothing and assessment for equipment provision.

*Nutrition* *and Swallowing*

During rehabilitation the patient’s levels of nutrition and hydration should be considered. Speech and Language Therapists will provide specialist clinical evaluation to determine the patient’s functional ability to swallow and maintain adequate levels of stamina throughout a meal. Instrumental swallowing assessment (i.e. Fibre optic Endoscopic Evaluation of Swallowing, or Video fluoroscopy) may be required for further information to optimise management and treatment of dysphagia. Dieticians will assess for adequate nutrition and hydration, management recommendations as appropriate. This may include recommendations for alternative feeding or supplements, and advice addressing other issues with meal preparation. General Practitioner will be contacted and hospital Dieticians will referral to the patient’s local Dietetic service as appropriate. Therapists will consider the impact of nutrition on patient’s ability to engage in rehab.

*Referral and Liaison*

Therapists will act as a signpost for further specialist services and support groups. They will have access or know how to access the wider MDT and make early referrals to such services. There will be identification of care needs and provision of information to both formal and informal care providers.

*Respiratory Function*

Patients with respiratory symptoms will be encouraged through training to develop self -management techniques for breathlessness and secretion clearance. Therapists will provide advice and support including information provision and education for patients and carers around breathlessness. Where appropriate, aerobic and strengthening exercise prescription will be considered including Pulmonary Rehabilitation. Therapists can also provide advice on pharmacological interventions such as Oxygen and Opiates, including inhaler technique. Patients with spinal cord compression may need closer monitoring of their respiratory status and provision of assistive technology for secretion clearance.

Patients with tracheostomies will be assessed for ability to tolerate cuff deflation and further tracheostomy weaning in joint assessments with a Physiotherapist and a Speech and Language Therapist.

*Activities of Daily Living*

Goal orientated rehabilitation will be implemented to enable maximum functioning in activities of daily living. Therapists will educate carers on the importance of facilitating the patient’s participation in activities of daily living in order to maintain existing function, quality of life and independence.

Assessment of the home environment will be completed either through interview, home visit or community services and provide appropriate equipment or adaptations to facilitate access and independence.

Therapists will provide advice and information on accessing/maintaining social and leisure activities   including providing information on accessing benefits advice, blue badge and shop mobility schemes.

*Work/ Education*

Those patients who wish to return to work or education or become involved in voluntary or unpaid work will have access to assessment of their ability to engage in such activities and support and advice regarding returning to these activities. Where such facilities are available referrals will be made to vocational rehabilitation programmes.

*Complementary/ Alternative medicine*

AHPs who have training in complementary and alternative medicine e.g. acupuncture, mindfulness based stress reduction, will offer these services to appropriate patients.

4.4 Discharge

*Acute settings*

Discharge from acute settings, or transfer to local hospital will be planned in partnership with the patient and their carers, ensuring discharge takes place at the appropriate point when acute therapeutic or medical intervention at King’s College Hospital is no longer required.

The need for referral to rehabilitation services will be identified and completed without delay.

Discharge planning will take into consideration the need to refer to other therapy services and statutory and voluntary services as required and referrals to these agencies should be activated without delay.

Where there is a transfer of care to another therapy team high quality verbal and/ or written handovers will be provided to the accepting team without delay to ensure a seamless transfer of care.

If it is anticipated that a patient being discharged from the acute setting will wait for a significant period for initial contact from community services the patient/carer will be provided with contact details of the acute trust therapists and advised to make contact for advice.

Equipment will be provided without delay- adaptive equipment, splints and orthotics, wheelchair referrals, liaison with nursing team regarding hospital beds, pressure care.

For those patients at a palliative or end of life stage, equipment provision will be completed urgently to facilitate the patient --- maintaining safety and dignity in their preferred environment.

Training will be given to family/ carers if required regarding manual handling, positioning, feeding and communication strategies.

*Rehabilitation settings*

For those patients in rehabilitation settings, discharge will occur once goals are achieved and recommendations implemented. The patient will be informed of any decisions made regarding their discharge from the service.

When patients have been discharged from a service, they will be given advice on how to re-access services should their needs change in the future.

**5.0 Neuro-Oncology MDMs**

Weekly Neuro-oncology MDM will be attended by AHP representatives in order to facilitate MDT decision making regarding appropriateness of onward rehabilitation referrals. Teenage and Young Adults, Pituitary and Spinal MDMs will be attended as requested when specific patients are being discussed.

**References**

London Cancer Services- proposed model of care.

National Institute for Health and Clinical Excellence (2004) [Guidance on Cancer Services. Improving Supportive and Palliative Care for Adults with Cancer.]. London: National Institute for Health and Clinical Excellence.

National Institute for Health and Clinical Excellence (2006) [Guidance on Cancer Services. Improving Outcomes for People with Brain and other CNS Tumours]. London: National Institute for Health and Clinical Excellence.

NHS National Cancer Action Team (2008). National Cancer Peer Review Programme. Manual for Cancer Services: Brain and CNS.

NHS National Cancer Action Team (2009). Rehabilitation Care Pathway Brain CNS.

LCA Brain/CNS Cancer Clinical Guidelines (2014) http://www.londoncanceralliance.nhs.uk/media/74514/LCA\_BCNS\_Guidelines\_FINAL.pdf

**Appendices**

**Appendix 1:** SELCN Neuro-oncology patient pathway

**Appendix 2:** Neuro-Oncology Clinic Self-Assessment - Information for before your appointment

**Appendix 3:** Speech & Language Awake Craniotomy referral form

 **Appendix 2**

Patient presents with symptoms of space occupying lesion

Investigations

At local hospital or +/- specialist centre as an out-patient or in-patient

Patient discussed at Neuro-oncology MDM at KCH

**Treatment**

At local hospital or specialist centre as an out-patient or in-patient

**SURGERY**

at **\*KCH**

**RADIOTHERAPY**

**CHEMOTHERAPY**

Remission / Follow up

Out-patient

Disease Recurrence

Active / Advanced Disease

Remains Well

Long term side effects

End of Life

In-patient / Out-patient / Community

**Palliative**

**Care**

In-patient / Out-patient / Community

**Treatment**

**Post Treatment**

**Palliative Care**

**End**

**of life**

**Pre Diagnosis**

**Diagnosis**

 **REHABILITATION & SUPPORTIVE CARE**

 **In-patient / Out-patient / Community**

\*KCH 🡪 Kings College Hospital Foundation Trust

**Appendix 1: SELCN Neuro-Oncology Patient Pathway**



**Neuro-Oncology Clinic Self-Assessment -**

**Information for before your appointment**

**Name: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Date of clinic:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**Hospital Number (CLINIC THERAPIST TO ADD): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**Date of Birth: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**Person completing the form: (Please circle): Patient/ friend/ family/ carer.**

*Or please let us know if you need any help completing this form.*

**Name and relationship of person attending clinic with you: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**Is English your first language? Yes No - My first language is:………………………**

*To enable us to understand how you’re currently managing, and to plan for any support that you may require at home, please can you and/or your friend/family answer the questions in the following sections by circling/ticking the appropriate box and providing any additional details if needed.*

**1. Your Social Situation and Support:**

**Please answer the following questions**

|  |  |  |  |
| --- | --- | --- | --- |
| Do you live with anyone? | Yes | No | Details: |
| Do you have any social support from family/friends? | Yes | No | If yes, who?: |
| Are you ever home alone for long periods? | Yes | No | Details: |
| Do you live with anyone that has complex care needs?  | Yes | No | Details: |
| Do you receive care from social services? | Yes | No | Details: |
| Do you work? (including any voluntary work) | Yes | No | What work do you do? |

**2. Home Environment:**

**What type of property do you live in?**

|  |  |  |  |
| --- | --- | --- | --- |
| House | Bungalow | Flat  | Other |

**Additional details: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**Please answer the following questions**

|  |  |  |  |
| --- | --- | --- | --- |
| Do you have external steps/ thresholds to access into your home | Yes | No | Details (e.g. rails/ number of steps or flights): |
| Do you have internal stairs at home? | Yes | No | Details (e.g. rails/ number of steps or flights): |
| Do you have any steps within the property i.e. to access rooms? | Yes | No | If yes, how many steps:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_Other details:  |
| If yes, do you have stair rails or bannisters? | Yes | No | Details |
| Do you anticipate any challenges with your home environment on your return home?  | Yes | No | Details:  |

**Please indicate which level of your property each room is on (please tick appropriate box and provide any additional details):**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Room | Upstairs | Downstairs | Both upstairs and down stairs | Only one level (i.e. within a flat/ bungalow | Additional Details |
| Lounge |  |  |  |  |  |
| Kitchen |  |  |  |  |  |
| Bedroom |  |  |  |  |  |
| Bathroom |  |  |  |  |  |
| Additional Toilet |  |  |  |  |  |

**3. Mobility and Getting On/Off Furniture:**

**How do you manage to walk around? (Please tick for the appropriate box)**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | **Independent** | **Walking stick** | **Hold furniture** | **Frame** | **Have help from someone** |
| Indoor |  |  |  |  |  |
| Outdoor |  |  |  |  |  |
| Stairs |  |  |  |  |  |

**Do you have any difficulty getting on/off the following furniture? (Please specify):**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **Yes** | **No** | **Equipment in situ?** | **How long have you had this problem?** |
| Bed |  |  |  |  |
| Chair |  |  |  |  |
| Toilet |  |  |  |  |
| Bath/Shower |  |  |  |  |

**Have you had any falls in the last 6 months? (Please circle/tick appropriate box and provide any additional details):**

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | No | If yes, how many? \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  | If yes were they **indoors** or **outdoors?** |

**If you answered yes to the question above please answer the following questions:**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| What caused your fall? | Dizziness | Slip | Trip | Other (please specify) |

**4. Neurological functions:**

**Please tell us if you experience any of the following problems.**

|  |  |  |  |
| --- | --- | --- | --- |
| Problems with your thinking skills? (E.g. knowing where you are, memory, attention, problem solving, planning what to do)  | Yes | No | Details: |
| Problems with your hearing?  | Yes | No | Details: |
| Problems with your vision? E.g. loss of part of your vision. | Yes | No | Details: |
| Problems with your swallowing? E.g. coughing on food or drink when you eat/ or avoiding certain foods. | Yes | No | Details: |
| Problems with speaking, understanding, reading or writing? | Yes | No | Details: |
| Weakness of your arms or legs? | Yes | No | Details: |
| Changes in your sensation? (E.g. Numbness, pins and needles) | Yes | No | Details: |
| Pain? | Yes | No | Details: |
| Fatigue/Tiredness | Yes | No | Details: |
| Mood & behaviour changes | Yes | No | Details: |
| Are you on steroids?If yes, have your symptoms improved? | Yes Yes  | NoNo | Details: |

**5. Functional Activities:**

**Please tell us by circling an answer if you have difficulties with these activities at home and if so how much help you need (i.e. can you manage independently or do you need help?):**

|  |  |  |  |
| --- | --- | --- | --- |
| **Activity** | **Difficulties?** | **How much help do you need?** | **Additional information** |
| Washing and Dressing | Yes | No | Help of 1  **or** 2 people  | Details: |
| Toileting | Yes | No | Help of 1 **or** 2 people  | Details: |
| Medication | Yes | No | Help of 1 **or** 2 people  | Details: |
| Snack Preparation | Yes | No | Help of 1 **or** 2 people  | Details: |
| Meal Preparation | Yes | No | Help of 1 **or** 2 people  | Details: |
| Shopping | Yes | No | Help of 1 **or** 2 people  | Details: |
| Housework | Yes | No | Help of 1 **or** 2 people  | Details: |
| Laundry | Yes | No | Help of 1 **or** 2 people  | Details: |
| Driving | Yes | No | Help of 1 **or** 2 people  | Details: |
| Life roles (Parent/ carer) | Yes | No | Help of 1 **or** 2 people  | Details: |
| Work | Yes | No | Help of 1 **or** 2 people  | Details: |

***Once this form is completed in the waiting room please give to a Therapist or the Receptionist. If you have any queries regarding the completion of this form please ask a staff member in the clinic.***

***Thank you***

|  |
| --- |
| ***For therapists use only******Name of Therapist in Clinic:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_******Form reviewed by Therapist: Yes / No*** ***Any immediate actions required from clinic: Yes / No******If Yes, Provide Details:*** |

**Appendix 3**

**Referral form for Speech and Language Therapy involvement in Awake Craniotomy surgery**

Name of patient: ……………………………………………………………………………

Date of surgery: ……………………………………………………………………………

Surgical Team: ……………………………………………………………………………………………………………………………

What other investigations are planned pre-surgery? E.g. TMS, PET, Neuropsychology assessment

In order for us to best plan our assessments and involvement it is helpful to have as much information as possible regarding surgical site. It is assumed that these are left sided regions unless you have reason to believe that the intended patient is right sided language dominant.

Do you currently anticipate that surgery will involve any of the following cortical sites/ subcortical pathways? Please tick all that apply:

|  |
| --- |
| **Frontal Regions:** |
| Inferior frontal gyrus |  |
| Posterior midfrontal gyrus |  |
| Supplementary motor area (posterior superior frontal gyrus) |  |
| Precentral gyrus |  |
| **Temporal Regions:** |
| Posterior superior temporal gyrus |  |
| Middle posterior superior temporal sulcus |  |
| Middle inferior temporal gyrus |  |
| Anterior middle temporal gyrus |  |
| **Parietal Regions:** |
| Supramarginal gyrus (SMG) |  |
| Angular gyrus (ANG) |  |

|  |
| --- |
| **Subcortical pathways:** |
| Subcallosal fascicle |  |
| Inferior fronto-occipital fascicle |  |
| Inferior longitudinal fascicle |  |
| Superior longitudinal fascicle (arcuate fascicle) |  |
| Uncinate fascicle  |  |
| Corticospinal tract |  |

Many thanks

**Hilary Wren Speech and Language Therapist, Neuro-Oncology**

X32307