West Yorkshire & Harrogate Cancer Alliance

Guidelines for the Management of Brain and Central Nervous System (CNS) Tumours

June 2018
## Document Control

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<tbody>
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<td>Dr Paul Hatfield</td>
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<td>West Yorkshire &amp; Harrogate Cancer Alliance</td>
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### Version Control

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<td>August 2014</td>
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</tr>
<tr>
<td>2.1</td>
<td>June 2018</td>
<td>Addition of skull base pathways. Also incidental findings, low and high grade referral pathways. Update to GP Guidelines for Referral from Primary Care and General Principles sections</td>
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### Contributors to current version

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<th>Contributor</th>
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</tr>
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<td>Contributors to current version</td>
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## Information Reader Box

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<td>Dr Paul Hatfield</td>
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<td>May - June 2018</td>
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<td>26th June 2018</td>
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<td>June 2018</td>
</tr>
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<td>June 2021 (or sooner if new guidance becomes available)</td>
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| **Proposed Target Audience for Consultation / Final Statement** | WY&H CA Brain and CNS Tumours MDT Teams  
WY&H CA Lead Nurses  
WY&H Cancer Managers  
WY & H Lead Cancer Commissioners |
| **Proposed Circulation List for Final Statement** | All WY&H Cancer Alliance guidelines will be made available electronically at the West Yorkshire & Harrogate Cancer Alliance. No hard copies will be supplied. |
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WF1 1LT |
Table of Contents

I DOCUMENT CONTROL ................................................................. 2
II INFORMATION READER BOX ..................................................... 4
III TABLE OF CONTENTS .................................................................. 5

1 INTRODUCTION .............................................................................. 9
  1.1 INCIDENCE, PREVALENCE AND MORTALITY ................................. 9
  1.2 AETIOLOGY ............................................................................... 14

2 PRIMARY CARE (PRESENTING SYMPTOMS) ....................................... 16
  2.1 GP GUIDELINES FOR REFERRAL FROM PRIMARY CARE .................. 16
  2.2 GENERAL PRINCIPLES ............................................................ 17

3 INVESTIGATION OF PATIENTS WITH SUSPECTED CNS TUMOURS ...... 18

4 ACCESS TO THERAPEUTIC SERVICES ........................................... 19
  4.1 STRUCTURE OF SERVICES IN LEEDS ......................................... 19
  4.2 THE ROLE OF CANCER UNITS .................................................. 20
    4.2.1 Area wide Communication Framework. Policy for communications between providers of care for brain and CNS tumours ................................................................. 20
    4.2.2 Registration ......................................................................... 21
    4.2.3 Referral criteria ...................................................................... 22
  4.3 THE NEUROSCIENCES MDT .......................................................... 23
    4.3.1 Composition ......................................................................... 23
    4.3.2 Referral mechanism ................................................................. 23
    4.3.3 Communication of outcomes .................................................... 23
  4.4 THE REHABILITATION AND NON-SURGICAL ONCOLOGY MDT ....... 25
  4.5 THE PITUITARY MDT .................................................................. 26

5 PATHWAYS ..................................................................................... 27
  5.1 AREA WIDE PRESENTATION / DIAGNOSTIC PATHWAY FOR ADULT PATIENTS ................................................................. 27
  5.2 HIGH GRADE INTRINSIC BRAIN TUMOURS .................................. 28
  5.3 LOW GRADE INTRINSIC BRAIN TUMOURS ................................... 30
  5.4 EXTRINSIC BRAIN TUMOURS ...................................................... 32
  5.5 ANTERIOR SKULL BASE PATHWAY ............................................. 33
  5.6 LATERAL SKULL BASE PATHWAY ............................................... 34
  5.7 LEEDS CHORDOMA AND CHONDROOSARCOMA PATHWAY .......... 35
  5.8 SKULL BASE REFERRAL PATHWAY .............................................. 36
  5.9 AREA WIDE METASTATIC PATHWAY ........................................... 37
  5.10 PITUITARY PATHWAY ................................................................. 39
  5.11 EPENDYOMA ............................................................................ 40
  5.12 PINEAL ..................................................................................... 40
  5.13 CNS LYMPHOMA ....................................................................... 40
  5.14 PAEDIATRIC ............................................................................. 40
  5.15 ADULT MEDULLOBLASTOMA .................................................... 41
  5.16 AREA WIDE FOLLOW-UP PATHWAY ........................................... 42
  5.17 INCIDENTAL FINDING, LOW GRADE AND HIGH GRADE REFERRAL PATHWAYS ................................................................. 43

ALLIED HEALTH PROFESSIONALS .................................................. 46
  5.18 NURSE SPECIALISTS .................................................................. 46
  5.19 OCCUPATIONAL THERAPY ......................................................... 46
  5.20 DIETICIANS ............................................................................ 49
  5.21 PHYSIOTHERAPY ....................................................................... 50
  5.22 SPEECH & LANGUAGE THERAPY .............................................. 53
    5.22.1 Role of the Brain and CNS Speech and Language Therapists ... 53
    5.22.2 Referring to Speech and Language Therapy Services ............ 53

Valid on the date of publication
11.1 HIGH GRADE GLIOMA - RADICAL - PRIMARY - (CHEMO) RT .................................................. 92
  11.1.1 Intent .................................................................................................................. 92
  11.1.2 Primary Outcome .............................................................................................. 92
  11.1.3 Toxicity .............................................................................................................. 92
  11.1.4 Patient information ......................................................................................... 92
  11.1.5 Scheduling ....................................................................................................... 92
  11.1.6 Pre-treatment process ..................................................................................... 92
  11.1.7 Target definition .............................................................................................. 92
  11.1.8 Prescribed dose and fractionation ................................................................. 92
  11.1.9 Treatment ....................................................................................................... 92

11.2 HIGH GRADE GLIOMA - PALLIATIVE - PRIMARY - RT ALONE ............................................ 94
  11.2.1 Intent .............................................................................................................. 94
  11.2.2 Primary Outcome ........................................................................................... 94
  11.2.3 Toxicity ........................................................................................................... 94
  11.2.4 Patient information ....................................................................................... 94
  11.2.5 Scheduling ..................................................................................................... 94
  11.2.6 Pre-treatment process ................................................................................... 94
  11.2.7 Target definition: .......................................................................................... 94
  11.2.8 Prescribed dose and fractionation ............................................................... 94
  11.2.9 Treatment ..................................................................................................... 94

11.3 LOW GRADE GLIOMA - RADICAL - PRIMARY - RT ALONE .................................................... 95
  11.3.1 Intent .............................................................................................................. 95
  11.3.2 Primary Outcome ........................................................................................... 95
  11.3.3 Toxicity ........................................................................................................... 95
  11.3.4 Patient information ....................................................................................... 95
  11.3.5 Scheduling ..................................................................................................... 95
  11.3.6 Pre-treatment process ................................................................................... 96
  11.3.7 Target definition ............................................................................................ 96
  11.3.8 Treatment ..................................................................................................... 96

11.4 MENINGIOMA - RADICAL - PRIMARY - RT ALONE ................................................................. 97
  11.4.1 Intent .............................................................................................................. 97
  11.4.2 Primary Outcome ........................................................................................... 97
  11.4.3 Toxicity ........................................................................................................... 97
  11.4.4 Patient information ....................................................................................... 97
  11.4.5 Scheduling ..................................................................................................... 97
  11.4.6 Pre-treatment process ................................................................................... 97
  11.4.7 Target definition ............................................................................................ 97
  11.4.8 Prescribed dose and fractionation ............................................................... 97
  11.4.9 Treatment ..................................................................................................... 97

11.5 PITUITARY - RADICAL - PRIMARY - RT ALONE ...................................................................... 98
  11.5.1 Intent .............................................................................................................. 98
  11.5.2 Primary Outcome ........................................................................................... 98
  11.5.3 Toxicity ........................................................................................................... 98
  11.5.4 Patient information ....................................................................................... 98
  11.5.5 Scheduling ..................................................................................................... 98
  11.5.6 Pre-treatment process ................................................................................... 98
  11.5.7 Target definition ............................................................................................ 99
  11.5.8 Prescribed dose and fractionation ............................................................... 99

12 CHEMOTHERAPY ............................................................................................................... 101
  12.1 PALLIATIVE SYSTEMIC .......................................................................................... 101
  12.2 INTRA-CAVITARY .................................................................................................. 101

13 PALLIATIVE & END OF LIFE CARE ......................................................................................... 102
  13.1 DEFINITIONS ........................................................................................................ 102
  13.2 WHO PROVIDES PALLIATIVE / END OF LIFE CARE? ............................................... 102
  13.3 SPECIALIST PALLIATIVE CARE .............................................................................. 103
  13.4 FURTHER LINKS AND INFORMATION ...................................................................... 104
  13.5 DIRECTORY OF WEST YORKSHIRE & HARROGATE CANCER ALLIANCE SPECIALIST PALLIATIVE CARE SERVICES ........................................................... 104

Valid on the date of publication
1 Introduction

Primary central nervous system (CNS) tumours are uncommon. The most numerous are brain tumours, which are said to account for only 1.6% of cancers in England and Wales. The variety of pathological tumour types is large. In addition, the following four important characteristics of tumours in the CNS determine why the terms ‘malignant tumour’ (often equated with ‘cancer’) and ‘benign tumour’ lack validity when applied to this clinical setting.

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

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

The anatomical location influences symptoms that include physical, cognitive and psychological components. For this reason, adults with CNS tumours pose a unique challenge to healthcare professionals; the patient may not be the best person to explain his or her symptoms, and cognitive dysfunction may greatly increase the need for psychological/psychiatric, social and physical support. In view of the poor survival of many patients, even with optimal treatment, an important aspect of improving outcome is maximising quality of life.

1.1 Incidence, prevalence and mortality

Approximately 6500 primary tumours of the CNS in those aged 15 years and over were registered annually in England and Wales between 1995 and 2000, of which 58% were classed as ‘malignant’ (Table 1). There is, however, evidence of significant under-registration of intracranial tumours in the UK, particularly low-grade tumours. It has been suggested that almost half of intracranial tumours are not recorded by cancer registries. The incidence of these tumours rises throughout adulthood (after a peak in childhood) to reach its highest among the 75–79-year age group at 37 registrations per 100,000 population per year over the above mentioned 6-year period (Figure 1). In the 10 years from 1991 to 2000 the rate of tumour registration increased by 17%. The rise was particularly marked in older age groups and registrations for these tumours more than doubled among very elderly people in that decade (Table 2). The reasons for this are unclear, but the increase may be due to more intensive investigation of neurological deficit in older patients in recent years. As the number of tumours registered in England and Wales has risen, hospital admissions recorded for this group of patients have also increased (Figure 2). The “Improving Outcomes for People with Brain and Other CNS Tumours” Report published by NICE in 2006 emphasises the need to accurately record and register new cases of CNS tumours (see Section 4.2.1).
### Table 1 Registrations and mortality from primary brain and central nervous system tumours in England and Wales, 1995–2000, people aged 15 and over (source: NICE Improving Outcomes for People with Brain and CNS Tumours 2006)

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<tr>
<th></th>
<th>Registrations</th>
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<tr>
<td></td>
<td>Number per annum</td>
<td>Crude rate per 100,000 ≥ 15</td>
</tr>
<tr>
<td><strong>Brain tumours</strong></td>
<td></td>
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<tr>
<td>Malignant</td>
<td>3550</td>
<td>8.54</td>
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<tr>
<td>Benign/uncertain behaviour</td>
<td>520</td>
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<td><strong>Intracranial meningiomas</strong></td>
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<tr>
<td>Malignant</td>
<td>54</td>
<td>0.13</td>
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<td>Benign/uncertain behaviour</td>
<td>758</td>
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<td><strong>Spinal cord tumours</strong></td>
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<td>Benign/uncertain behaviour</td>
<td>56</td>
<td>0.13</td>
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<tr>
<td><strong>Spinal meningiomas</strong></td>
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<tr>
<td>Malignant</td>
<td>5</td>
<td>0.01</td>
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<tr>
<td>Benign/uncertain behaviour</td>
<td>60</td>
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<td><strong>Pituitary tumours</strong></td>
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<td><strong>Cranial nerve tumours</strong></td>
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<td><strong>Pineal tumours</strong></td>
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<td><strong>Other registered as CNS tumours</strong></td>
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<td>Total malignant</td>
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<tr>
<td>Total benign/uncertain</td>
<td>2895</td>
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<tr>
<td>Total</td>
<td>6462</td>
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Data supplied by the National Cancer Intelligence Centre of the Office for National Statistics and the Wales Cancer Intelligence and Surveillance Unit. As these data use the International Classification of Diseases (ICD) coding, CNS lymphomas are not distinguished as a separate group, registrations (ICD-10) and mortality (ICD-9) codes may not match exactly.

*Including cranio-pharyngeal tumours.

**Figure 1** Age-related rates per 100,000 population for total primary tumours, subdivided as 'malignant'/non 'malignant’, 1995–2000 (source: NICE Improving Outcomes for People with Brain and CNS Tumours 2006)
Data supplied by the National Cancer Intelligence Centre of the Office for National Statistics and the Wales Cancer Intelligence and Surveillance Unit
Table 2  Age-specific registration rates for primary brain/central nervous system tumours per 100,000 population per year among those aged 15 years and older; selected ages x year (1991–2000) (source: NICE Improving Outcomes for People with Brain and CNS Tumours 2006).

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<th>30–34</th>
<th>40–49</th>
<th>55–59</th>
<th>65–69</th>
<th>75–79</th>
<th>85+</th>
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<td>34.3</td>
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<td>6.1</td>
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<td>28.9</td>
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<td>31.4</td>
<td>41.5</td>
<td>37.3</td>
<td>16.1</td>
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Double line indicates transition from ICD-9 to ICD-10; definitions of tumour groups included do not match exactly across this transition. ‘All ages’ refers to crude rate in those aged 15 and over. Data supplied by the National Cancer Intelligence Centre of the Office for National Statistics and the Wales Cancer Intelligence and Surveillance Unit. ICD, International Classification of Diseases.
Figure 2 Inpatient bed days and registrations for patients with brain tumours (‘benign’, ‘malignant’ and ‘uncertain’) 1995–2001 (source: NICE Improving Outcomes for People with Brain and CNS Tumours 2006).

Hospital activity data represent any admission for patients with a known diagnosis of this tumour type. Data supplied by the National Cancer Services Analysis Team (Hospital Episodes Statistics/Patient Episode Database in Wales data; year refers to commencement of financial year (incomplete data available for financial year 1997–98), National Cancer Intelligence Centre of the Office for National Statistics and the Wales Cancer Intelligence and Surveillance Unit.
1.2 Aetiology

The aetiology of tumours of the CNS is largely unknown. The only unequivocally identified causative factors are inherited cancer syndromes and, in rare cases, ionising radiation. Unlike a number of other cancers, currently there is no evidence that brain tumours can be prevented by lifestyle changes. Immunosuppression, for example as a result of AIDS, is a well-recognised risk factor for cerebral lymphoma.

The risk of developing CNS tumours is dependent on age and gender, and also shows an inverse social gradient. Tumours of the brain are more common among more affluent groups, and this is also true for mortality. The reverse trend is evident for brain metastases.

Geographical variation in CNS tumours is less than for most human neoplasms. Less developed countries have a lower incidence than more developed countries. There is also evidence that in multicultural communities those of African or Asian descent have a lower incidence than those of Caucasian descent. Japan is a developed country with a particularly low level of reported tumours, although it is not clear if this is related to inadequate registration. There is no consistent regional variation within England and Wales.

A number of familial syndromes give rise to an increased risk of tumours of the CNS. These syndromes are shown in general in autosomal dominant conditions, and many have distinctive skin features (phakomatoses). Neurofibromatosis type 1 is the most common of these syndromes with a prevalence of 1 in 3000. Neurofibromatosis type 2 has an incidence of about 1 in 40,000. Multiple endocrine neoplasia type I, associated with pituitary tumours, is sometimes included in this group.
Table 3 Familial Syndromes associated with CNS tumours (source: NICE Improving Outcomes for People with Brain and CNS Tumours 2006)

<table>
<thead>
<tr>
<th>Syndrome</th>
<th>Gene</th>
<th>Chromosome</th>
<th>Nervous system</th>
</tr>
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<tbody>
<tr>
<td>Neurofibromatosis type 1</td>
<td>NF1</td>
<td>17q11</td>
<td>Neurofibromas, malignant nerve sheath tumour, optic nerve gliomas, astrocytoma</td>
</tr>
<tr>
<td>Neurofibromatosis type 2</td>
<td>NF2</td>
<td>22q12</td>
<td>Bilateral acoustic schwannomas, multiple meningiomas, astrocytomas, glial hamartomata</td>
</tr>
<tr>
<td>von Hippel–Lindau Syndrome</td>
<td>VHL</td>
<td>3p25</td>
<td>Haemangioblastomas</td>
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<tr>
<td>Tuberous sclerosis</td>
<td>TSC1</td>
<td>9q34</td>
<td>Subependymal giant cell astrocytoma, cortical tubers</td>
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<tr>
<td></td>
<td>TSC 2</td>
<td>16p13</td>
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<tr>
<td>Li–Fraumeni</td>
<td>p53</td>
<td>17p13</td>
<td>Astrocytomas/primitive neuroectodermal tumour</td>
</tr>
<tr>
<td>Cowden’s disease</td>
<td>PTEN</td>
<td>10q23</td>
<td>Dysplastic gangliocytoma of the cerebellum</td>
</tr>
<tr>
<td>Turcot’s syndrome</td>
<td>APC</td>
<td>5q21</td>
<td>Medulloblastoma</td>
</tr>
<tr>
<td></td>
<td>HMLH1</td>
<td>3p21</td>
<td>Glioblastoma</td>
</tr>
<tr>
<td></td>
<td>HPSM2</td>
<td>7p22</td>
<td></td>
</tr>
<tr>
<td>Naevioid basal cell carcinoma syndrome (Gorlin syndrome)</td>
<td>PTCH</td>
<td>9q22</td>
<td>Medulloblastoma</td>
</tr>
</tbody>
</table>
2 Primary care (presenting symptoms)

The following symptoms should raise the possibility of a CNS tumour:

- Subacute neurological deficit developing over days to weeks (e.g. weakness, sensory loss, dysphasia, ataxia)
- New onset seizures characterised by one or more of the following:
  - Focal seizures
  - Prolonged post-ictal focal deficit
  - Status epilepticus
  - Associated inter-ictal focal deficit
- Patients with headache, vomiting and papilloedema
- Cranial nerve palsy (e.g. diplopia, visual failure including optician defined visual field loss, unilateral sensorineural deafness).
- Patients with non-migrainous headaches of recent onset, accompanied by features suggestive of raised intra-cranial pressure (e.g. woken by headache; vomiting; drowsiness)
- Patients who have a history of headaches who present complaining of an altered pattern or severity of headaches
- Patients aged 45 years onwards, who do not normally complain of headaches, now presenting with headache.

Clinical features and differential diagnosis advice for patients who have a suspicion of pituitary disease are given in a supplementary guidance document – Guidelines for the Management of Pituitary Tumours.

2.1 GP guidelines for referral from primary care

The Fast Track Pathway for brain tumours has changed recently to a "straight-to-test" pathway (rather than referral to a neurology clinic). GPs can request a "fast track" MRI scan at their local hospital if the following criteria are met:

Consider an urgent direct access MRI scan of the brain (or CT scan if MRI is contraindicated) (to be performed within 2 weeks) to assess for brain or central nervous system cancer in adults with progressive, sub-acute loss of central neurological function. This will lead to one of several outcomes:

1) No tumour found: report sent back to GP who will be responsible for further management of the patient and their symptoms

2) Benign tumour found: report sent back to GP with instructions how to refer the patient to the Leeds Neuro MDT for advice on further management. If the scan was performed in
Leeds then the case will automatically be discussed at the MDT and the advice / management plan will be communicated to the GP

3) Suspicion of high grade primary brain tumour: the diagnostic centre will flag up the result to their local acute oncology team for further management / onward referral to Leeds. Leeds patients will be picked up automatically by the MDT and rapid assessment arranged in the High Grade Clinic.

4) Brain metastases seen: result will be flagged to the patient's oncology team (if there is a past history of cancer) and the site-specific MDT will take responsibility for assessing the patient's performance status and symptoms. They will also arrange staging investigations and refer on to the Neuro MDT in Leeds as appropriate if neurosurgery / radiosurgery are being considered. If no prior diagnosis of cancer is known then the CUP (carcinoma of unknown primary team) would see and make the appropriate initial assessments.

2.2 General principles

- Urgent suspected cancer referrals to the diagnostic unit remain the responsibility of the GP until the patient attends an appointment at the diagnostic centre / Leeds.
- Responsibility for requesting further diagnostic tests, staging investigations or onward referral to the Leeds MDT will be as described in Section 2.1.
- Subsequent responsibility is determined by the treatment planning decision of the MDT.
- Throughout the pathway there should be on-going access to the Clinical Nurse Specialists and the MDT.
- Timely and detailed communication with primary care colleagues is essential at all times.

Support and guidance are provided by the specialist nurses after a tumour is diagnosed and subsequently during further management.

Relevant MDT meeting discussions inform the most appropriate treatment options (whether it be adjuvant treatment, surgery or palliative treatment).

The patient must be provided with all the necessary information and support to make decisions.

Where appropriate, the specialist nurse should provide advice and counselling.

Normal rules for the timing of "fast track treatment" will be followed for malignant brain tumours discovered by this pathway.
3 Investigation of patients with suspected CNS tumours

In Cancer Units
Once the diagnosis of a CNS tumour is suspected, patients will require imaging of the brain +/- spine. In many units, initial scanning of the brain will be with a contrast-enhanced CT scan. If this suggests a tumour (and the patient is suitable for further treatment) then an MRI with contrast should be performed to provide the greatest degree of anatomical information. MRI will also complement CT, in many cases, allowing the nature of the tumour itself to be better determined.

If the imaging findings suggest that the patient may have metastatic disease then the patient should be assessed fully to determine the nature, extent and severity of their disease. This will include a detailed history and examination with assessment of performance status (see Section 18). Some patients may be considered for mammography +/- USS breast. Most will require a staging CT scan of chest / abdomen and pelvis. Tumour markers have a very limited role in the diagnosis of cancer except perhaps for PSA (prostate cancer) and AFP/βhCG (testicular cancer).

There are specific guidelines for the investigation and management of patients suspected to have pituitary disease, these guidelines are supplementary to the Guidelines for the Management of Brain and Central Nervous System (CNS) Tumours.

In Leeds Teaching Hospitals
Increasingly, more sophisticated MRI techniques are being used to evaluate brain tumours. These include perfusion-weighted imaging, diffusion-weighted imaging and spectroscopy. Such techniques require special training, validated protocols and experience to interpret. The results can be useful in detecting signs of transformation to higher grade tumours, differentiating radiation-induced necrosis from recurrent disease and can also guide biopsies to particular areas of concern within large tumours.

Positron-emission tomography (PET) is also used occasionally to assess brain tumours. It is another technique that can be used to try and distinguish radiation induced necrosis from recurrent tumours.

Histological confirmation of diagnosis by biopsy or surgical decompression should be attempted for all patients unless it is felt this would not alter management.
4 Access to therapeutic services

4.1 Structure of services in Leeds

The provision of specialist services for patients with CNS tumours in West Yorkshire & Harrogate Cancer Alliance is in Leeds (see Figure 3).

Neurosurgery is based at the Leeds General Infirmary and Neuro-oncology at St. James’s Institute of Oncology, St James’s University Hospital.

Most cases with new diagnoses will be referred to the neurosciences MDT but a separate pituitary MDT also exists for this sub-group of patients. Both have access to an MDT that can coordinate the supportive care for these patients.

Although not constituted as a separate MDT a specialist base of skull clinic exists which has multi-disciplinary membership. This allows complex base of skull cases to be managed in a cooperative fashion between different surgical specialists (eg maxillofacial, neurosurgery and ENT services). Members of this clinic can also provide radiosurgical advice.

Figure 3 The structure of specialist neurological services in Leeds.
4.2 The role of cancer units

Patients with CNS tumours may present in a multitude of ways. For individual teams the identification of a CNS tumour may well be an unusual event, given the rarity of these tumours and the number of routes through which they may come to light. The initial diagnosis will usually be made by medical staff working in cancer units, often after referral by local GPs.

The importance of providing all CNS tumour patients access to appropriate support has been emphasised in the NICE Improving Outcomes for People with Brain and CNS Tumours 2006 report. If this is to occur, robust mechanisms need to be put in place in each unit to rapidly identify such patients and direct them towards appropriate management.

In practice this means that units will need:

- A mechanism to identify patients with brain tumours on imaging (“Flagging” up reports for discussion and action)
- A system for discussing these patients in a multi-disciplinary setting (to ensure that appropriate referrals have been made and to help coordinate local care).
- To direct the majority to the Leeds Neurosciences MDT unless specific reasons exist for this not to happen (see below). If this is not done, then to keep accurate records of such patients for the purpose of audit. See Section 4.2.1 below.
- All patients to be allocated a key worker / access to a clinical nurse specialist.
- All patients to be offered Holistic Needs Assessment in accordance with the National Cancer Action Team Guidance.
- To offer patients anti-convulsants and steroids (especially Dexamethasone from 2mg twice daily to 16mg per day) as necessary to improve symptoms due to local and global swelling, and control these symptoms until definitive treatment can be commenced.

In some situations the radiological findings may be suspicious for the presence of a tumour but not confirmatory. In this situation the local MDT may choose to repeat the imaging after an interval or refer the case directly to a neuroradiologist at the cancer centre for a second opinion. At this stage the case will not usually need discussion at the neurosciences MDT.

4.2.1 Area wide Communication Framework. Policy for communications between providers of care for brain and CNS tumours.

- Patients with an initial imaging diagnosis of a CNS tumour should be logged on to a dataset of the NSMDT within one week of the date of the image report.
- A clinical summary from the clinician in charge of the patient at the time of the imaging diagnosis should have been received by the NSMDT within two working days of the date of the imaging report.
- A written summary of the proposed management plan be sent out from the NSMDT within one working day of the MDT meeting to the referring clinician, the CNMDT and the GP.
- The patient or their carers are informed of the diagnosis within one working day for inpatients and five working days for outpatients of the NSMDT meeting at which it is confirmed.
The patient or their carers are informed of the management plan by the NSMDT within one working day for inpatients and five working days for outpatients of the NSMDT meeting at which it is decided.

A referral for relevant patients is sent to the rehabilitation or palliative care service within one working day of the decision being made.

A referral of relevant patients for management by a member of the CNMDT is sent within two days of discharge from neurosurgical care.

Patients or their carers are informed of the identity and role of their key worker within one working day for inpatients and five working days for outpatients of the NSMDT meeting.

A referral back to the neuroscience MDT for further management of possible recurrence is sent from the multidisciplinary specialist clinic within one working day of the decision.

That should the assessment made by the MDT indicate that the diagnosis is more likely to be a cerebral abscess than a tumour, this should be communicated urgently to the referring hospital and arrangements should be made for urgent transfer.

4.2.2 Registration

A key driver for the IOG document has been the need to provide a comprehensive service for all patients with brain tumours. For this to occur, it is vital that mechanisms exist to accurately identify such patients (this can also facilitate audit). It must be possible to answer questions such as “How many patients with brain tumours have been detected this year?” “Is it more than last year?” “How many were confirmed histologically?” “How many were discussed at the neurosciences MDT?”

The only system within the Network that can realistically facilitate this is PPM. This has the advantage of containing detailed demographic information, having access to histological diagnoses and also treatment events such as surgery, radiotherapy and chemotherapy. It is also the method for recording MDT discussion, key worker details and AHP involvement.

For the purposes of this guideline “registration” is therefore defined as a patient being entered into PPM with a provisional diagnosis of a brain tumour. This will usually occur after a radiological diagnosis and is therefore dependent on comprehensive and accurate “flagging” of these cases (the term “flagging and logging” is therefore a description of this process of registering provisional radiological diagnoses into PPM).

A proportion of these patients will subsequently be referred to neurosurgery for biopsy or surgical excision. Once a histological diagnosis is available this will also be entered into PPM. As such, PPM will be able to answer the questions described above, since it can be “searched” as necessary.

Most registration will be done by the MDT coordination staff in Leeds but provisional diagnosis could potentially be done in the Units as local mechanisms for reviewing newly identified brain tumours develop. It is envisaged that the date of this diagnosis would be the date of the scan which first identified the tumour. In cases where an initial scan is indeterminate for a tumour then recording a provisional diagnosis should be deferred until subsequent imaging makes this the accepted diagnosis after radiological review (probably by the Neurosciences MDT).
4.2.3 Referral criteria

The IOG states that:
“The neuroscience MDT should meet at weekly intervals to review all new patients and advise on the initial management of their disease in accordance with national cancer waiting times standards.”

It is therefore assumed that cancer units will refer all patients with new brain tumours for discussion.

In some unusual circumstances this may not apply:

- Brain metastases cases falling outside of the criteria for referral (see Section 5.5) whose holistic care needs are already being met by a relevant site-specific team in the cancer unit.
- Patients where the diagnosis of a tumour remains unclear and it is felt that repeat or further imaging will help distinguish between a tumour and some other differential diagnosis.
- Occasional patients with incidentally diagnosed tumours (e.g. small meningiomas) that are unrelated to symptoms and where the patient’s frailty or general condition means that further intervention or scanning would be inappropriate.

Nevertheless, it is important that cases such as these have access to the same supportive care as other brain tumour patients. Once a tumour is felt to exist they should also be registered for audit purposes (see Section 4.2.1).
4.3 The Neurosciences MDT

The IOG defines the roles of the neurosciences MDT as described in Figure 4.

The meeting occurs weekly (Wednesday 9.30am LGI, Radiology Academy) and is responsible for the diagnosis and initial management of most adult patients with CNS tumours (currently pituitary and non-intrinsic spinal tumours are discussed elsewhere).

Contact Leeds Teaching Hospitals NHS Trust for the detailed standard operating procedures.

4.3.1 Composition

The meeting is attended by consultant neurosurgeons, neuro-oncologists, neuroradiologists and neuropathologists. Also present are the MDT coordinators, nurse specialists, medical trainees in the above specialties, radiographers and allied health professionals (e.g. occupational therapy, physiotherapy, palliative care).

4.3.2 Referral mechanism

Many cases are discussed after referral from cancer units. Given that the managing team are not able to attend in person, it is vital that as much clinical information is available as possible (it is envisaged the appointment of more nurse specialists will help bridge this gap as much as possible). Access to relevant imaging is also essential.

The deadline for adding cases to the list is the end of Monday afternoon. It will not be possible for imaging received after this time to be reviewed prior to the meeting.

Referral is done by completing the MDT referral form available from Leeds Trust on the Leeds Neurosurgery website (http://www.leedsneurosurgery.com/).

4.3.3 Communication of outcomes

A typed summary of the meeting outcome will be available on PPM within 24 hours. Plans are being made for outcomes to be sent to secure nhs.net e-mail addresses when referrers do not have access to PPM. In the interim, outcomes can also be faxed to referrers if appropriate details are provided on the referral form.

It is hoped that an electronic mechanism to inform GPs within the network can be developed using PPM and possibly nhs.net e-mail. This is part of a much larger piece of work being developed by the Cancer Centre to speed communication with GPs about a range of issues.
## Figure 4 The roles of the Neurosciences MDT

- Establish a diagnosis for the optimal clinical management of the patient
- Develop management plans for patients with CNS tumours at first presentation, to include initial supportive care needs, diagnostic and surgical interventions, non-surgical oncology interventions, treatment of symptoms and follow-up
- Nominate and record a key worker to act as point of contact for patients, their relatives and carers. This should be agreed with the patient, their relatives and carers
- Agree who is responsible for implementing the next stage of the management plan
- Inform the diagnostic clinician/team at the local referring hospital and GP of the management plan (see communication below)
- Inform the cancer network MDT of the management plan (usually via a representative who is a member of the neurosciences MDT and also in writing)
- Review and advise on patients referred back from the cancer network MDT on disease progression or relapse
- Develop MDT protocols, in collaboration with the cancer network MDT, to define appropriate follow-up imaging requirements for patients with CNS tumours
- Implement the national management protocols for CNS lymphoma, medulloblastoma, pineal tumours and optic gliomas (see Chapter 7)
- Act as an educational resource for local service providers
- Develop and maintain evidence-based local management protocols covering all aspects of the patient pathway
- Participate in regular site-specific group meetings to review care pathways and protocols
- Introduce and maintain systems for data entry across the area of service provision including links to cancer registries
- Audit practice against this guidance and other national guidelines as they are published
- Facilitate the entry of patients into appropriate National Cancer Research Network (NCRN) and local clinical trials
- Liaise with the cancer network MDT
The roles of the Rehabilitation and Non-Surgical Oncology MDT are defined in the IOG. They are outlined in Figure 5.

**Figure 5 The roles of the MDT**

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

Who will be discussed?

- Patients who are referred to the Neurosciences MDT for a clinical decision (their rehab and supportive needs will be co-ordinated by the IOG CNS).
- Patients who have a recently confirmed histopathological diagnosis
- Oncology patients whose supportive and rehabilitation needs have changed
- Patients who are for best supportive care.

For detailed standard operating procedures for the Cancer Alliance MDT see Section 15. The overall structure of Network rehabilitation services is also described in Section 17

### 4.5 The Pituitary MDT

This MDT meets weekly (Wednesday) to consider the management of patients with pituitary tumours. The meeting involves endocrinologists in addition to pathologists, radiologists, oncologists and neurosurgeons.

This service has a separate SOP and specific guidelines which are supplementary to the Guidelines for the Management of Brain and Central Nervous System (CNS) Tumours
5 Pathways

5.1 Area Wide Presentation / Diagnostic Pathway for Adult Patients

West Yorkshire Cancer Alliance Area Wide Brain and CNS Presentation/Diagnostic Pathway for Adult Patients
April 2017

Patient Presents with Symptoms of to Local Services - includes Pituitary, Spinal Cord primaries, Skull Based Tumours, tumour recurrence & metastatic presentation (Section 2 in Network Guidelines)

- GP
- Outpatient
- Optician
- A&E
- Ward

Imaging
- Section 2 of Network Guidelines (p.18)

Scan shows Brain / CNS Tumour / Cerebral Metastases / Disease recurrence

Flag Local process by Radiology to alert Local Diagnostic Brain & CNS Team

- Repeat / other test
- Result to the Referring Team +/- the Local Diagnostic Brain & CNS Team

Local Diagnostic Team / Acute Oncology Services

New Primary Brain & CNS Tumours should be referred to the NSMDT within 2 working days

- Log / Register Patient locally if possible if able to access PPM or complete the registration form and send to NS MDT for registration
- Network Guidelines (p.21/22)

On-call Neurosurgical Registrar

- Emergency Surgery Referral
- If inappropriate register only discuss at CN MDT - decision for care locally within 1 working day

NS MDT
- Network Guidelines (p.23)

RNS MDT
- Network Guidelines (p.25)

Report to the referrer

Please Note: The TYACN pathway for initial management is in the local TYA designated hospitals with subsequent referral on to the specialist cancer site specific MDT for treatment. This is the same pathway as per older adults

Patient care returns to referring Unit for Best Supportive Care, Palliative Care and Local rehabilitation support

Decision of Centre MDT available within 24 hours via PPM

Please Refer To the Relevant Tumour Treatment Pathway for Next Steps – High Grade Intrinsic Brain, Low Grade Intrinsic, Extrinsic and Metastatic Tumour Pathways
5.2 High grade intrinsic brain tumours

West Yorkshire Cancer Alliance Primary High Grade Brain Tumour Pathway
April 2017

Weekly Neurosciences MDT
All new suspected High Grade Glioma patients to be referred to the N.S.MDT
If imaging compatible with High Grade Glioma, refer to High Grade Glioma Clinic

Specialist High Grade Clinic
(weekly - Wednesday)
Key worker details given, holistic assessment initiated, treatment options discussed.
Referral to neuropsychology and Brain and CNS AHP’s as indicated.
Epilepsy support is provided in clinic by Leeds CNS – who will liaise with unit Neurologists

Surgery - biopsy or debulking

Histology reviewed at NS MDT and told to patient at specialist High Grade Clinic
PPM updated to show histological diagnosis

High Grade confirmed

No
Appropriate alternative pathway

Yes

Best Supportive Care

More Surgery

Oncology

RT

Chemo

Chemo & RT

Oncology Follow-up

Progression

Looks like High Grade Tumour

RNS MDT
RNS MDT to be notified of all new suspected High Grade Tumour pts.

May have radiological surveillance if diagnostic uncertainty

No longer looks like tumour

Appropriate alternative pathway
Patients with Grade 3 Disease

- Where possible, these patients should be identified at the initial MDT discussion and the option of Gliadel Wafers be considered prior to surgery.
- Patients receiving radiotherapy should be commenced within 2 weeks of biopsy or 4 weeks of decompression surgery.
- Molecular markers (1p19q and MGMT promoter methylation) determine the choice of adjuvant treatment.

Patients with Grade 4 Disease

Patients suitable for active treatment should be offered radiotherapy alone or combination therapy (radiotherapy and Temozolomide; RT/TMZ). NICE approval has been given for concomitant Temozolomide with radiotherapy, followed by adjuvant treatment for newly diagnosed Glioblastoma in patients who are WHO performance 0 or 1. This follows the EORTC-NCIC trial. The benefit from combined modality treatment appears greatest for patients with favourable prognostic characteristics.

- Treatment should ideally be commenced within 2 weeks of biopsy or 4 weeks of decompression surgery.
- Depending on performance status and patients’ wishes, these patients should be managed in a defined pathway of care e.g. palliative care or active management.
5.3 Low grade intrinsic brain tumours

West Yorkshire Cancer Alliance Low Grade Glioma Pathway
April 2017

Weekly Neurosciences MDT
All new suspected Low Grade Glioma patients to be referred to the N.S.MDT.
If imaging compatible with Low Grade Glioma, refer to Low Grade Glioma Clinic.

RNS MDT
RNS MDT to be notified of all new suspected L.G.G pts.

‘Low Grade Clinic’
(3 weeks a month - Monday)
Key worker details given. Holistic assessment initiated, treatment options discussed.
Referral to neuropsychology and Brain and CNS AHP’s as indicated.
Epilepsy support is provided in clinic by Leeds CNS – who will liaise with unit Neurologists.

Surgery

Observation

Stable

No

Yes

Histology reviewed at NS MDT
PPM updated to show histological diagnosis

Low Grade confirmed

No if high grade revert to high grade path

Yes

No adjuvant therapy (ie observation)

XRT

Primary Chemo

XRT and Chemo

Stable

No

Yes

Back to weekly N.S. MDT

Continue in LGGC

Referral to the Brain & CNS Specialist Nurses and AHP’s can be made at any stage in the pathway as required.

All Leeds patients with seizures or any patients with seizures who are potential surgical candidates are referred to Leeds Epilepsy Service.
These patients should be seen in the Low Grade Glioma clinic in Leeds. This is a fortnightly multidisciplinary clinic comprising 2 consultant neurosurgeons, a consultant oncologist, an epilepsy specialist nurse and an oncology nurse specialist.

The optimal management of cerebral low grade glioma remains debated. The EORTC developed a prognostic score based on two large, randomized, multicentre trials (EORTC 22844\(^3\) and 22845\(^4, 5\)). In multivariate analysis, age ≥ 40 years, astrocytic tumour type, tumour size > 6cm, tumour crossing the midline, and neurologic deficit at diagnosis (before surgery) were significant adverse factors. A favourable prognostic score was defined as the presence of no more than two of these adverse factors and was associated with a median survival of 7.7 years (95% CI = 6.6, 9.3). The presence of 3-5 factors was associated with a median survival of 3.2 years (95% CI = 3.0, 4.0).

Maximal safe resection at presentation should be considered if deemed safe. Histological confirmation of diagnosis should be achieved prior to radiotherapy or chemotherapy. It may also provide important prognostic information. Since foci of transformation to high grade tumours can develop within low grade tumours such biopsies can suffer from sampling error. This can occur even if biopsies are directed to areas of contrast enhancement or increased perfusion, since none of these provides complete accuracy.

Early radiotherapy can delay time to progression and control symptoms but does not impact overall survival (EORTC 22845\(^4, 5\)). Due to potential radiotherapy toxicity (in particular neurocognitive decline which is associated with reduction in quality of life), asymptomatic patients predicted to have a favourable outcome can be offered active surveillance rather than immediate radiotherapy.

Radiotherapy should be considered in the following patients if not suitable for resection alone (adapted from EORTC criteria):

- Age ≥ 40 years
- Radiologically proven progressive lesion
- Neurological symptoms others than seizures only (focal deficits, signs of raised intracranial pressure, mental deficits)
- Intractable seizures
- Large unresectable infiltrating tumours (> 6cm) and those crossing midline.
  - For these patients however it would be reasonable to also consider whether a limited debulking operation could be used first to reduce volume and allow space for post-radiotherapy swelling.

Primary chemotherapy remains under investigation but may be an option for patients unsuitable for surgery or radiotherapy. It may also be used to try and shrink the tumour away from eloquent area’s to facilitate safer or more complete resection. Whatever the location of tumour, strong consideration should be given to a biopsy being performed prior to chemotherapy.

Active surveillance should initially include 3-6 monthly reviews with MRI and may be nurse or consultant led. More extended interval reviews (6-12 monthly) may be appropriate in stable clinical situations. Patients undergoing active surveillance should be offered treatment in response to their clinical condition and MRI results as the need arises and after Specialist MDT discussion. Decisions are made on a case by case basis.
Recent evidence suggests that Grade 2 oligodendrogliomas with 1p 19q co-deletion may do particularly well if given early radiotherapy and adjuvant PCV chemotherapy. This option is increasingly being considered for this group.

5.4 Extrinsic brain tumours

The majority of these will be meningiomas and the vast majority of these will be WHO grade 1. Occasionally, higher grade meningiomas or rarer tumours such as haemagiopericytomas can arise.

Many meningiomas are removed surgically. This is particularly the case with those tumours in accessible locations and those that are causing pressure effects. In some cases, the location of the tumour or the age / condition of the patient will make this inappropriate.

Smaller tumours can be watched expectantly since the rate of growth is often very slow and this avoids the risks of surgery/treatment. Alternatively they can be treated by radiosurgery if there is evidence of tumour growth. Conventionally fractionated radiotherapy can be used for larger lesions that cannot be removed surgically (either due to location or because of patient co-morbidities). Occasionally, a combined approach can be considered - debulking the majority of a tumour where this is safe to do so and reserving radiotherapy/radiosurgery for a residual volume of tumour that cannot easily be excised without unacceptable risk to the patient.

Completely resected WHO grade 1 meningiomas are followed up radiologically in surgical clinics and rarely require scans more than yearly. Even incompletely resected grade 1 tumours can be followed radiologically unless the location of the residual disease threatens adjacent critical structures. Completely resected grade 2 tumours can be monitored radiologically although (at least early on) more frequent scans are required. It is usual to perform the first follow up scan at 3-6 months and then 6 monthly scans for 2 years. Most incompletely resected grade 2 tumours and all grade 3 tumours require immediate radiotherapy.

**Acoustic schwannoma**

These tumours are usually identified during investigations of auditory symptoms (e.g. balance or hearing). Occasionally, they can be an incidental finding on scans performed for some other reason. The main treatment options include "watch and wait" (since many tumours only grow very slowly and this avoids treatment-related morbidity), radiosurgery or surgery. All these patients should be discussed in the Leeds multi-disciplinary base of skull clinic. Decision making will be influenced by patient age and preference, degree of symptoms and tumour size / growth rate.
5.5 Anterior Skull Base Pathway

[Flowchart showing the pathway]

- Olfactory Neuroblastoma Suspected Head and Neck MDT
- Anterior Skull Base Tumour Suspected
- Skull Base Melanoma Malignancy Suspected Melanoma MDT

- Pituitary & Anterior Skull Base MDT

- Tumour Confirmed
  - Endocrinology or Ophthalmology Assessment
  - Surveillance
  - Trans-nasal Endoscopy Surgery (AT or NP)
  - Cranotomy +/- involvement of ENT/Ophthalmology/Plastics
  - SRS (NP)
  - Radiotherapy

June 2017
5.6 Lateral Skull Base Pathway

Lateral Skull Base Pathway

- Suspected Lateral Skull Base Tumour
  - Neuroscience MDT for Image Review
    - Lateral Skull Base Tumour Confirmed
      - Lateral Skull Base MDT Clinic
        - Management and treatment option discussed and agreed with patient
          - Radiological Surveillance
            - SRS
              - Follow Up in SRS Clinic
            - Surgery
              - Follow Up in Surgical Clinic
            - Radiotherapy
              - Follow Up in Oncology Clinic
5.7 Leeds Chordoma and Chondrosarcoma Pathway
5.8 Skull Base Referral Pathway
Referral to Brain & CNS Specialist Nurses and AHP’s can be made at any stage in the pathway as required and where the patient’s assessment/rehabilitation needs are primarily caused by neurological deficits.

**5.9 Area Wide Metastatic Pathway**

**West Yorkshire Cancer Alliance Area Wide Metastatic Brain & CNS Tumour Pathway**

**April 2017**

- **New Diagnosis of a Cerebral Metastasis on CT / MRI** (contact surgical on-call registrar if in doubt)
  - Significant and clinically symptomatic mass effect on scan requiring urgent intervention
  - Staging of extracranial disease by local MDT
  - Prognosis of more than 6 months
  - Management by 1st site MDT
  - Neurosciences MDT
    - Register metastatic patients at MDT
    - Criteria for Referral to Neurosciences MDT:
      - Good Karnofsky ≥ 70%
      - Primary disease
      - Prognosis over 6 months life expectancy
      - Treatment offered as per clinical guidelines
    - RNS MDT
      - CNS / RNS MDT / 1st site MDT to coordinate Rehab & supportive care

- **Emergency surgery not required**
  - Known Primary
  - Primary Unknown
  - Screening Investigations
    - History & examination
    - Chest, abdomen & pelvis mamography?
  - Primary found
  - No primary found
  - Refer to MDT
    - Consider biopsy

- **Emergency surgery**
  - Inoperable
  - Operable
    - Best supportive care
  - Involve Local Oncology and Local Support Services

- **Consult on-call neurosurgeon**
  - Scans sent via PACS

- **Known Primary**
  - Determined operable vs inoperable
  - Staging of extracranial disease by local MDT
  - Prognosis of more than 6 months
  - Management by 1st site MDT
  - Neurosciences MDT
    - Register metastatic patients at MDT
    - Criteria for Referral to Neurosciences MDT:
      - Good Karnofsky ≥ 70%
      - Primary disease
      - Prognosis over 6 months life expectancy
      - Treatment offered as per clinical guidelines
    - RNS MDT
      - CNS / RNS MDT / 1st site MDT to coordinate Rehab & supportive care

- **Follow Up x 1 then Oncology FU**
  - Follow Up Gamma Knife Team & Oncology
  - Follow Up x 1 then Oncology FU
  - Referred back to 1st site MDT for WBRT / chemo / BSC Local Follow Up

- **Referred to the Brain & CNS Specialist Nurses and AHP’s can be made at any stage in the pathway as required and where the patient’s assessment/rehabilitation needs are primarily caused by neurological deficits.**
Metastases to the brain are commoner than primary brain tumours. They are particularly associated with certain types of cancer such as lung, breast and melanoma. More rarely, they are found in patients with renal, gynaecological and GI cancers. Very occasionally they are seen with sarcomas. Sometimes brain metastases can be the presenting site of disease from an unknown primary.

The prognosis from brain metastases is often poor. Results from several large trials of whole brain radiotherapy (WBRT) identified clear prognostic groups by recursive partitioning analysis (RPA). Key factors were performance status, control or absence of extracranial disease, age and whether metastases were solitary or multiple. Median survival varied from just over 2 to just over 7 months depending on group.

Performance status is particularly important and is a powerful predictor of outcome in nearly every study. For patients with a poor performance status (Karnofsky performance score - KPS <70) the main decision is usually between best supportive care and WBRT.

Trial evidence suggests that the following group stand to benefit most from other therapies such as surgery or radiosurgery:

- KPS >= 70
- Controlled or absent extracranial disease (prognosis estimated at >6 months by site-specific team)

Surgical biopsy may also be justified in cases requiring histology (ie no clear extracranial primary to biopsy)

Large lesions (particularly those >3cm) causing significant pressure symptoms are often considered for surgery to achieve rapid decompression. Radiosurgery is more often used when lesions are in eloquent areas and are <3cm (although the ability to fractionate radiosurgery is slightly extending this limit). Where multiple lesions exist, radiosurgery has advantages over surgery, since all the metastases can be treated in a single visit without the need for general anaesthetic(s). Occasionally a combined approach can be used.

All patients meeting the above criteria should be considered by the neurosciences MDT. Other patients where the site-specific MDT feel a more aggressive approach is justified can also be discussed. It can be seen that referral will usually require an assessment of performance status by the referring team, up-to-date staging information (CT chest, abdomen, pelvis), an opinion from the site-specific team where the primary site is known (about treatment options and likely prognosis of extracranial disease) and an MRI of the brain (which more accurately defines metastasis size, location and number). Since brain metastases can progress quickly it is important that this occurs in a timely fashion to avoid missing the opportunity for more aggressive therapy.
West Yorkshire Area Wide Pituitary Presentation, Diagnostic and Treatment Pathway

May 2017

Referral received by Leeds Teaching Hospital NHS Trust
Referral letter from Endocrinologist, GPs, Ophthalmologist

Pituitary MDT Management Plan formed

Further investigation

By day 7

Specialist Clinic
Agree a Management Plan with the Patient

Further investigation

By day 14

Surgery

Observation

Further investigation

Out-Patient Appointment

Radiosurgery
Fractionated Radiotherapy

Further Surgery

By day 54

Follow up plan discussed on completion of treatment and will depend on individual patients needs – support from the RNS MDT as appropriate

Please complete the Pituitary MDT Referral Form and send it via e-mail to: leedsth-tr.leedscancercentre@nhs.net
Imaging should be sent by image link from the referring hospital To Leeds General Infirmary
Cases will NOT usually be discussed at the Wednesday MDT meeting unless this form and the relevant imaging and Endocrinology/ Ophthalmology results are received by 3.30 pm on the preceding Monday.
Please note the Pituitary MDT is currently held every Wednesday.
5.11 Ependymoma

Ependymomas are commonest in childhood. They can occur in both the brain and spine. They can also metastasise within the cerebrospinal fluid. The mainstay of treatment is surgical excision and adjuvant therapy depends on the extent of resection and tumour grade as follows:

<table>
<thead>
<tr>
<th>Grade</th>
<th>Completely excised</th>
<th>Incompletely excised</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Surveillance</td>
<td>Adjuvant RT (if further surgery)</td>
</tr>
<tr>
<td>II</td>
<td>(usually) Adjuvant RT</td>
<td>Adjuvant RT</td>
</tr>
<tr>
<td>III</td>
<td>Adjuvant RT</td>
<td>Adjuvant RT</td>
</tr>
</tbody>
</table>

All patients require a full assessment of the craniospinal axis to determine the full extent of disease before commencing therapy.

5.12 Pineal

Please see national guidance document at:

http://www.bnos.org.uk/raretumours.html

5.13 CNS lymphoma

Please see national guidance document at:

http://www.bnos.org.uk/raretumours.html

5.14 Paediatric

National guidelines are constantly being reviewed by the Children’s Cancer and Leukaemia Group. Please see this national guidance document at:

http://www.cclg.org.uk/

The Yorkshire and Humber TYA Group have produced a generic Teenage and Young Adult (16 – 24) For brain and CNS, the TYACN pathway for initial management is in the local TYA designated hospitals with subsequent referral on to the specialist cancer site specific MDT for treatment. This is the same pathway as per older adults.

Contact Details: Teenage and Young Adult Service, The Peadiatric Oncology Offices, D Floor, Martin WingLeeds General Infirmary. LS1 3EX

The TYA Cancer Network Pathway can be obtained from the above contact
5.15 Adult medulloblastoma

Please see national guidance document at: http://www.bnos.org.uk/raretumours.html
West Yorkshire Cancer Alliance Area Wide Follow Up Pathway for Adult Patients

April 2017

Patient in the Community, Post Surgery / Oncology Treatment in an agreed FU Programme or discharged from FU

Clinical Change

May follow presentation pathway or direct to CNS who will liaise with the clinical team for next step. May be referral to dedicated CPA or referral to NSMDT / RNS MDT within 1 working day of decision

CNS refer to NSMDT within 1 working day of decision

Palliative Care - Manage Care Locally

Further follow-up recommendations are in the Clinical Guidelines for:
- High grade Gliomas p.54
- Low Grade Gliomas p.54
- Metastases p.55
- Meningioma p.55
- Vestibular Schwannoma p.70
- Pituitary adenoma p.73
- Glomus jugulare tumours p.79
- Pineal region tumours p.80

Rehabilitation assessment, best supportive care, palliative care needs discussed at the RNS MDT which follows the Neuroscience MDT. Patients may referred back to Locality for ongoing management
5.17 Incidental Finding, Low Grade and High Grade Referral Pathways

At the point where a tumour has been identified
(on a GP fast track referral scan) and referred to the Brain MDT in Leeds - (flag and log etc.)

Incidental Finding
(i.e. asymptomatic unexpected finding e.g. small meningioma)

Outcome sent to the GP in a standard way with advice on further management

  e.g. -

  • no intervention or follow up required

  • or follow up imaging recommended (with guidance to the GP on how to do this and when to refer back)

  • or advice to refer to a specific neurosurgeon for a routine appointment to discuss findings

  • GP to inform the patient
Low Grade Glioma

- Outcome sent to the GP in a standard way
- GP to inform the patient of a radiological diagnosis and then refer in to Mr Goodden or Mr Chumas at the Leeds Teaching Hospitals NHS Trust and the Low Grade Clinic
High Grade Tumour (Glioma / metastasis / lymphoma)

a) Looks like met(s) and known to oncology team before:
   - Suggest to GP urgent assessment by oncology team (after patient made aware): they can assess PS (Performance Status), prognosis and sort staging CT scan. MDT states if suitable for SRS (Stereotactic Radiosurgery)/ surgery depending on this assessment.
   (Please note this pathway may be activated in a local hospital before referral to Leeds - then Leeds will have information necessary to advise on SRS/surgery)

b) Looks like met(s) but no history of cancer:
   - Mechanism to be seen by the CUP team in the relevant trust (to ensure staging scan, assessment of PS and determination of suitability for further tests e.g. biopsy) after the GP tells the patient the radiological diagnosis.
   - MDT states if suitable for SRS / surgery depending on this assessment.
   (as above this may happen in local units before referral to Leeds)

c) Typical high grade glioma/lymphoma or solitary lesion where glioma and met both possible:
   - Direct contact with the GP by the CNS team / neurosurgeons.
   - Arrange urgent review in the High Grade clinic.
   - (Potentially neurosurgeons to get CT staging to check no extracranial primary, if met possible).
5.18 Nurse specialists

Patients with brain and other central nervous system tumours have very particular clinical needs which require their plan of care to be structured quite differently from those for people with more common cancers. In particular:

- Their healthcare needs are complex
- Many patients are severely disabled by their disease
- Many patients have a poor prognosis
- There are significant differences in the care needs of patients with tumours of different histological types and arising in different parts of the CNS.
- Many patients experience long-term, progressive cognitive, physical and emotional problems.

Therefore the role of the CNS within this speciality is pivotal in providing continuity and coordination of care across the pathway as well as managing transitions of care when required.

This can best be achieved by ensuring that every patient has a clearly identified key worker. The key worker is the identified point of contact for patients, their relatives and carers. CNS’s are responsible for ensuring that the supportive care needs of the patient and their relative are met.

As core members of the MDT, they also provide a variety of other services such as advice, information and facilitation of appropriate referrals to AHP’S, Palliative Care and Community Services, ensuring that access to such services is always safe, easy and equitable.

They also provide education to Healthcare Professionals working with this group of patients.

5.19 Occupational therapy

Occupational Therapy is a person centred holistic service which aims to facilitate people with a brain and CNS tumour to maximise their health and wellbeing through participating in meaningful activity.

Occupational Therapists use activities to both assess and treat changes in an individual’s cognition/perception, sensory, physical and emotional abilities in relation to how they impact on function. The impact of social, cultural, and environmental factors on a person’s performance is also taken into consideration. This information is combined to create person centred goals and a treatment plan that may include a mix of restorative, compensatory and palliative supportive rehabilitation approaches. (Dietz, 1998).

Patients with Brain and CNS tumours may require specialist neuro-oncology occupational therapy input at any stage of the cancer pathway; from pre diagnosis through to treatment and subsequent rehabilitation survivorship and palliation.
The neuro-oncology occupational therapy service consists of an inpatient service based on the neurosurgical wards at the Leeds General Infirmary and an outpatient team based at the St James’s Institute of Oncology, Bexley Wing.

Pre-operative assessments are undertaken for patients undergoing awake craniotomies for low grade brain tumours following referral by the treating team.

The inpatient service aims to screen all neuro oncology patients admitted to the neurosurgical wards. The team undertakes a holistic assessment of those who have had undergone major cranial surgery to identify changes in performance. This enables a clearer understanding of post-surgery needs and can inform plans to support a safe discharge from hospital. Any further rehabilitation goals can be addressed in the community.

The outpatient Occupational therapy clinics run four days per week offering a rapid access to the service for patients who experience significant changes in function. This supports them to remain in their preferred place of care. The outpatient service employs a collaborative approach. Where appropriate, AHP’s undertake joint sessions to address identified needs in a holistic manner.

The occupational therapist organises a 6 monthly training event for AHP’s and social care professionals who work with neuro oncology patients across the region. The aim is a) to improve both communication links and b) develop the knowledge and skills of the professionals about neuro oncology. Thus enhancing the quality of interventions provided to this patient group.

The role of the Occupational therapist as a core member of the MDT is recognised in the Improving Outcomes Guidance for People with Brain and other CNS Cancers (2006). The Occupational therapist will liaise closely with other members of the MDT e.g. Clinical Nurse Specialists, Speech and Language Therapists, Dieticians, and Physiotherapists in order to facilitate and optimise patient care.

- **Role of the Brain and CNS Occupational Therapists**

Occupational therapists aim to:

- Provide specialist screening and assessment of a patient’s occupational performance skills at any stage of the pathway and provide advice, guidance and treatment, based on individual needs, goals and circumstances.
- To agree specific timely realistic achievable goals with the patient and monitor progress throughout rehabilitation.
- Provide a patient-centred approach to treatment and identify the most appropriate format for therapy provision (i.e. in-patient, out-patient, central or local) and to liaise with other service providers / clinicians as appropriate.
- Provide outpatient clinics and telephone follow ups.
- Liaise closely with other MDT members.
- Provide specialist pre-operative assessments for patient with low grade brain tumours following referral from the treating team.
- Provide ongoing support to patients, families and carers.
- Develop resources for patients, carers, and health professionals within the local and regional service.
- Participate in site-specific group meetings to review care pathways and guidelines.
- Undertake discipline-specific audits and research, and contribute to MDT u-te audits and research
- Provide professional advice and education / training to local specialist AHP’s and service providers as required.
- On-going evaluation of the quality of outpatient interventions through the use of outcome measures and patient feedback.

Referring to Occupational Therapy Services

Referrals to the Occupational Therapy out patient service can be made via the MDT, directly from any health care professional within the region, or via self-referral from patients or carers.

Neurosurgical in-patients undergoing major surgical procedures will automatically generate a referral to the service. The aim is for all neuro-oncology patients undergoing neurosurgery to be assessed post-operatively for occupational performance deficits to enable a clearer understanding of needs and to inform safe discharge, oncology treatment planning and rehabilitation.

- **Criteria for Referral**

Changes in any of the following domains which are impacting on function:

- Cognition (orientation, insight, memory, attention, executive skills)
- Perception (visuospatial skills, gnosis, praxis)
- Sensory (tactile, visual, auditory, proprioceptive, pain)
- Motor (tonal changes, reduction in range of motion, strength, coordination, balance)
- Emotional (adjustment / adaptation to changes in functional ability, roles, future aspirations and life limiting condition)
- Social (carer strain, support requirements)
- Fatigue

Changes in the patient’s ability to safely and independently participate in:

- Personal activities of daily living
- Domestic activities of daily living
- Work / education
- Leisure pursuits
- Any other life roles

Contact Details
Telephone: 0113 2067912 (Answering machine available)
Bleep: 80-4307 and 80-4481
Fax: 0113 2067976
5.20 Dieticians

Patients may require dietetic input at any stage of the pathway from diagnosis, through treatment and subsequent rehabilitation and palliation. Patients with Brain and CNS tumours may be nutritionally compromised as a result of specific treatments for their tumours e.g. radiotherapy and chemotherapy. Dietetic management may include oral and artificial nutrition support and texture modified diets.
Patient’s can be referred to the Dietician service by any member of the MDT by completing the appropriate referral form.

Role of the Neuro-oncology Dietitian

- To provide nutritional screening and assessment of a patient’s nutritional concerns at any stage of the pathway and to provide advice and guidance based on an individual’s needs and circumstances
- To monitor a patient’s progress through treatment in order to optimise nutritional status
- To liaise closely with other MDT members
- To provide ongoing support to patients, families and carers
- To develop resources for patients, carers and health professionals within the regional service

Patients must be under the care of the Brain/CNS Network MDT before being assessed by a Neuro-oncology Specialist Dietician.

The above service relates to Leeds Teaching Hospitals NHS Trust. Dietetic service levels vary across the region and in view of this not all areas can provide a service as described above. Please contact your local dietetic department for information on their service.
5.21 Physiotherapy

The role of the physiotherapist as a core member of the MDT is recognised in the Improving Outcomes Guidance for People with Brain and other CNS Cancers (2006). The physiotherapist will liaise closely with other members of the MDT e.g. Clinical Nurse Specialists, Speech and Language Therapists, Dieticians, and Occupational Therapists in order to facilitate and optimise patient care.

Patients may require physiotherapy input at any stage of the pathway from pre-diagnosis, through treatment and subsequent rehabilitation, palliation, and survivorship. Patients with brain and other CNS tumours may present with a broad spectrum of symptoms, varying in complexity, which are amenable to rehabilitation, or require supportive adaptation.

6.5.1 Role of the Neuro-Oncology Physiotherapist

- To provide a specialist neurological physiotherapy service, including specialist screening and assessment of a patient’s physiotherapy needs, at any stage of the pathway and provide advice, guidance, and treatment based on individual needs and circumstances.
- To provide an on-site service available to support those with physiotherapy needs through radiotherapy.
- To liaise closely with the MDT.
- To provide on-going support to patients, families, and carers.
- To develop resources for patients, carers, and health professionals within the local and regional service.
- To participate in site specific group meetings to review care pathways and guidelines.
- To undertake individual audits and research, and to contribute to audits and research as part of the MDT.
- Pre-assessment and intra-operative testing/monitoring for patients referred for physiotherapy input during awake craniotomy

6.5.3 Criteria for Referral

- Changes in mobility
- Sensory or motor disturbance affecting limbs/face/trunk
- Balance disturbance +/- Falls
- Pain
- Vestibular dysfunction/ dizziness affecting balance/mobility
- Facial weakness
- Advice on returning to activity/vocation/hobbies

6.5.4 Contact Details

St James's Institute of Oncology

Telephone: 0113 2067656
Bleep: 80-4309
5.22 Speech & Language Therapy

Patients may require Speech and Language Therapy input at any stage along the pathway from the diagnosis and care planning stage to end of life care.

The role of the Speech and Language Therapist as a core member of the MDT is recognised in the Improving Outcomes Guidance for People with Brain and other CNS Cancers (2006). The Speech and Language Therapist will liaise closely with other members of the MDT e.g. Clinical Nurse Specialists, Occupational Therapists, Dietitians, and Physiotherapists in order to facilitate and optimise patient care.

Patients with brain and other CNS tumours may present with dysarthria, dyspraxia, aphasia, cognitive language difficulties and/or dysphagia. Speech and Language Therapists will offer support, education and rehabilitation as appropriate to any patients that present with difficulties.

5.22.1 Role of the Brain and CNS Speech and Language Therapists

- To provide specialist screening and assessment of a patient's Speech and Language Therapy needs at any stage of the pathway and provide advice, guidance, and treatment based on individual needs and circumstances.
- To monitor patients' progress throughout treatment and make any necessary changes to optimise functional status.
- To liaise closely with other MDT members.
- To provide ongoing support information and advice to patients, families, and carers.
- To develop resources for patients, carers, and health professionals within the local and regional service.
- To participate in site specific group meetings to review care pathways and guidelines.
- To undertake individual audits and research, and to contribute to audits and research as part of the MDT.
- To provide education and training to locality specialist AHPs and service providers.
- To support communication in assessment of mental capacity as required.
- To assess and monitor patients pre, during and post awake craniotomy.
- To provide instrumental assessments (Fibreoptic Endoscopic Evaluation of Swallowing/ Videofluoroscopy) as required.
- To initiate onward referrals to other professionals (e.g. ENT).
- To establish clear communication pathways with local services in the region to ensure a seamless transition of care.
- To ensure prompt and accessible services.
- To attend the MDT on a weekly basis.
- To provide training and support as needed to patients and family/carers, MDT members, local Speech and Language Therapy services, hospices, nursing/residential homes, support groups/charities.

5.22.2 Referring to Speech and Language Therapy Services

Any patient with speech, language (including cognitive communication disorders), swallowing, oromotor and/or voice difficulties should be referred for specialist Speech and Language Therapy input. A referral to Speech and Language Therapy can be made at any
point of the patient pathway from the diagnosis and care planning stage through to end of life care. Any patient who does not have these difficulties pre-operatively, but may acquire them should also be referred for pre-operative and post-operative assessment.

Referrals are accepted from any member of the multidisciplinary team (MDT)... The Speech and Language Therapy team will respond to referrals within 2 working days for in-patients and 10 working days for outpatients.

All inpatients attending Leeds General Infirmary for a biopsy, debulking or excision of a brain tumour (excluding pituitary tumours) will be screened by Speech and Language Therapy and input provided as required.

5.22.3 Criteria for Referral to Speech and Language Therapy

- Speech difficulties
- Expressive/receptive language difficulties
- Cognitive language difficulties
- Reading/writing difficulties
- Swallowing difficulties
- Oromotor deficit impacting on speech or swallowing
- Vocational rehabilitation needs

5.22.4 Contact Details

Telephone: 0113 2067752 / 0113 3923968
Bleeps: 2650 4885
5.23 Neuropsychology / Clinical Psychology

5.23.1 Introduction

People with brain tumours can experience a range of cognitive and psychological sequelae. In addition to varying types and levels of cognitive difficulties (e.g. problems with memory, concentration, planning, problem-solving, thinking speed, language and personality change), people with brain tumours might experience significant psychological distress, difficulties in adjustment and coping, depression, anxiety and poor quality of life. Consequently, a biopsychosocial model is important to understand the complex interaction between the neurological, cognitive and physical effects, as well as the psychological/ emotional impact and changes in behaviour, social roles and relationships for people with brain tumours and their families and carers.

The Improving Outcomes for People with Brain and other CNS Tumours NICE guidance (2006) recognised the core role of neuropsychology and clinical psychology in the care of people with brain tumours. The Neuropsychology/ Clinical Psychology service is for adult brain tumour patients experiencing cognitive or psychological difficulties relating to their tumour(s) or treatment. The service is based at St James’s University Hospital, Leeds and patients must be under the care of the local Brain/ CNS Network MDT.

5.23.2 Services offered

1. Specialist comprehensive neuropsychological assessment for patients experiencing cognitive difficulties or those involved in the surgery/ treatment process. The aims of assessment might include the following:

   - Determining whether there is evidence of organic brain dysfunction or changes in cognitive abilities.
   - Describing the nature and extent of cognitive impairment (cognitive strengths and weaknesses, deciphering tumour related difficulties from other neurodegenerative processes).
   - Elucidating how cognitive functioning might be affected by surgery, radiotherapy, medication and other treatments.
   - Measuring whether cognitive performance is changing over time (deterioration or recovery).
   - Clarifying the practical consequences of cognitive impairment (e.g. capacity to consent to medical procedures, care needs, independent living, returning to work and education).
   - Understanding the implications of the pattern of the cognitive strengths and weakness and psychological well-being for the rehabilitation process.
   - Formulating how mood is affected by brain dysfunction and vice versa.

2. Neuropsychological interventions and rehabilitation (restitutive or compensatory) for complex cognitive and behavioural problems.

3. Psychological assessment of patients experiencing moderate-severe levels of psychological distress in their adjustment to living with a brain tumour.

4. Provision of a range of evidence-based psychological interventions for people with cancer whilst facilitating service-user choice and preference.
5. Psychological consultation (e.g. advice to help staff keep individuals safe when there are risk issues) and supervision of other staff.

5.23.3 Referral Criteria

It is recommended that neuropsychological assessment/ intervention is available for patients with brain tumours under the care of the Yorkshire Neuro-Oncology MDT.

Examples of appropriate reasons for referral include:

- Prior to surgery (to facilitate functional mapping) or other treatments
- Post-surgery or other treatments to facilitate neuropsychological rehabilitation as well as clarification of care needs and future planning
- For patients experiencing cognitive difficulties or changes in behaviour and/or personality
- To facilitate differential diagnosis of tumour-related cognitive deficits from other neurological conditions
- Input into complex capacity issues

Referrals for psychological assessment and therapy for adults experiencing significant psychological distress that does not resolve, interferes with general activities or treatment, is disproportionate to the circumstances and is not more appropriately dealt with by another member of the team or voluntary services.

Examples of the psychological difficulties to be referred are:

- A disproportionate emotional response to illness (negative beliefs, difficulties adjusting and coping).
- Problems coping with complex treatment regimes or isolation.
- Depression, anxiety, panic or phobias associated with their cancer care.
- Low self esteem and body image/ appearance issues (e.g. after treatment).
- Survivorship issues - anxiety about the future, returning to work.
- Psychological issues around death and dying.
- Health anxiety (e.g. extreme fears of the cancer returning despite good prognosis).
- Non-urgent risk review of (suicide/ harm to self or others).
- Impact of pre-existing mental health difficulties upon cancer care.

Priority is determined by a number of factors including the needs of the patient and timing/ type of medical treatment. Clinically urgent referrals will be prioritised following liaison with the referrer.

Some patients’ needs might be best met by local psycho-oncology services, community mental health teams or local mental health provision. This will be ascertained through liaison with referrers and/ or patients to determine the most appropriate and timely service for the individual.
5.23.5 Contact Details

If you would like to make a referral or discuss a potential referral, please contact:

Dr Daniel O’Hara,
Clinical Psychologist
Department of Clinical and Health Psychology
Fielding House
St James’ University Hospital
Beckett Street

Telephone: 0113 206 5897
Fax: 0113 206 4079
Email: Daniel.O’Hara@leedsth.nhs.uk
6 Genetic disorders

Rarely, brain tumours may be part of a genetic syndrome. Suspicion will be raised if there is a relevant family history, typical skin lesions or other cancer types in the same patient—particularly when these have occurred at a young age (see section 1.2). Such patients and their families may benefit from referral to the local genetics service in Leeds for assessment. This can be useful for counselling and screening other family members who may be at risk, as well as obtaining up-to-date advice about recommended screening of the patient themselves for other tumour types.

Decisions concerning genetic referral are usually made by the Neurosciences MDT.
7 Pathology

7.1 Specimen collection and transportation

7.1.1 Intraoperative diagnosis:
Representative excisional/incisional/stereotactic biopsy specimens sent fresh in an adequately labelled specimen pot or petri-dish and accompanied by an adequately labelled and completed request form. All such cases should be booked well in advance to the event and adequately notified to the laboratory. Ideally, the frozen section laboratory requires to be situated adjacent to the operating theatres to allow rapid transport and good communication.

7.1.2 Routine diagnosis:
Representative excisional/incisional/stereotactic biopsy specimens sent in an adequately labelled specimen pot filled with formalin (formalin should be approximately 20 times the volume of the specimen).

7.2 Tumour classification
CNS tumours are classified and graded according to the criteria laid down in the 2016 World Health Organization Classification of Tumors of the Central Nervous System which more extensively incorporates cytogenetics into routine diagnostic methodology.

7.3 Immunohistochemistry
Immunohistochemistry has an increasingly crucial role in both the diagnosis and prognosis of CNS tumours. Immunohistochemistry is used routinely to classify tumours, differentiate tumours which have similar morphology on an H&E stain, assess proliferation status of tumours (to aid in predicting biological behaviour and classification), and now, more recently, to identify tumours more or less susceptible to various modalities of adjuvant therapy.

7.4 Cytogenetics
Fresh samples of CNS tumours, especially gliomas are sampled and transported to the cytogenetics laboratory for karyotyping, FISH and DNA studies as required. Cytogenetic studies are a useful adjunct to histopathology and immunohistochemistry, especially where the diagnosis is not apparent on paraffin histology. This is especially so for paediatric CNS tumours. Certain other techniques e.g. FISH on fresh or paraffin tissue (1p/19q status) and DNA studies (MGMT methylation analysis) are useful for prognostication and assessment for susceptibility to adjuvant therapy.
7.5 Output

Results are electronically authorized, and then become available for viewing on the Trust's results server / PPM. A hard copy of the report is sent to places where the results server is not accessible.
8 Radiology

8.1 Diagnosis

The role of radiology in diagnosis has been described in Section 3.

8.2 Follow up

There are no clearly defined national criteria for radiological follow up in brain tumours. The following are a guide to local practice:

8.2.1 High grade gliomas

Patients for best supportive care do not require further routine imaging since it will not alter management.

Patients who have had surgery should have post-operative imaging within 48-72 hours to establish the extent of resection. Ideally this is with MRI (incorporating radiotherapy planning sequences).

Patients who have received radiotherapy alone are imaged at about 10-12 weeks with a baseline post-treatment MRI scan if they are likely to be considered for further therapy on progression. This provides a meaningful comparator in the future. Subsequent scans would only usually be done to investigate new symptoms. This can establish if progression is occurring and provide a new baseline for monitoring treatment response.

Patients having CRT for GBM will have a scan at 1 month (approximately the time of first adjuvant chemotherapy) and again at 6 months, unless new symptoms dictate an assessment earlier. As above, subsequent scans would only usually be done to investigate new symptoms.

During chemotherapy, scans are usually done at about 3-monthly intervals to assess response to treatment. Earlier scans may be performed if progression is suspected.

8.2.2 Low grade gliomas

Many of these patients will be kept under radiological review. Imaging is being performed to determine rate of tumour growth and to identify any worrying features suggesting transformation to a higher grade. MRI is the preferred modality. T2, FLAIR, T1 +/- gadolinium are all routine sequences. Occasionally, other MRI techniques are used to gain further information (eg PWI, DWI, Spectroscopy and functional MRI).

Imaging frequency will depend on clinical concern and will often be more frequent soon after diagnosis (e.g. 3 monthly) to establish the biological behaviour of the tumour. The interval can be extended to 6 or 12 monthly at a later timepoint depending on the behaviour of the tumour. Increase in tumour volume is associated with transformation of tumour grade, so it is important that accurate comparison of tumour size is made. Sometimes the changes are so
subtle that minor changes from one year to the next can be missed. To avoid this, it would be advisable to compare imaging over a multiple number of years.

### 8.2.3 Metastases

For patients having best supportive care, or those treated by whole brain radiotherapy (WBRT), where no further brain treatments are being considered, there is no role for routine imaging.

Patients who have had surgery or radiosurgery alone, where WBRT is being kept in reserve, justify frequent imaging to detect new metastases early, allowing timely salvage therapy before deterioration of performance status. This would often be done 3-monthly for the first year and 4-monthly for the second year if the disease has not progressed during that time. Only occasional patients will be progression-free after 2 years.

Rarely, there will be some patients who have received WBRT and have absent, minimal or controlled extracranial disease with an excellent performance status. These patients would be candidates for salvage radiosurgery and can justify intensive follow up imaging as above.

### 8.2.4 Meningioma

Following the uncomplicated complete excision of a grade 1 meningioma annual imaging would be entirely reasonable. Incompletely excised tumours close to eloquent structures or higher grade meningiomas will require more frequent scans initially to assess tumour behaviour (see Section 3). The total length of radiological follow up required is unclear and is dependent on the histological type and grade of the tumour as well as the tumour location and the patient's age and comorbidities. In general most meningioma's are followed radiologically for around 10 years.

### 8.3 Management of seizures

Many patients with brain tumours will present with seizures. A variety of effective drugs are available but, for many patients, there will be a potential for subsequent treatment with other drugs such as chemotherapy. Generally, levetiracetam (Keppra) is a good first choice in patients with brain tumours. It is effective and has very little impact on the metabolism of other drugs (unlike many commonly used anti-epileptics). If escalation of the dose fails to control seizures, or if it is not tolerated, then expert advice from a neurologist is usually required. Converting patients from one anti-epileptic to another is also a complex process for which expert advice is generally required.

### 8.4 Use of steroids

Corticosteroids are recommended to provide temporary relief of symptoms related to raised intracranial pressure and oedema secondary to brain tumours. The exact mechanism of action is unclear. Although evidence suggests that peri-tumoral oedema is reduced on follow-up imaging this may not be the only reason for symptomatic improvement.

For patients who are mildly symptomatic, a starting dose of 4–8 mg/day of dexamethasone should be considered. If patients exhibit severe symptoms, consistent with increased
intracranial pressure, it is recommended that higher doses such as 16 mg/day be considered.

If corticosteroids are given, dexamethasone is the best drug choice given the available evidence. Its minimal mineralocorticoid action would appear optimal when trying to reduce oedema. Corticosteroids, if given, should be tapered slowly over a 2 week time period, or longer in symptomatic patients, based upon an individualized treatment regimen and a full understanding of the long-term sequelae of corticosteroid therapy (see below). Patients should always receive the lowest dose of steroids that is effective.

There is no convincing evidence for the use of steroids in asymptomatic patients. Steroids are often used prophylactically prior to cranial radiotherapy, especially when large fraction sizes are used. There is no clear evidence that this is superior to an expectant approach. Side effects of oral corticosteroids that are used on a short-term basis include:

- an increase in appetite,
- weight gain,
- insomnia,
- fluid retention, and
- mood changes, such as feeling irritable, anxious or depressed.

Side effects of oral corticosteroids used on a long-term basis (weeks to months) include:

- osteoporosis (fragile bones),
- hypertension (high blood pressure),
- diabetes,
- weight gain,
- altered body shape (truncal obesity, proximal muscle wasting, round face)
- increased vulnerability to infection,
- cataracts and glaucoma (eye disorders),
- thinning of the skin,
- bruising easily, and
- muscle weakness.

If patients have been taking steroids for many weeks/months and they are then stopped it is safest to do this cautiously and gradually to allow the body’s natural steroid production time to recover.
9 Surgical management of CNS tumours

9.1 Emergency Surgical Intervention Protocol

This protocol covers the West Yorkshire & Harrogate Cancer Alliance and deals with emergency surgical interventions in patients with CNS malignancy, for intra-CNS problems caused by the tumour or its treatment. The Emergency surgical intervention protocol should be agreed Network-wide, by the chair of the Brain & CNS Network Group and the Trust Lead Clinicians. The protocol has been distributed to A&E departments, surgeons on the acute surgical take rota and neurosurgeons.

There are occasions when a brain tumour patient is referred to the neurosurgical team in Leeds (the site of neurosurgical care for the Network) as an emergency. Such a patient may be identified by a team within Leeds Teaching Hospitals NHS Trust or one of the referring hospitals in the Network (Airedale, Bradford, Calderdale & Huddersfield, Harrogate, Mid Yorkshire and York).

In the presence of acute neurological features, the on-call team performs the necessary imaging within the hospital before referral. If a brain or other CNS tumour is revealed, the local treating team should refer the patient to the neurosurgical registrar on call for advice on any emergency treatment and / or transfer the patient to Leeds Teaching Hospitals for emergency neurosurgical intervention. Images must be made available for review by the on-call consultant neurosurgeon (+/- neuroradiologist if necessary). Within the Network, this is achieved by electronic image transfer for patients outside of Leeds. In occasional circumstances it may be appropriate for a neuro-oncologist to be contacted for an opinion (this would usually be done by the neurosurgical team if required).

The timing of the Neurosciences MDT must not delay the start of either urgent treatments or investigations. If the on-call consultant neurosurgeon decides that emergency management should be carried out immediately then treatment will be delivered as soon as possible by the most appropriate member of the team who is available. Such patients will still be discussed in the next available Neuroscience MDT / MDT meeting. The patient will be allocated, if necessary, to an appropriate neuroscience core member. The long term follow up of these patients will depend on the condition that was treated and will be decided by the MDT.

9.2 Introduction

Modern neurosurgery is highly complex and only a summary can be provided in this document.

The basic principles include:

- Selecting a surgical approach which achieves optimal access to the tumour
  - (some tumours may require more than one procedure, using different approaches, to achieve maximal resection).
- Causing minimum disruption to the normal brain and eloquent structures such as the cranial nerves.
- Achieving complete or maximal resection where possible
Obtaining a histological diagnosis
Preserving function, allowing patients to maximise their subsequent quality of life

To maximise resection and preserve function, the following techniques are used:

- Pre-operative functional MRI scanning allows the surgeon to map the location of the important functional areas of the brain.
- Intraoperative neuronavigation: This systems informs the surgeon where an instrument is in relation fo the tumour. It allows accurate placement of craniotomies and more complete resection of the tumour.
- Awake craniotomy this allows real-time assessment of eloquent areas of the brain and mapping their relationship to the tumour. This maximises the opportunity to remove tumour and preserve function. It is particular useful in low grade glioma surger but also has a role for other tumours close to eloquent brain areas.
- Use of the CUSA (Cavitron Ultrasonic Suction Aspirator). In particular this allows sub-pial resection of tumour, preserving nearby structures.
- New techniques being developed to help increase the extent of resection include intraoperative ultrasound, intraoperative MRI scanning and intraoperative fluorescence techniques.
- Endoscopic techniques – allow better surgical visualisation of tumours with less disruption of normal tissues. This is increasingly used for skull base pituitary surgery in particular.
- Evoked responses (motor or sensory) and cranial nerve monitoring can also be used in patients under general anaesthesia to help identify and preserve critical structures.

The type of tumour dictates how much risk a surgeon takes in trying to remove it. A tailored approach is always required, taking into account the type and location of the tumour, the potential adjuvant therapy options and the importance (or not) of obtaining a complete resection. Sometimes a staged approach to resection is required to allow more complex resection to be achieved, for example, where a tumour involves eloquent cortex.

The following sections outline key surgical issues for different tumour types.

### 9.3 Intrinsic high grade

High grade intrinsic brain tumours are incurable. There are four surgical options for this group of patients:

- Palliative care - many patients will choose to avoid hospital and accept a shorter life expectancy. There is also a group where their functional level is too poor for them to cope with surgery and adjuvant treatments.
- Biopsy - This is done to obtain a histological diagnosis. The main concern about biopsy is that the diagnosis obtained can sometimes be unreliable as it comes from only a few small areas of the tumour. The technique is used where “debulking” surgery is not possible usually because the tumour is in eloquent parts of the brain. The risk of a complication from a biopsy are low (2%). Biopsies are performed with image guidance and it is thus possible to place a needle with a high degree of
accuracy anywhere in the brain. Biopsy is well tolerated and is even being done as
day cases in some centres (including Leeds).

- **Debulking surgery** - There is building (though not conclusive) evidence that survival is
improved by debulking surgery (Stummer). There is an understanding that the aim of
debulking surgery should be >90% resection of the tumour. Partial debulking (50%)
is probably of limited benefit. Cure is impossible so preservation of function is
considered to be more important than complete macroscopic resection. The main
risks are 2% mortality and 5-10% morbidity depending on the tumour location.

- **Debulking surgery with intraoperative Carmustine wafers.** Carmustine is a
chemotherapy agent that is held in wafers. It can be used at the end of a debulking
procedure where the histology has been confirmed as a high grade tumour and
greater than 90% resection has been achieved. It increases the risk of brain swelling,
wound infections and early seizures but does improve survival.

Surgery for recurrent disease carries higher risks and less benefit. It is however used
occasionally in highly selected cases where the tumour morphology allows. Redo surgery is
frequently supported by Carmustine wafers. This is not an indication considered by NICE. It
would usually be used only in grade IV tumours.

### 9.4 Intrinsic low grade

Low grade intrinsic tumours usually present in younger patients than higher grade tumours.
They are more likely to present with seizures, the tumours grow more slowly and are more
frequently in eloquent areas. There is a stronger evidence base for maximal surgical
resection but only if 90% of the tumour can be removed. For these reasons low grade
tumours are managed by subspecialists. The surgical options are:

- **No surgery** - often patient choice. There are also some patients with very small
incidental tumours or stable tumours that are not progressing that can be managed
this way.

- **Biopsy** - This carries the same risks and limitations as biopsy for high grade tumours.
An important consideration is the risk of undergrading tumours where a biopsy is
taken from a grade II part of the tumour but the prognosis is dictated by a higher
grade part of the tumour.

- **Debulking** - This provides the best histological grade. The emphasis of debulking
surgery must be to try and remove >90% of the tumour. Because of the need to
avoid eloquent brain these patients frequently require functional MRI scanning and
awake craniotomy.
  - Due to neuronal plasticity (repair and re-connection processes) it is possible
to undertake staged resections and operate a second time on a remnant area
of tumour abutting eloquent brain areas and achieve a satisfactory further
tumour clearance.

### 9.5 Extrinsic

Most extrinsic tumours are benign. The aim of surgery is as complete removal as possible
and obtaining a histological diagnosis. Biopsy alone is rarely indicated.
Many tumours can be removed completely. The complexity (and therefore the risk) of surgery is dependant on the location, type and consistancy of the tumour.

Some tumours cannot be removed completely where for example they are in the cavernous sinus. These tumours are usually maximally debulked and the residual is monitored radiologically. Radiotherapy and gamma knife techniques can sometimes be used for the residual tumour. Recurrent surgery is sometimes appropriate.

Tumours of the skull base are frequently closely related to the cranial nerves and major cranial vessels. Nerve monitoring is frequently used.

Tumours extending through the skull base into the face or orbit will usually require a team approach bringing together neurosurgical, ophthalmology, maxillo facial and sometimes plastic surgical teams.

9.6 Base of skull

A variety of tumours can involve the base of skull (some are benign whilst others can be malignant). Tumours from below (invading upwards) are usually managed by the Head and Neck MDT, whereas tumours from above (invading down) are managed by the Neurosciences MDT. Depending on the tumour’s location it may also be necessary to involve neurosurgeons, ENT surgeons, ophthalmic surgeons to perform combined procedures. The appropriate team to tackle a particular case is decided at the neurosciences MDT.

9.7 Pituitary fossa

The overwhelming majority of pituitary tumours are benign pituitary adenomas. The aim of surgery is to obtain a histological diagnosis, preserve vision and prevent excess hormone production. The following options are available:

- No surgery - Many of these tumours grow very slowly and are non-functioning. Radiological and endocrine monitoring is all that is required.
- Trans-spenoidal approaches - these may be microscopic or endoscopic.
- Transcranial approaches - this is used infrequently but is sometimes necessary for large tumours extending well above the pituitary fossa.

Close team working with endocrinologists is essential in managing these patients successfully.

9.8 Spinal

Malignant bony spinal tumours are outside the scope of this document. Primary spinal tumours may be intramedullary, intradural and extramedullary or extradural. There is a separate group of lesions that are related to spinal dysraphism. They are managed differently:
- Intramedullary tumours. These are rare and usually either benign or low grade. Some can be observed, some can only be biopsied, a few can be removed completely. The spinal cord is functionally critical and spinal cord monitoring is essential.
- Extramedullary, intradural tumours. These are mostly benign tumours and complete surgical resection is usually carried out. Some may be multiple where there is an underlying genetic predisposition. In these only symptomatic or growing tumours are removed.
- Extradural tumours. Excluding bony metastases this is a rare group. They are usually treated with surgical removal supported by radio and or chemotherapy as appropriate.
10 Stereotactic radiosurgery

10.1 Introduction

Stereotactic radiosurgery is a method for delivering large, single doses of radiation to intra-cranial targets. It relies on very accurate tumour localisation and patient positioning. Within the West Yorkshire & Harrogate Cancer Alliance this is performed at the Leeds Gamma Knife Centre. The Elekta Gamma Knife Perfexion™ system consists of a radiation unit (with patient positioning system integrated into the couch) and a control station, with operator console and office computer. The treatment is delivered by 192 beams of ionizing radiation that converge on a focal point (an isocentre). Most targets are treated using multiple, overlapping isocentres or “shots”, in compliance with a pre-prepared treatment plan. The cumulative effect of treating these isocentres is calculated in real time by the planning software (Gammaplan® PFX™) during a forward planning process. The tissue in the target is thus treated by radiation, while significantly sparing surrounding tissue, due to the sharp drop off of dose possible using so many intersecting beams. The ionizing radiation is obtained from cobalt-60 sources arranged in eight sectors and embedded within the shielded radiation unit. The beams of gamma radiation that emanate from the cobalt sources coincide at a fixed focal point within the radiation unit. The delivered dose is shaped to the precise contour of the target by combining shots that can use different collimator sizes (4, 8 and 16mm) with composite shots also possible using different collimator sizes or blocking of individual sectors.

10.2 The Process

10.2.1 Patient’s Treatment Sequence

- Arrive Level 4 suite (Bexley Wing).
- Identity check & consent if not already done. Review of notes / scans and assessment of current clinical condition. Confirmation of lesion to be treated.
- Frame fitting with subsequent check of “frame cap” fit, post/screw measurements and skull measurements.
- Wait in lounge
- Imaging (MRI +/- CT +/- angiogram) wearing stereotactic box.
- Wait in lounge while planning takes place
- Treatment (level -2).
- Frame removed.
- Patient either discharged or admitted overnight depending on situation
### 10.2.2 Imaging

<table>
<thead>
<tr>
<th>Target</th>
<th>T1 (-)</th>
<th>T1 (+)</th>
<th>CISS</th>
<th>T2 3D Turbo</th>
<th>T1 fat sat</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vestibular Schwannoma</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Metastases</td>
<td>(X)</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td>T1 (-) if recent bleed or surgery. Use “subtraction” for planning</td>
</tr>
<tr>
<td>Meningioma</td>
<td></td>
<td></td>
<td></td>
<td>(X)</td>
<td></td>
<td>T1 fat sat for orbit, skull base, jugular foramen</td>
</tr>
<tr>
<td>AVM</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td>Will also need angiogram</td>
</tr>
<tr>
<td>Pituitary</td>
<td>X (a,c)</td>
<td>X</td>
<td>X (c)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trigeminal neuralgia</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cavernous haemangioma</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(a) = axial sequence, (c) = coronal sequence

[T1 sequences: 1 mm slice thickness over 5cm for small lesions. 1.5-2 mm slice thickness when whole brain to be scanned]

[Patients who cannot have an MRI (eg permanent pacemaker) will need CT].

### 10.2.3 Planning Workflow

The basic elements of treatment planning are:

- Importing the necessary image sets into Gammaplan
- Entering information on skull dimensions and frame cap fit (+/- post/screw dimensions)
- Defining dose-calculation matrices around the lesion(s) to be treated
- Outlining target volume(s) and organ(s) at risk (OAR).
- Choosing “shots” to treat target volumes.
- Choosing isodose to which treatment dose will be prescribed for each target volume.
- Choosing dose for each target volume.
- Assessing DVH data for target and OAR.
- Calculation of quality indices (conformity, selectivity, gradient)
- Approval of plan if these are satisfactory
- Print plan and sign off.
- Export plan.
10.2.4 Quick guide to dose tolerances

In SRS there is a significant dose-volume effect. As treated volumes increase, the safe dose falls. As a result, SRS is usually only used for lesions up to 3-4 cm across in the cerebral hemispheres. Lesions spread across the base of skull may be treated if they are up to 5cm long in one dimension, with max volume about 15cm$^3$. Dose to critical structures can have a major effect on the safe dose.

The radiobiological consequence of previous external beam RT is hard to model. In particular, the possibility of repair is uncertain. However, previous RT to the area being targeted should usually result in a reduction of prescribed dose to both target and OAR.

10.2.5 Tolerances of OAR:

Cochlea: Ideally < 4 Gy to any part of the cochlea in patients who have serviceable hearing. In some situations, this will be hard to achieve (esp. larger tumours extending down the canal). A recent retrospective analysis from Pittsburgh\(^8\) suggests that a central point dose < 4.2 Gy to the cochlea is associated with good hearing preservation rates so, in difficult cases, attempts should be made to achieve this at least.

Optic nerve: 8 Gy (3Gy if previous RT)

Cranial nerve III, IV, VI - No toxicity seen with cavernous sinus lesions treated to margin doses of 13 Gy\(^9\). In the same study of 176 patients, 5 developed trigeminal nerve problems at this dose (1 temporary, 2 neuralgia, 2 corneal problems)

Cranial nerve V, VII, VIII\(^10\) - data from acoustic neuroma work.

Brain stem: Max point dose 15 Gray. Volume receiving 12 Gy ≤ 10 mm$^3$.

Retina: 8 Gy
10.2.6 Doses to cerebral lesions:

Early work using single-isocentre proton treatment established a 1% radionecrosis isoeffect line which guided the early pioneers of SRS \textsuperscript{11}.

The Pittsburgh group then published an “integrated logistic formula” model which predicted 3% necrosis risk for different sized lesions treated by Gamma Knife \textsuperscript{12}. This has continued to be very influential.

An RTOG study \textsuperscript{13} of patients who had all received previous fractionated RT >3/12 before (which included primary tumours and mets), performed dose escalation until unacceptable levels of toxicity were seen in each size group (although this level was not reached in the <2 cm group). It is worth noting that what was considered “acceptable” (Grade 3-4 acute toxicity <20%) was quite significant.

The results of these three studies are combined below as a guide to dose selection for parenchymal lesions (where other critical OAR are not an issue).

\begin{table}
\centering
\begin{tabular}{cccc}
\hline
Diameter, mm & Volume, cm$^3$ & 1% isoeffect, Gy & 3% ILF, Gy & RTOG, Gy \\
\hline
12.5 & 1.02 & 27.5 & 34.0 & 24\textsuperscript{a} \\
15.0 & 1.77 & 25.0 & 29.0 & 24\textsuperscript{a} \\
17.5 & 2.81 & 22.5 & 23.0 & 24\textsuperscript{a} \\
20.0 & 4.19 & 20.0 & 18.0 & 24\textsuperscript{a} \\
22.5 & 5.96 & 18.7 & 16.5 & 18 \\
25.0 & 8.18 & 17.5 & 14.5 & 18 \\
27.5 & 10.9 & 16.5 & 13.5 & 18 \\
30.0 & 14.1 & 15.0 & 13.0 & 18 \\
32.5 & 18.0 & 14.0 & 12.5 & 15 \\
\hline
\end{tabular}
\caption{A comparison of dose-volume prescription guidelines from Kjellberg’s 1\% radionecrosis isoeffect line, 3\% necrosis risk predictions from the integrated logistic formula (ILF), and the RTOG phase 1 maximum tolerated doses for <20\% grade 3–5 toxicity sequelae within 3 months\textsuperscript{a} [8, 9, 14]}
\end{table}

\textsuperscript{a}Maximum tolerated dose was not reached for tumors <2 cm in diameter.

Location within the brain is also important, with some eloquent areas more prone to damage. This particularly applies to AVM SRS treatment.
10.2.7 Record keeping:

**Minimum data set – at treatment**

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treatment Date</td>
<td>Date</td>
</tr>
<tr>
<td>Localisation method</td>
<td>Text</td>
</tr>
<tr>
<td>GTV</td>
<td>cm³</td>
</tr>
<tr>
<td>Treatment margin</td>
<td>mm</td>
</tr>
<tr>
<td>Encompassing isodose</td>
<td>%</td>
</tr>
<tr>
<td>Dose to encompassing isodose</td>
<td>Gy</td>
</tr>
<tr>
<td>Prescription volume</td>
<td>cm³</td>
</tr>
<tr>
<td>Volume of half prescription dose</td>
<td>cm³</td>
</tr>
<tr>
<td>Fractions</td>
<td>N</td>
</tr>
<tr>
<td>Imaging modality used for planning</td>
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</tr>
<tr>
<td>Slice thickness of imaging modality</td>
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</tr>
</tbody>
</table>

**Minimum data set – at follow up**

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<th>Parameter</th>
<th>Value</th>
</tr>
</thead>
<tbody>
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<td>Follow up date</td>
<td>Date</td>
</tr>
<tr>
<td>Time following treatment</td>
<td>Months</td>
</tr>
<tr>
<td>Imaging modality used</td>
<td>Text</td>
</tr>
<tr>
<td>Slice thickness of imaging modality</td>
<td>mm</td>
</tr>
<tr>
<td>GTV</td>
<td>cm³</td>
</tr>
</tbody>
</table>

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10.3 Site / Disease- specific protocols

Patient selection for treatment should be through specialist MDTs. All tumours should have been discussed by the Leeds Neuro MDT.

10.3.1 Brain Metastases:

Focal treatment for brain metastases (with surgical resection) has been shown to improve local tumour control and prolong survival, particularly when combined with whole brain radiotherapy \(^4\). However, surgical resection may be contraindicated for many patients because of co-morbid conditions or unresectable locations. SRS can act as an alternative in this situation. Whilst it cannot produce a rapid decrease in intracranial pressure like surgery, the morbidity is significantly less than a craniotomy.

SRS has been shown to be effective in the treatment of metastases arising from “radio-resistant” tumours (eg renal cell carcinoma and melanoma) that respond poorly to conventionally fractionated EBRT \(^5, 6\) although local control rates remain worse when compared to other histological types.

Local tumour control with SRS is consistently greater that 80% in non-randomised trials and the majority of patients in these studies have died of systemic disease progression \(^5, 7-28\).

There is no good randomised data comparing SRS with surgery for the management of solitary mets (and there is unlikely to be any).
Two published trials have compared WBRT with WBRT + SRS. A survival advantage was only shown in the sub-group analysis of patients with solitary mets in one of these studies. However, both showed that the addition of SRS improved local control in the brain.

One randomised trial has compared SRS alone with SRS + immediate WBRT. The combined strategy produced better local control within the brain but no difference in survival (although it was underpowered for this end-point).

Various models have been proposed to predict outcome and thereby aid patient selection. The RPA (recursive partitioning analysis) performed by the RTOG remains the most widely used.

Various proposed strategies for newly presenting mets have been proposed using this system (eg the flow diagram below from). * = best supportive care could be considered
Or this, from 34 which is a more North American approach.
10.3.2 Main indications for radiosurgery

- First-line treatment to avoid toxicity of WBRT. In this context, WBRT or further SRS is being held in reserve and more frequent F/U imaging will be required. This may be particularly useful in “radioresistant” tumour types.
- Boost treatment, given in combination with WBRT, to maximise control of intra-cerebral disease.
- Salvage treatment after failure of previous WBRT.
- (Treatment to surgical site if incomplete resection of metastasis).

Patient selection

It is expected that all patients will have been discussed by both a site-specific and neuro MDT before treatment. This should establish the appropriateness of more aggressive treatment to the brain and allow consideration of other strategies such as surgery.

Patients who have a poor prognosis from their systemic disease will not live long enough to benefit from SRS and treatment in this situation is inappropriate. Predicting prognosis is very difficult however. In most studies, the following have been shown to be the most useful criteria

- Good performance status (KPS ≥ 70)
- Extra-cranial disease absent or controllable (with estimated prognosis from site-specific MDT of at least 6 months)
- Younger age (but no clear cut off can be defined)

The significance of lesion number and volume is controversial and opinions vary widely around the world. In general, in the UK, SRS is not considered for more than 3 metastases but, in exceptional circumstances (eg a young woman with breast cancer presenting with brain mets as the first site of metastatic disease and a KPS of 100), the prognosis may be very good if intra-cranial disease can be controlled and here one could possibly consider treatment of 4 or more lesions. Maximum diameter of a treated metastasis should be <3cm.

OAR

Since mets can occur throughout the brain there are no typical OAR. Therefore see Section 10.2.4.

Prescribed dose

If previous WBRT: 16-20 Gy.
If no WBRT: 18-24 Gy

Specific points to note

In patients who have had previous WBRT the SRS prescription dose may be reduced slightly (see above). If WBRT is to be given with SRS, then many people would drop the dose of WBRT to 25Gy in 10#. If a year or so has elapsed one could consider full dose WBRT.

Follow up

This will depend on the referring team and clinical situation. If WBRT is being withheld then frequent MRI scans every 3/12 or so will be required to enable this, or further SRS, to be used as salvage.
10.3.3 Vestibular Schwannoma

Vestibular (and other) cranial schwannomas respond well to SRS, even as the prescribed dose has tended to fall in recent years. Tumour control rates in the order of 91-98% are reported, with increasingly long term results. This can be achieved with hearing preservation (defined as unchanged functional grade) in 75% of patients, with a very low risk of damage to the facial (around 1%) and trigeminal nerves (about 4%).

Microsurgery is indicated in young patients with large tumours, or where significant mass effect, such as brain stem compression, is present. Some patients may elect to undergo microsurgery in preference to SRS. Surgery leads to longer hospital stays and significantly longer time off work as patients recover.

Following radiosurgery, certain post-treatment sequelae occur which referring clinicians should be aware of. As for other slow growing tumours (e.g. meningioma, low grade astrocytoma), these tumours may remain the same size for several years after therapy (5-60% in the Pittsburgh series). More alarming to the uninitiated is that in a minority of patients the tumours may actually swell. In such cases the six month scan demonstrates a larger mass, with a low signal intensity centre, and a brightly enhancing perimeter (which is thought to be a host inflammatory response and not viable tumour persistence). The tumour swelling phenomenon at this time is a good rather than a bad prognostic sign, and predicts for later implosion and long term control of the tumour. It is not an indication for surgery (unless there is compressive pathology, resistant to steroids, leading to hydrocephalus).

There is at least a theoretical risk of late carcinogenesis either outside the tumour or within it, and it must be accepted that this latter risk does not exist if the tumour is surgically excised. Any such risk does seem to be very small, although it may be increased in NF-2 patients who carry an oncogene. Nevertheless, SRS controls growth or defers the need for surgery (or both) even in these patients.

Counselling should address all of the above issues, in an attempt to give patients as fully informed a choice as possible.

Finally, a recent analysis concludes that the primary costs of SRS are lower than those of microsurgery for established radiosurgical indications. These economic considerations may be of importance to large scale purchasers of health care in the current political and financial climate.

**Koos Grading Scale**

<table>
<thead>
<tr>
<th>GRADE</th>
<th>TUMOUR SIZE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>0-10mm, intracanicular</td>
</tr>
<tr>
<td>2</td>
<td>10-20mm total, 0-10mm extrameatal</td>
</tr>
<tr>
<td>3</td>
<td>Upto 30mm total</td>
</tr>
<tr>
<td>4</td>
<td>&gt;30mm, brain stem deformation</td>
</tr>
</tbody>
</table>
Gardner Robertson Scale

<table>
<thead>
<tr>
<th>GRADE</th>
<th>Pure tone audiogram (db)</th>
<th>Speech discrimination (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 (good excellent)</td>
<td>0-30</td>
<td>70-100</td>
</tr>
<tr>
<td>2 (serviceable)</td>
<td>31-50</td>
<td>50-69</td>
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<tr>
<td>4 (poor)</td>
<td>91-max</td>
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<td>5 (none)</td>
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Note if PTA and speech do not correlate, use lower class.

Main indications for radiosurgery

- Extracanalicular tumour, diameter less than 2.5-3.0 cm, although larger tumours can be considered if not compressing the brain stem.
- Elderly or medically unfit patients
- Patients retaining useful hearing
- Recurrent or residual tumour post surgery
- Patient refuses other forms of treatment

Patient selection

Treatment recommendations according to Jean Regis (Marseille):

- Koos I (GR 1 or 2) SRS
- Koos I (GR > 2) MRI FU or SRS
- Koos II or III SRS
- Koos IV Microsurgery
- Koos IV young / facial palsy major issue combined approach MS & SRS

OAR

From 10
Cochlea 4 Gy  
Brain stem volume receiving 12 Gy ≤ 10 mm³

Prescribed dose
The data in Section 0 have led to a steady reduction in prescribed dose in recent years. Currently, 12 Gy (with at least 95% tumour coverage if possible) is becoming standard. Jean Regis might use 11 Gy in someone with very good hearing.

Specific points to note
Try to achieve steep dose drop off anteriorly and posteriorly in region of facial nerve. Outline cochlea as an OAR using bone views of CT if available or CISS sequence. Consider dynamic shaping to help protect cochlea.

Follow up
Patients with vestibular schwannoma should have follow up at 1,2,3,5 years and then at 5 yearly intervals thereafter. Follow up includes MRI, audiology and facial nerve assessment.

Minimum data set – VS Specific

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### 10.3.4 Pituitary adenoma

Pituitary adenomas are benign neoplasms which arise from the epithelial tissues comprising the anterior portion of the pituitary gland. In most cases management is primarily by surgery, which has a high success rate in relieving both local and systemic manifestations. However, following surgery, there is a significant recurrence rate that can be reduced by postoperative radiotherapy, albeit at the expense of gradually ablating any remaining normal pituitary function.

Gamma knife radiosurgery (SRS) holds out the prospect of controlling recurrence at least as effectively as conventional radiotherapy, whilst reducing complications such as damage to the optic apparatus, and possibly sparing the remainder of pituitary function. Furthermore, by means of dose volume histograms, precise calculation of optic chiasm and brain stem exposure is possible, enabling the therapist to ‘reverse plan’ and ensure acceptable limits are not exceeded.

Proton beam radiosurgery was achieving good results in large numbers of patients with acromegaly and Cushing’s disease almost a quarter of a century ago. More recently medium to long term results of SRS for pituitary adenoma have started to emerge. Landolt et al. concluded that in acromegaly normalisation of GH occurs faster with radiosurgery than with conventional radiotherapy and a variety of other series have been reviewed by Witt et al.

The Pittsburgh data are published so far on 35 patients. Of eleven evaluable Cushing’s disease patients, eight developed normal hormone levels and two developed decreased levels. Of eight evaluable acromegalics, serum GH was normalised in three and decreased in a further three. Two complications arose – one involving the optic apparatus. More recently the same group has published results on 42 patients who underwent adjuvant SRS for residual or recurrent nonfunctioning pituitary adenoma, following conventional treatments including trans-sphenoidal resection, craniotomy and radiotherapy. With mean follow up of 31.2 months (6-102) tumour control was achieved in 100% of patients with microadenomas and 97% of patients with macroadenomas.
The London experience has been with recurrent tumours in previously irradiated patients, and is heavily loaded with cavernous sinus recurrences. Their data confirms that such retreatment therapy by radiosurgical means produces a response in these difficult patients (personal communication).

**Main indications for radiosurgery**

The exact place of SRS as primary therapy has yet to be established. It is likely that this role will be reserved for small discreet tumours away from the chiasm, particularly those extending into the cavernous sinus. There is a more definite role with regard to recurrent disease, especially when parasellar structures are being invaded. The Pittsburgh group use a mean radiation dose of 16 Gy in this situation, but previous irradiation and proximity to the optic chiasm might argue for a lower dose prescription in particular cases.

**Patient selection**

Surgery is the primary therapy for most pituitary adenomas, allowing decompression of the optic apparatus (where there is suprasellar extension) and the most rapid means of controlling hormone over-secretion. Recurrent disease that is intimately associated with the optic tracts is best treated with fractionated radiotherapy but other recurrences, clear of the optic pathways (ideally > 5mm) can be considered for SRS. It is often advocated in situations where the cavernous sinus is involved. Staged procedures can be considered for large tumours, where the optic chiasm is decompressed by surgery and residual adenoma (eg in cavernous sinus) can then be treated by SRS.

There is a trend to offer SRS to small microadenomas as a primary therapy, but this remains non-standard treatment except in patients where surgery is contra-indicated.

**OAR**

Optic nerve / chiasm 8 Gy (3Gy if previous external beam RT).

Hypophysis (may require radiologist to help outline): Dr Lescak recommends keeping mean dose to <15 Gray.

**Prescribed dose**

25 Gy \(^{38}\) if possible. At least 20 Gy otherwise. About 16 Gy if prior external beam RT. Lower doses may also be adequate for non-functioning adenomas (eg 14-16 Gy). The main factor governing prescribed dose is the optic tract which must be carefully identified on the planning scan and outlined as an OAR. The prescribed dose can be calculated by working back from the acceptable dose to be delivered to the optic tract and identifying what isodose is related to it.

(Dr Lescak said that in hormone-releasing tumours he would push the dose to the tumour up to 30-35 Gy as long as the optic tract dose constraints could be met.)

**Specific points to note**

Pituitaries are one of the most challenging structures to treat because of the proximity of the optic tracts and the desire to give higher than average doses. Consider altering (usually increasing) the gamma angle (this is one of the few situations where it is useful) to reduce dose passing through optic tracts. Try dynamic shaping to increase the dose gradient. There is evidence that absence of suppressive medications at the time of radiosurgery correlates with hormonal cure \(^{44}\). At the Mayo clinic they stop such medicines 4-6 weeks before therapy.
Follow up
Requires expert endocrine clinic involvement as well as intermittent imaging. At the Mayo patients are seen 6-monthly for 2 years, then annually.

10.3.5 Meningioma

Although meningioma is a benign tumour (arising from the arachnoid fibroblast), Miraminoff et al 45 reported a ten-year disease free survival rate of only 45% after subtotal resection, excision being necessarily incomplete in many cases.

Conventional radiotherapy has been shown to reduce the post-surgical recurrence rate in various studies, with absolute rates depending on the extent of surgical resection and the proportion of atypical tumours 46-48. Total dose has been shown to be important 49 for disease control. There is concern about the long-term radiation-induced toxicity in this patient group, since many of them will live for many years 50-52.

Stereotactic radiosurgery provides an alternative radiation therapy modality that seems attractive for what are often well-circumscribed tumours. Skull base lesions, and particularly those in relatively inaccessible sites such as the cavernous sinus, are particularly well suited to this technique, and of the 253 patients reported by the Charlottesville group 53 36% were at this site. In their follow up period only one of these 96 tumours showed any increase in size, and in 68% a decrease in volume was reported. The mean marginal dose in this study was 15Gy (9 – 20).

In recent years evidence has emerged on a site-by-site basis to support SRS as a means of dealing with these difficult tumours. Anterior foramen magnum 53, petroclival 54, 55, cavernous sinus 55-58, anterior skull base 59, tentorial 60 and parasellar 61 tumours have all been demonstrated to be manageable safely and effectively by SRS. Pendle et al 62 reported stabilisation or decrease in tumour size in 98% of a large series (197 patients with at least two years follow up) of skull base meningiomas as a whole. Long-term results have also been reported 63, and show that SRS continues to be safe and effective at controlling residual or recurrent disease at seven years.

Parasagittal meningiomas also present a difficult problem with frequent tumour recurrence and relatively high morbidity following surgery. Kondziolka et al 64 concluded that small parasagittal meningiomas are best managed by radiosurgery alone but that larger tumours, or tumours producing neurological deficits by virtue of their mass effect, should first undergo resection followed soon afterwards by second stage radiosurgery for any residual tumour nodule or neoplastic dural remnant.

Complications following SRS for meningioma have a low reported incidence. Eustacchio et al 65 reported a 1.7% incidence of cranial nerve dysfunction and Morita 66 suggests that this complication is dose related with the optic apparatus tolerating 10Gy, and trigeminal neuropathy being associated only with doses to Meckel’s cave higher than 19 Gy. This compares favourably with microsurgical series.

Given that most patients being treated by SRS for benign tumours have not had a biopsy to confirm the diagnosis there is of course a small risk that some other lesion is actually being treated. Flickinger et al 67 state this risk as 2.3%, but go on to state that the high rate of tumour control justifies the small morbidity that may be associated with this.
Convexity, parasagittal and falcine meningiomas have a higher incidence of peritumoural imaging changes after SRS 68, presumably because a larger proportion of the total surface area of the tumour is in direct contact with the cortical surface, and caution should be exercised in the use of SRS in these patients.

Ojemann et al 69 described experience of treating 22 patients with malignant meningioma. It seems that this relatively rare sub group of meningiomas can also be treated successfully with acceptable toxicity. Five year survival was 40% although five patients developed radiation necrosis.

In London, policies 70 have been best defined for cavernous sinus meningiomas, of which 40 cases were referred in their first decade of radiosurgical service. It was concluded that where the meningeal base measured up to three centimetres there were strong advantages to a radiosurgical approach, with fractionation used if the disease encroached too close to critical structures. However, where the meningeal base or tumour was greater than three centimetres then conventionally fractionated radiotherapy was preferred for reasons of safety. Their dose prescription is typically 15Gy to the margin, (12 – 18Gy), depending on dose to critical adjacent structures and tumour size.

**Main indications for radiosurgery**
- Intimate relationship of tumour to vascular or nervous structures making conventional surgery dangerous (eg para-sagittal, cavernous sinus)
- Excessive risk factors for surgery (eg age, co-morbidities)
- Multiple lesions.

**Patient selection**
All cases to be discussed at CNS MDT. Patients with small, asymptomatic lesions may be offered observation alone. Patients with symptomatic lesions in accessible sites will probably be offered surgery if fit. Others may be considered for SRS.
Cavernous sinus (Jean Regis):
- Enclosed cavernous sinus tumour
- Small/mid-sized
- Clear of the visual pathway
- No visual deficit
- Recent & incomplete oculomotor deficit
- Trigeminal pain
- Growing tumor if asymptomatic
- Benign or atypical if previously operated
OAR
Will depend on site. Cavernous sinus oculomotor nerves (III, IV and VI) appear to tolerate the doses used in this region (ie no dose reduction required even if they run through tumour. Vth nerve is slightly more sensitive and some patients will experience nerve dysfunction. Dose to the optic tract should be kept below 8 Gy (3 Gy if area has already been treated by EBRT)

Prescribed dose
12-15 Gray (with at least 95% tumour coverage if possible) 38. Lower doses are used for larger lesions or where doses to OAR are too high. In atypical meningiomas a slightly higher dose (16 Gy) may be appropriate 72.

Specific points to note
- Swelling is more common in parasagittal location (?vascular effect).
- Control rates higher for smaller lesions.
- Possibility of late vascular effects (eg occlusion of carotid artery if cavernous sinus region treated).

Follow up

10.3.6 Haemangioblastomas
Haemangioblastoma is a rare benign tumour of the central nervous system, accounting for 1-2% of all intracranial tumours. Most commonly presenting in the 3rd decade, these tumours show a predeliction for the posterior fossa (90%) and the spinal cord. They are extremely rare in the supratentorial compartment. In Von Hippel Lindau (VHL) disease, inherited by a dominant trait, there is a tendency to produce multiple lesions. Sporadic cases (the majority) are usually discovered because of symptoms associated with local mass effect. VHL patients may be screened and discovered to have asymptomatic lesions.

Histologically they display bland cytology and low mitotic counts. Macroscopically they often take the form of solid mural nodules and associated cysts. Symptoms of mass effect are commonly the result of the cystic component 73.

Little is known about the natural history of these lesions. What information there is, comes from VHL patients rather than sporadic cases. Wanebo et al 73 followed the radiological progression of 655 haemangioblastomas in 160 VHL patients. Among the 88 patients who underwent serial imaging for 6 months or longer (median 32 months), 164 (44%) of 373 hemangioblastomas and 37 (67%) of 55 tumor-associated cysts enlarged. No tumors or cysts spontaneously diminished in size. Cysts appeared to grow at a faster rate than solid
components. Growth was often seen to occur in “spurts” separated by quiescent phases. Similar findings were seen in a smaller study by Slater et al 74.

Symptomatic haemangioblastomas are usually treated with surgery. They are also reasonably radiosensitive, and good results have been reported with conventionally fractionated radiotherapy 75, 76.

Radiosurgery has also been shown to be effective. Patrice et al 77 treated 38 tumours (minimum tumour dose range 12 to 20Gy) and concluded that stereotactic radiosurgery (by Gamma knife or Linac) controls the majority of primary and recurrent haemangioblastomas. Furthermore, the ability to treat multiple lesions in a single session was considered particularly important in patients with VHL. The Shanghai group 78, 79 treated a total of 29 tumours in 17 patients, reporting 92% local tumour control at one year, falling to 75% at four years. Niemela et al 80 reported very similar results from 23 tumours treated in 15 patients. The London group described the results of linac-based stereotactic treatment of five haemangioblastomas in four patients. They observed complete radiological response in four, with static disease in the fifth 81. Other series include those by Chang et al 82, Jawahar et al 83, and Rajaraman et al 84.

Overall, these series demonstrate that SRS is an effective treatment for small or medium sized solid tumours, but that it is less effective at treating any associated cystic portion, which will often require surgical aspiration. This should generally be carried out following, rather than prior to, SRS; as the cyst fluid provides a useful ‘cushion’ between the target and surrounding normal tissue. Increased rates of local control are seen with higher doses, but rates of radionecrosis will also increase.

Following SRS, new lesions are frequent in VHL patients. External beam radiotherapy to the whole posterior fossa may be a sensible first step in these patients.

**Main indications for radiosurgery**
In symptomatic patients, surgery (complete resection if possible) is the preferred first line treatment (unless there are other contraindications) since it will reduce mass effect straight away. External beam radiotherapy (55-60 Gy in 30#) is often considered for unresectable lesions, multiple lesions, recurrent lesions after previous partial resections or those unfit for surgery. Radiosurgery can be considered for recurrent disease after previous external beam treatment or possibly for localised sporadic cases that are inoperable.

**Patient selection**
Cases should be discussed at the CNS MDT.

- Patient unfit for surgery or surgery carries unacceptable risks
- External beam radiotherapy already used or considered unacceptable by patient. (VHL patients need to be aware of likely development of new lesions if SRS used alone)
- Posterior fossa rather than spinal lesion
- Small volume disease (<3cm across max diameter)

**OAR**
Brain stem: Max point dose 15 Gray. Volume receiving 12 Gy ≤ 10 mm³.
**Prescribed dose**
Most series describe margin doses in the range of 12-20 Gray (average about 15-16 Gy). Dose will reflect tumour size, previous radiotherapy and proximity of OAR.

**Follow up**
Patients with VHL will need FU in specialised clinics due to the risk of further hamangioblastomas and other tumour types.
10.3.7 Glomus jugulare tumours

Glomus jugulare tumours are rare neoplasms of the skull base. They are typically slow-growing, hypervascular and histologically benign. They arise from the paraganglia of the chemoreceptor system (hence the synonyms chemodectoma and paraganglioma). They can invade widely into the temporal bone causing symptoms such as progressive deafness, pulsatile tinnitus, imbalance or cranial nerve lesions.

There is a good body of literature on the efficacy of conventionally fractionated radiotherapy for the control of glomus jugulare tumours 85-87. Furthermore, in recent years, considerable evidence has emerged in the literature confirming the effectiveness of SRS in treating these tumours.

Several series, of between 8 and 25 patients 88-93, treated by SRS, report high rates of tumour control with low morbidity. Two of them 88, 91 point out the need for long-term follow up (to ten years), before a cure for these slow growing tumours can be said to have occurred. Nevertheless, with a total of more than 100 cases now reported in the peer reviewed literature, it is clear that good control rates, combined with a high degree of safety can be offered by GKRS.

LINAC based treatment 94, 95 would also appear to offer safe and effective tumour control, but again the question of long term tumour control rates is not yet answered 95. The London team believe that SRS is frequently the primary treatment of choice for this often complex skull base tumour.

Main indications for radiosurgery

Surgery can produce immediate elimination of the tumour but is often associated with significant complications due to the proximity of critical vascular and neuronal structures 96. Fractionated radiotherapy may be indicated to increase radiobiological sparing for large tumours but the extreme precision of SRS may be useful for smaller lesions. SRS may reduce complications such as xerostomia.

Patient selection

- Volume < 10 cm³.
- Surgery considered high risk or recurrence post-surgery.

OAR

Brainstem, cochlear, cranial nerves.

Prescribed dose

Prescribed margin doses have ranged from 12-25 Gy 90, 94, 95. Typically a single dose of 20 Gy is prescribed to the margin when tumours are small, although this may need to be less for larger tumours or ones involving cranial nerves/ close to critical structures. Lower cranial nerves appear tolerant of radiosurgical margin doses of between 12 and 18 Gy 89.

Follow up

Needs to be long-term due to slow-growing nature of the tumours.
10.3.8 Pineal region tumours

The pineal gland is a solitary structure, lying between the posterior third ventricle rostrally and the cerebellar vermis caudally. Its physiological role includes the release of melatonin, which controls circadian sleep/wake patterns. It sits in a highly vascular, central location which makes surgical approaches and biopsies challenging.

4 main types of pathology arise there:

- Germ cell tumours (germinoma, teratoma etc)
- Pineal parenchymal tumours (pineocytoma, pineoblastoma - a variety of PNET)
- Glial tumours
- Miscellaneous (including metastases, menigioma, ependymoma etc)

Tumours are rare (although commoner in Asia) and usually present with symptoms of mass effect (e.g. hydrocephalus or Parinaud’s syndrome). Management is critically dependent on tumour type, so biopsy (open, endoscopic or stereotactic) is very important. Evaluation of CSF for germ cell tumour markers (AFP, β-hCG) and staging MRI of the whole neuraxis are also required in most cases.

Surgery for benign lesions can afford permanent cure and avoid the need for CSF diversion but is associated with mortality of up to 10%. Morbidity can also be significant. The role of surgery in malignancy is less clear. Germ cell tumours are very sensitive to radiation therapy. Traditionally craniospinal treatment was combined with local boosts. In children, particularly, this is a very toxic approach with long-term sequelae. Increasingly, chemotherapy has been used to avoid large radiation fields.

SRS may have a role as an alternative to surgery for benign disease (especially in those considered unfit for surgery), or to supplement sub-total resection. It may also be used as a “boost” technique. Evidence comes from several small case series examining mixtures of different pathological sub-types. These suggest that non-germinomatous germ cell tumours are less sensitive to SRS than germinoma. As expected, local control rates are high but, in malignant disease, distant failure is common, emphasising the importance of therapy directed at micro-metastatic disease (e.g. chemotherapy or cranio-spinal radiotherapy).

**Main indications for radiosurgery**

As an alternative to surgery for benign disease.

Treatment of residual tumour after sub-total resection of benign disease.

**Patient selection**

Cases to be discussed by CNS MDT. Issues such as need for CSF decompression, tumour size, biopsy results and fitness for / risk of surgery considered when deciding management strategy.

**OAR**

Brainstem

**Prescribed dose**

Most series use a marginal dose of 12-16 Gy (mean 14 Gy) depending on target size.
**Follow up**
Dependent on histology.
11 Conventional Radiotherapy

11.1 High Grade Glioma - Radical - Primary - (Chemo) RT

11.1.1 Intent

- Radical in patients with WHO PS 0-1
- The combination with chemotherapy is used for the fittest GBM patients.

11.1.2 Primary Outcome

- Survival benefit
- Prognostic factors include, histology, grade, age and performance status
- Median survival gain with radiotherapy alone 22 weeks

11.1.3 Toxicity

- Acute: Headache, fatigue, hair loss, scalp erythema, nausea, mucositis (if nasopharynx included), temporary hearing loss (if ear canal included), and temporary loss of taste (if nasopharynx included).
- Chemotherapy can produce nausea, myelosuppression, bowel disturbance and occasionally allergic phenomena
- Early Delayed: somonolence

11.1.4 Patient information

- ‘Radiotherapy for Brain Tumours: Long Course’

11.1.5 Scheduling

- Radiotherapy (54-60 Gy in 30 fractions over 6 weeks).
- If for chemotherapy- Concurrent temozolomide 75mg/m\(^2\) daily seven days a week during RT, followed, after 4 weeks, by up to 6 cycles of adjuvant temozolomide at 150-200mg/m\(^2\) given days 1-5 every 28 days.

11.1.6 Pre-treatment process

**Essential pre-treatment documentation**

- Clinical history and examination
- Operation note
- Histology report
- Pre-op CT or MRI
- Post-op CT or MRI scan (if performed)
- SJIO RT booking document
- SJIO Mould Room Booking document
- MRI request card if CT/MRI fusion required
Patient positioning/immobilisation
- Polyester Beam Direction Shell
- A thermoplastic shell may be used (depending on Mould Room capacity).
- Supine position for majority, prone for posterior tumours.

Imaging
- Contrast enhanced CT virtual simulation scan.
- CT-MRI co-registration if tumour ill defined on CT.
- Scan limits Vertex to C3.

11.1.7 Target definition
- GTV- Enhancing tumour together with the cavity following any surgical resection.
- CTV- GTV+ 2.0-2.5cm edited where there is an anatomical barrier to spread (eg.bone, tentorium). CTV may also be edited in regions in close proximity to OARs
- PTV- CTV + 0.5cm.
- Organs at risk- Recommended dose limits for different organs in 2Gy fractions are the following but dose constraints should be relaxed if clinically indicated:
  1. Optic chiasm, optic nerves and tracts: 50Gy
  2. Lens < 5Gy, and retina ≤ 40Gy
  3. The maximum dose to the whole brainstem should be ≤ 54Gy
  4. The cochlea: 50-55Gy
  5. The normal brain dose contralateral to the tumour should be < 50-60% of the total dose.
  6. The tolerance of the hypothalamic-pituitary axis may be as low as 40Gy but because of the ease of hormone replacement it is not usual to limit the dose or volume of irradiation.

11.1.8 Prescribed dose and fractionation
- 54-60 Gy in 30 daily fractions over 6 weeks
- Dose-distribution- Computer planned
- Prescribed to ICRU Reference Point.

11.1.9 Treatment
- Review pre-simulation then weekly to assess PS, plus analgesic, anticonvulsant, steroid, anti-emetics and chemotherapy prescriptions.
- Patients receiving concomitant chemotherapy require weekly FBCs and biochemistry
- Responsibility- Treating Clinician or Clinical Nurse Specialist
11.2 High Grade Glioma - Palliative - Primary - RT Alone

11.2.1 Intent
- Palliative in poor prognosis patients

11.2.2 Primary Outcome
- Barthel score improved or stable in 68%. Median survival: 5 months, 1 year survival 12%

11.2.3 Toxicity
- Acute: Headache, fatigue, hair loss, scalp erythema, nausea, mucositis (if nasopharynx included), temporary hearing loss (if ear canal included), and temporary loss of taste (if nasopharynx included)
- Early Delayed: somonolence

11.2.4 Patient information
- ‘Radiotherapy for Brain Tumours: Short Course’

11.2.5 Scheduling
- Radiotherapy alone

11.2.6 Pre-treatment process

**Essential pre-treatment documentation:**
- Clinical history and examination
- Operation note
- Histology report
- Pre-op CT or MRI
- Post-op CT or MRI scan (if performed)
- SJIO RT booking document
- SJIO Mould Room Booking document

**Patient positioning/immobilisation:**
- Thermoplastic shell, supine

**Imaging**
- Contrast enhanced CT virtual simulation scan
- Scan limits: Vertex to C3

11.2.7 Target definition:
- GTV- Enhancing tumour on CT virtual simulation
- CTV- GTV + 1.5 – 2.0cm
PTV- CTV + 0.5cm  
Field- PTV + 0.5cm ie GTV + 2.5 - 3.0cms  
Organs at risk- In view of short prognosis the usual dose constraints for most CNS critical structures are not applicable. Fields are shaped/angled to reduce the dose to the lens and orbit as much as possible.

11.2.8 Prescribed dose and fractionation

- 30Gy in 6 fractions over 2 weeks (Mon, Wed, Fri.).  
- 30Gy in 10 fractions over 2 weeks is an alternative fractionation for large volumes or gliomatosis cerebri.  
- Dose-distribution- Non-computer planned.  
- Parallel opposed equally weighted lateral fields best fit to PTV.  
- Prescribed to isocentre.  
- For a well lateralised tumour, beams may be differentially weighted.

11.2.9 Treatment

- Review- Pre-simulation then in 2nd week of treatment to assess PS, plus analgesic, anticonvulsant, steroid, anti-emetics requirements.  
- Responsibility- Treating Clinician or Clinical Nurse Specialist.

11.3 Low Grade Glioma - Radical - Primary - RT Alone

11.3.1 Intent

- Radical in patients with WHO PS 0-1.

11.3.2 Primary Outcome

The optimal management of cerebral low-grade glioma is unknown and the identification of patients needing treatment is based on prognostic factors which include: age ≥ 40 years, astrocytic tumour type, tumour size > 6 cm, tumor crossing the midline, and neurologic deficit at diagnosis (before surgery). Radiotherapy improves progression free but not overall survival.

11.3.3 Toxicity

- Acute: Headache, fatigue, hair loss, scalp erythema, nausea, mucositis (if nasopharynx included), temporary hearing loss (if ear canal included), and temporary loss of taste (if nasopharynx included).  
- Early Delayed: somolence.  
- Late: White matter changes, cognitive deficits and radiation necrosis.

11.3.4 Patient information

- ‘Radiotherapy for Brain Tumours: Long Course’.
11.3.5 Scheduling

- Radiotherapy alone.

11.3.6 Pre-treatment process

**Essential pre-treatment documentation**

- Clinical history and examination.
- Operation note.
- Histology report.
- Pre-op CT or MRI
- Post-op CT or MRI scan (if performed).
- SJJO RT booking document.
- SJJO Mould Room Booking document.
- MRI request card if CT/MRI fusion required.

**Patient positioning/immobilisation**

- Polyester Beam Direction Shell or relocatable sterotactic frame.
- Supine position for majority, prone for posterior tumours.

**Imaging**

Contrast enhanced CT virtual simulation scan.
CT-MRI co-registration if tumour ill defined on CT.
Scan limits: Vertex to C3.

11.3.7 Target definition

- GTV - is the region of high signal intensity area on T2 weighted MRI corresponding to the hypodense area on CT images including any possible areas of enhancement on CT. If the patient has undergone surgery GTV should be defined, on post-operative imaging, as the operative cavity and the residual tumour.
- CTV - GTV + 1.0 - 1.5cm edited when an anatomical barrier to spread (eg. bone, tentorium). CTV may also be edited in regions in close proximity to OARs. The CTV extends to the contralateral hemisphere only when a midline structure such as the corpus callosum is invaded by tumour as visualized on T2 weighted MRI.
- PTV - CTV + 0.5cm.
- Organs at risk - Recommended dose limits for different organs in 2Gy fractions are the following but dose constraints should be relaxed if clinically indicated:
  1. Optic chiasm, optic nerves and tracts: 50Gy.
  2. Lens < 5Gy, and the retina ≤ 40Gy.
  3. The maximum dose to the whole brainstem should ≤ 54Gy.
  5. The normal brain dose contralateral to the tumour should be < 50-60% of the total dose.
  6. The tolerance of the hypothalamic-pituitary axis may be as low as 40Gy but because of the ease of hormone replacement it is not usual to limit the dose or volume of irradiation.
11.3.8 Treatment

- Review- Pre-simulation then weekly to assess PS, plus analgesic, anticonvulsant, steroid, and anti-emetic requirements.
- Responsibility Treating Clinician or Clinical Nurse Specialist.

11.4 Meningioma - Radical - Primary - RT Alone

11.4.1 Intent

- Radical.

11.4.2 Primary Outcome

- Local control rates of 75-85 % at 10 years in incompletely resected.
- benign meningiomas. 5-year overall survival rates for non-benign.
- meningiomas 28 - 70%.

11.4.3 Toxicity

- Acute: Headache, fatigue, hair loss, scalp erythema, nausea, mucositis (if nasopharynx included), temporary hearing loss (if ear canal included), and temporary loss of taste (if nasopharynx included).
- Early Delayed: somnolence.
- Late: white matter changes, cognitive deficits and radiation necrosis. Radiation induced second tumours.

11.4.4 Patient information

- ‘Radiotherapy for Brain Tumours: Long Course’.

11.4.5 Scheduling

- Radiotherapy alone.

11.4.6 Pre-treatment process

Essential pre-treatment documentation

- Clinical history and examination.
- Operation note.
- Histology report.
- Pre-op CT or MRI.
- Post-op CT or MRI scan (if performed).
- SJIO RT booking document.
- SJIO Mould Room Booking document.
- MRI request card if CT/MRI fusion required.
Patient positioning/immobilisation
- Polyester Beam Direction Shell or relocatable stereotactic frame.
- Supine position for majority, prone for posterior tumours.

Imaging
- Contrast enhanced CT virtual simulation scan.
- CT-MRI co-registration [T1 + Gad].
- Scan limits Vertex to C3.

11.4.7 Target definition

Simpson’s Resection Grade 1-3
- GTV- No GTV.
- CTV- CTV should be estimated on the basis of the preoperative imaging demonstrating the meningioma attachment and the information in the neurosurgeon’s operative report on tumour attachment and microscopic tumour residue.
- PTV- CTV + 0.5cm.

Simpson’s Resection Grade 4 & Simple Decompression
- GTV- Residual enhancing mass including dural tails (enhancing but not thickened dura is included).
- CTV- GTV + 0.5-1.5cm (may be increased to 2-2.5cm for malignant meningiomas).
- PTV- CTV + 0.5cm.
- Organs at risk- Recommended dose limits for different organs in 2Gy fractions are the following but dose constraints should be relaxed if clinically indicated:
  1. Optic chiasm, optic nerves and tracts: 50Gy.
  2. Lens < 5Gy, and the retina ≤ 40Gy.
  3. The maximum dose to the whole brainstem should ≤ 54Gy.
  5. The normal brain dose contralateral to the tumour should be < 50-60% of the total dose.
  6. The tolerance of the hypothalamic-pituitary axis may be as low as 40Gy but because of the ease of hormone replacement it isn’t usual to limit the dose or volume of irradiation.

11.4.8 Prescribed dose and fractionation
- 50-50.4 Gy in 28-30 daily fractions over 6 weeks for optic nerve sheath meningioma.
- 54 Gy in 30 daily fractions over 6 weeks for benign or atypical meningiomas.
- 60 Gy in 30 daily fractions over 6 weeks for malignant meningiomas.
- Dose-distribution- Computer planned.
- Prescribed to ICRU Reference Point.

11.4.9 Treatment
- Review- Pre-simulation then weekly to assess PS, analgesic, anticonvulsant, steroid and anti-emetic requirements.
- Responsibility- Treating Clinician or Clinical Nurse Specialist.
11.5 Pituitary - Radical - Primary - RT Alone

11.5.1 Intent
- Radical

11.5.2 Primary Outcome

Non Functioning Macroadenomas
- control rate improves from 60-70% to over 90% with radiotherapy. In patients without cavernous sinus invasion, marked suprasellar extension or extensive post-operative residuum radiotherapy can be deferred.

Functioning macro and microadenomas
- surgery and medical management are the primary treatments. Where unsuccessful radiotherapy can reduce hormone levels; 60% reduction in GH at 10 years.
- In patients unfit for trans-sphenoidal surgery, radiotherapy alone has control rates of 70-80%.

11.5.3 Toxicity
- Acute: Headache, fatigue, hair loss, scalp erythema, nausea, mucositis (if nasopharynx included), temporary hearing loss (if ear canal included), and temporary loss of taste (if nasopharynx included).
- Early Delayed: somonolence.
- Late: Hypopituitarism, radiation induced second tumours and possible increased risk of CVAs.

11.5.4 Patient information
- 'Radiotherapy for Brain Tumours: Long Course'

11.5.5 Scheduling
- Radiotherapy alone

11.5.6 Pre-treatment process

Essential pre-treatment documentation
- Clinical history and examination.
- Operation note.
- Histology report.
- Current visual fields.
- Current pituitary function.
- Pre-op CT or MRI.
- Post-op CT or MRI scan (if performed).
- SJIO RT booking document.
- SJIO Mould Room Booking document.
• MRI request card if CT/MRI fusion required.

**Patient positioning/immobilisation**

• Polyester Beam Direction Shell or relocatable stereotactic frame.
• Supine position.

**Imaging**

• Contrast enhanced CT virtual simulation scan.
• CT / MRI co-registration (T1+Gad).
• *Scan limits* Vertex to C3.

11.5.7 Target definition

• GTV- Any residual gross or presumed tumour.
• CTV = GTV.
• PTV- CTV + 0.8 – 1.0cm.
• Organs at risk- Retina ≤ 40Gy.
• Lens:< 5Gy.
• Chiasm ≤ 48Gy (ie avoid hot spots within the chiasm).

11.5.8 Prescribed dose and fractionation

• 45 Gy in 25 fractions over 5 weeks.
12 Chemotherapy

Most brain tumours show only modest response rates to chemotherapy. It is most commonly used for the palliation of recurrent gliomas, although it may sometimes be used for rarer tumour types. In GBM it can be used concurrently with radiotherapy (see section 11.1) and trials are evaluating this approach in Grade 3 tumours. In high grade gliomas, chemotherapy can also be placed into surgical cavities as drug-impregnated wafers. This local release can extend survival.

12.1 Palliative systemic

Standard first line palliative treatment for recurrent gliomas is PCV:

- Procarbazine 100 mg/m\(^2\) po for 10 days (max 200 mg).
- CCNU (lomustine) 100 mg/m\(^2\) po day 1.
- Vincristine 1.5 mg/m\(^2\) (max 2mg) iv day 1 repeated every 42 days.

Second line chemotherapy uses temozolomide:

- Temozolomide 200 mg/m\(^2\) po po for 5 days repeated every 28 days.

Currently there is no standard third line chemotherapy although occasionally carboplatin (AUC 5 every 3 weeks) can be considered. There is also interest in the use of the vascular endothelial growth factor (VEGF) inhibitor, bevacizumab, although this is not currently funded by the NHS.

12.2 Intra-cavitary

At present, there is only one intra-cavitary product in routine use for brain tumours. Carmustine implants (Gliadel, Link Pharmaceuticals) are biodegradable copolymer discs impregnated with an alkylating agent called carmustine. They are about the size of a 5-pence coin, and are implanted into the resection cavity at the time of surgery. Each implant contains 7.7 mg of carmustine, which interacts with DNA, thereby preventing the proliferation of cells. Carmustine implants have a UK marketing authorisation for the treatment of newly diagnosed high-grade malignant glioma (as an adjunct to surgery and radiation), and for the treatment of recurrent GBM (as an adjunct to surgery).

Carmustine implants are not recommended for the treatment of newly diagnosed high-grade glioma for patients in whom less than 90% of the tumour has been resected.
13 Palliative & End of Life Care

13.1 Definitions

Palliative care is part of supportive care. It embraces many elements of supportive care.

Palliative & End of life care is care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last year(s) of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.

The Department of Health (2008) definition of end of life care states that it includes:

- Adults with advanced, progressive, incurable illness (e.g. advanced cancer, heart failure, COPD, stroke, chronic neurological conditions, dementia);
- Care given in all settings (e.g. home, acute hospital, ambulance, residential/nursing care home, hospice, community hospital, prison);
- Care given in the last year(s) of life
- Patients, carers and family members (including bereavement care).

End of Life Strategy, Department of Health 2008
National Council for Palliative Care Services 2006

13.2 Who Provides Palliative / End of Life Care?

Palliative / end of life care is provided by two distinct categories of health and social care professionals:

- All health care and social care professionals providing the day-to-day care to patients and carers in any care setting
- Those who specialize in palliative care (consultants in palliative medicine and clinical nurse specialists in palliative care, for example) who care for palliative care patients who have complex needs

Those providing day-to-day care should be able to:

- Assess the care needs of each patient and their families across the domains of physical, psychological, social spiritual and information needs
- Meet those needs within the limits of their knowledge, skills, competence in palliative care
- Know when to seek advice from or refer to specialist palliative care services

Training and education in the skills required for palliative / end of life care should be available to and undertaken by all health and social care professionals.

The national strategy Ambitions for Palliative and End of Life Care 2015-2020 sets out the vision to improve end of life care through partnership and collaborative action between organisations at local level throughout England.

More information can be found at: http://endoflifecareambitions.org.uk/
For more information about local improvements, frameworks, tools to support best practice please contact your local End of Life Care Lead or Specialist Palliative Care Team. One aspect of care is to discuss with individuals, if they wish, their preferences regarding the type of care they would wish to receive and where they wish to be cared for in case they lose capacity or are unable to express a preference in the future. This is the process of Advance Care Planning (ACP).

An ACP discussion might include:
- the individual’s concerns and wishes,
- their important values or personal goals for care,
- their understanding about their illness and prognosis,
- their preferences and wishes for types of care or treatment that may be beneficial in the future and the availability of these.

Such discussions can also inform shared decision-making regarding treatments with palliative intent. Local arrangements for recording this information for each individual patient will differ. Many services are developing/have developed Electronic Palliative Care Coordination Systems (EPaCCS) where by this information can be shared across professionals and settings (e.g on SystmOne). Contact your local specialist palliative care team for more information.

13.3 Specialist Palliative Care

Is provided by specialist multidisciplinary palliative care teams in services or units whose core specialty is palliative care (for example hospices, community or hospital palliative care teams). The specialist teams should include palliative medicine consultants and palliative care nurse specialists together with a range of expertise provided by physiotherapists, occupational therapists, dieticians, pharmacists, social workers and those able to give spiritual and psychological support.

Eligibility for referral to specialist palliative care services is based on patient need not diagnosis. The agreed criteria for referral are as follows:

1. The patient has active, progressive and usually advanced disease for which the prognosis is limited (although it may be several years) and the focus of care is quality of life.

2. The patient has unresolved complex needs that cannot be met by the caring team, for example:
   - Uncontrolled or complicated symptoms (e.g. symptoms not adequately controlled within 48 hours by the referring team, or sooner if causing overwhelming distress).
   - Complex psychological/emotional difficulties.
   - Complex social or family issues.
   - Difficult decision making about appropriate future care.

Patients fulfilling these criteria should be referred to and assessed by a member of the specialist palliative care team.
The subsequent care package will be dependent on this assessment and should be made in agreement with the patient, carer(s) and referring team. It is not appropriate for specialist palliative care services to be committed to patients by professionals outside these services. Equally, specialist services should ensure that the assessment process is accessible and responsive to patients in need.

The level of specialist palliative care support required may fluctuate. Shared care of patients between the specialist palliative care professionals and the referring team (for hospital patients) or the primary care team (for patients at home / care home) is usually appropriate. Timely and effective communication is essential in these situations. For these patients advice from specialist palliative care services on a 24 hour basis should be available in all care settings.

Sometimes the specialist palliative care consultant and team may take the lead role in patient care, usually in a specialist in-patient unit (hospice) or designated specialist palliative care beds.

Referral systems for specialist palliative care services vary in different areas. They should be clear to all local referring consultants and primary care teams.

13.4 Further Links and Information

Contact the local Specialist Palliative Care Team for further information

13.5 Directory of West Yorkshire & Harrogate Cancer Alliance Specialist Palliative Care Services

The Directory has been checked and updated in May 2017

Bradford, Airedale, Wharfedale and Craven
Bradford Teaching Hospitals NHS Foundation Trust
Airedale NHS Foundation Trust
NHS Bradford, Airedale, Wharfedale and Craven
Website: www.palliativecare.bradford.nhs.uk

<table>
<thead>
<tr>
<th>Service</th>
<th>Tel</th>
<th>Fax</th>
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<tr>
<td>Airedale General Hospital Palliative Care Team</td>
<td>01535 292184</td>
<td>01535 295016</td>
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<td></td>
<td>01535 295036</td>
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<tr>
<td>Sue Ryder Care – Manorlands Hospice (Oxenhope)</td>
<td>01535 642308</td>
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<td></td>
<td>01535 642902</td>
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<tr>
<td>Bradford Teaching Hospitals Palliative Care Team</td>
<td>01274 364035</td>
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<td>01274 366851</td>
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<tr>
<td>Bradford Community Palliative Care Team</td>
<td>01274 323511</td>
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<tr>
<td>Marie Cure Hospice (Bradford)</td>
<td>01274 337000</td>
<td>01274 337095</td>
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<tr>
<td>Out of Hours Advice via on-call Palliative Medicine Consultant via Marie Curie Hospice / Manorlands Hospice</td>
<td>01274 337000</td>
<td>01535 642308</td>
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**Calderdale and Huddersfield**
Calderdale & Huddersfield NHS Foundation Trust
NHS Calderdale
NHS Kirklees

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<td>Calderdale Community Palliative Care Team</td>
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<td>01422 378425</td>
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<tr>
<td>Overgate Hospice</td>
<td>01422 379151</td>
<td>01422 384210</td>
</tr>
<tr>
<td>Kirkwood Hospice and Community Palliative Care Team</td>
<td>01484 557906</td>
<td>01484 557918</td>
</tr>
<tr>
<td>Out of Hours Advice via Hospices</td>
<td>01422 379151</td>
<td>01484 557900</td>
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**Harrogate and District**
Harrogate NHS Foundation Trust
NHS North Yorkshire and York
Website: [https://www.hdft.nhs.uk/services/palliative-care/](https://www.hdft.nhs.uk/services/palliative-care/)

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<td>Harrogate Hospital and Community Palliative Care Team</td>
<td>01423 553464</td>
<td>01423 555763</td>
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<tr>
<td>St Michael’s Hospice</td>
<td>01423 872658</td>
<td>01423 815454</td>
</tr>
<tr>
<td>Out of Hours Advice via Hospice</td>
<td>01423 879687</td>
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**Leeds**
Leeds Palliative Care
Website: [www.leedspalliativecare.co.uk](http://www.leedspalliativecare.co.uk)

<table>
<thead>
<tr>
<th>Leeds Teaching Hospitals NHS Trust Specialist Palliative Care Team</th>
<th>Tel 0113 2064563</th>
<th>Fax 0113 2064863</th>
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<tbody>
<tr>
<td>Sue Ryder Care - Wheatfields Hospice and Community Palliative Care Team (West Leeds)</td>
<td>Tel 0113 2787249</td>
<td>Fax 0113 2302778</td>
</tr>
<tr>
<td>St Gemma’s Hospice and Community Palliative Care Team (East Leeds)</td>
<td>Tel 0113 2185500</td>
<td>Fax 0113 2185524</td>
</tr>
<tr>
<td>Out of Hours Advice via SJUH Switchboard</td>
<td>Tel 0113 2433144</td>
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**Mid Yorkshire**
Mid Yorkshire Hospitals NHS Trust
NHS Wakefield District
Kirklees PCT
Website: [https://www.midyorks.nhs.uk/palliative-care1](https://www.midyorks.nhs.uk/palliative-care1)

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<tr>
<th>Dewsbury Hospital and Community Palliative Care Team</th>
<th>Tel 01924 816052</th>
<th>Fax 01924 543883</th>
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<tbody>
<tr>
<td>Dewsbury Day Support and Drop-in (Rosewood Centre)</td>
<td>Tel 01924 512039</td>
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<tr>
<td>Mid Yorkshire Hospitals NHS Trust Palliative Care Team</td>
<td>Tel 01924 543801</td>
<td>Fax 01924 543883</td>
</tr>
<tr>
<td>Pontefract Community Palliative Care Team (Prince of Wales Hospice)</td>
<td>Tel 01977 781456</td>
<td>Fax 01977 796209</td>
</tr>
<tr>
<td>Prince of Wales Hospice (Pontefract)</td>
<td>Tel 01977 708 868</td>
<td>Fax 01977 600097</td>
</tr>
<tr>
<td>Wakefield Hospice</td>
<td>Tel 01924 331400</td>
<td>Fax 01924 362769</td>
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<tr>
<td>Out of Hours Advice via Pinderfields Hospital Switchboard</td>
<td>Tel 01924 541000</td>
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**York**
York Hospitals NHS Foundation Trust
NHS North Yorkshire and York
[https://www.yorkhospitals.nhs.uk/our_services/az_of_services/palliative_care/](https://www.yorkhospitals.nhs.uk/our_services/az_of_services/palliative_care/)

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<th>York Hospital Palliative Care Team</th>
<th>Tel 01904 725835</th>
<th>Fax 01904 726440</th>
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<tr>
<td>Community Palliative Care Team</td>
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14 Neurosciences MDT – SOPs

The IOG defines the roles of the neurosciences MDT as described in Figure 4.

- Establish a diagnosis for the optimal clinical management of the patient
- Develop management plans for patients with CNS tumours at first presentation, to include initial supportive care needs, diagnostic and surgical interventions, non-surgical oncology interventions, treatment of symptoms and follow-up
- Nominate and record a key worker to act as point of contact for patients, their relatives and carers. This should be agreed with the patient, their relatives and carers
- Agree who is responsible for implementing the next stage of the management plan
- Inform the diagnostic clinician/team at the local referring hospital and GP of the management plan (see communication below)
- Inform the cancer network MDT of the management plan (usually via a representative who is a member of the neuroscience MDT and also in writing)
- Review and advise on patients referred back from the cancer network MDT on disease progression or relapse
- Develop MDT protocols, in collaboration with the cancer network MDT, to define appropriate follow-up imaging requirements for patients with CNS tumours
- Implement the national management protocols for CNS lymphoma, medulloblastoma, pineal tumours and optic gliomas (see Chapter 7)

- Act as an educational resource for local service providers
- Develop and maintain evidence-based local management protocols covering all aspects of the patient pathway
- Participate in regular site-specific group meetings to review care pathways and protocols
- Introduce and maintain systems for data entry across the area of service provision including links to cancer registries
- Audit practice against this guidance and other national guidelines as they are published
- Facilitate the entry of patients into appropriate National Cancer Research Network (NCRN) and local clinical trials
- Liaise with the cancer network MDT

The meeting occurs weekly (Wednesday 9.30am LGI, Radiology Academy) and is responsible for the diagnosis and initial management of most adult patients with CNS tumours (currently pituitary and non-intrinsic spinal tumours are discussed elsewhere).

For detailed standard operating procedures contact Leeds Teaching Hospitals NHS Trust

14.1.1 Composition

The meeting is attended by consultant neurosurgeons, neuro-oncologists, neuroradiologists and neuropathologists. Also present are the MDT coordinators, nurse specialists, medical
trainees in the above specialities, radiographers and allied health professionals (e.g. occupational therapy, physiotherapy, palliative care).

14.1.2 Referral mechanism

Many cases are discussed after referral from cancer units. Given that the managing team are not able to attend in person, it is vital that as much clinical information is available as possible (it is envisaged the appointment of more nurse specialists will help bridge this gap as much as possible). Access to relevant imaging is also essential. The deadline for adding cases to the list is the end of Monday afternoon. It will not be possible for imaging received after this time to be reviewed prior to the meeting. Referral is done by completing the MDT referral form (details in Section 10.9). Attempts are being made to allow this to be achieved via the internet.

14.1.3 Communication of outcomes

A typed summary of the meeting outcome will be available on PPM within 24 hours. Plans are being made for outcomes to be sent to secure nhs.net e-mail addresses when referrers do not have access to PPM. In the interim, outcomes can also be faxed to referrers if appropriate details are provided on the referral form.

It is hoped that an electronic mechanism to inform GPs within the network can be developed using PPM and possibly nhs.net e-mail. This is part of a much larger piece of work being developed by the Cancer Centre to speed communication with GPs about a range of issues.
The roles of the Rehabilitation & Non-Surgical Oncology MDT are defined in the IOG. They are outlined in Figure 5.

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

15.1.1 Who will be discussed?

- Patients who are referred to the Neurosciences MDT for a clinical decision (their rehab and supportive needs will be co-ordinated by the IOG CNS).
- Patients who have a recently confirmed histopathological diagnosis.
- Oncology patients whose supportive and rehabilitation needs have changed
- Patients who are for best supportive care.

For detailed standard operating procedures contact Leeds Teaching Hospitals NHS Trust

The overall structure of Network rehabilitation services is also described in Section 19.
16 Pituitary MDT – SOPs

This meets weekly to consider the management of pituitary tumours. The meeting involves endocrinologists in addition to pathologists, radiologists, oncologists and neurosurgeons.
17 Rehabilitation services

17.1 Introduction

This operational policy is for in-patient and community neuro-rehabilitation facilities with regard to the management of patients with Brain and CNS tumours.

St James’s University Hospital believe rehabilitation makes a real difference to patients and their carers. It is recognised that rehabilitation works and is best provided by an integrated team of specialists. It is understood that inpatient rehabilitation is required at times, but also know that people want to go home as quickly as possible. Effective and efficient inpatient and outpatient rehabilitation programmes are provided to meet people’s needs regardless of the cause of the deficit experienced by the patients.

As part of the brain and CNS service developments, funding was agreed increase the remit of the Clinical Nurse Specialist and the Specialist Allied Health Professional for brain and CNS services in order to provide dedicated support to Brain and CNS patients. These posts are hosted by Leeds Teaching Hospitals NHS Trust. The CNSs and the Specialist AHPs are responsible for leading and co-ordinating a network wide rehabilitation service for adults with brain and CNS tumours as well as providing specialist services for other patient groups. Both the CNSs and the Specialist AHPs are core members of the Neuroscience MDT and the Network MDT. They support in-patients and out-patients, as well as linking to hospitals within the Yorkshire and Community Services. The CNS service have allocated a nominated CNS to each Trust to support local service development, local patient support and to act as an education resource as required.

The Trusts supported by the Acute Specialist Neurological Rehabilitation Team based in Leeds Teaching Hospitals NHS Trust include:

- Airedale NHS Foundation Trust.
- Bradford Teaching Hospitals NHS Foundation Trust.
- Calderdale and Huddersfield NHS Foundation Trust.
- Harrogate and District NHS Foundation Trust.
- Leeds Teaching Hospitals NHS Trust.
- Mid Yorkshire Hospitals NHS Trust.
- York Teaching Hospitals NHS Foundation Trust.

17.2 The Neuro-Rehabilitation Service

The aim of rehabilitation services is to maximise functional outcome and improve quality of life regardless of the overall life expectancy of the individual. The acute specialist rehabilitation services are open to patients with brain and CNS tumours, whose rehabilitation needs are caused by their tumour or its treatment. These patients should not be excluded from the facilities scope of practice on the grounds alone of the diagnosis of a tumour.
The acute specialist neurological rehabilitation team aims to find practical and therapeutic solutions to the specific problems that limit a person’s activities and help them to reduce the restrictions on their full and independent participation.

Referrals to any of the AHP’s are welcome from any member of the clinical team in the hospital. A formal referral from the patient’s consultant physician or surgeon is required to access the Neuro rehabilitation Consultant service. Patients referred to the service may have multiple complicated needs arising from either a long-term disabling neurological condition and an acute medical or surgical illness, or, a newly diagnosed neurological condition arising from another condition or its treatment.

Patients with complex needs without an underlying neurological diagnosis may also be reviewed on a case-by-case basis. A triage system is operated to ensure that patients with the greatest needs receive appropriate and timely treatment. An advice service is available to guide referring teams to arrange further rehabilitation within the Acute Trust or to refer to Community Services. Once an episode of rehabilitation is complete patients can be re-referred either through their General Practitioner, Local Hospital Medical Team or their Key-worker who could be a Clinical Nurse Specialist or a Specialist AHP.

### 17.3 Patient Referral

The specialist rehabilitation services are led by the following consultants:

<table>
<thead>
<tr>
<th>Lead Consultant</th>
<th>Specialist Area</th>
<th>Resources</th>
<th>Base</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr Rory O’Connor – Neuro-oncology Rehabilitation Lead</td>
<td>Neurological rehabilitation, rehabilitation medicine research and medical education</td>
<td>In patient beds – St Mary's Hospital, Community Rehabilitation Unit Chapel Allerton Hospital</td>
<td>St James's University Hospital</td>
</tr>
</tbody>
</table>

Referrals should be sent to the relevant AHP. Patients are assessed using a range of standardised, generic and conditions-specific measures depending on where the patient is in their rehabilitation journey. The team uses a goal-orientated approach, taking into account a person’s own priorities and interests, and agrees a rehabilitation programme with the person and his or her family and carers. Assessment and intervention is usually carried out in Bexley wing, St James Hospital. The team can advise on changes or alterations to patient’s homes and checks that the patients are receiving the right personal support for his or her needs.

### 17.4 Clinical Nurse Specialist and Specialist AHP Services for Brain and CNS Patients
The CNSs and Specialist AHP service details are included in guidelines for The Management of Brain and CNS Tumours. The guidelines describe services available and referral criteria for brain and CNS tumour patients for:

- Clinical Nurse Specialist for Brain and CNS Patient.
- Occupational Therapy Service.
- Physiotherapy.
- Speech and Language Therapy.
- Neuro Psychology

Referral to these services occur during the Neuroscience MDT and the Network MDT as well as direct ward and clinician referral.

17.5 Brain and CNS Rehabilitation Audit

Regular clinical and service improvement audits are undertaken by the MDT to ensure that high standards are upheld consistently and new practices are adopted in line with new guidelines and current research.
The performance status of a patient is almost always a powerful predictor of outcome in brain tumour patients. Accurately assessing it is important when selecting appropriate treatment and determining response.

Two systems are widely used:

### 18.1 Karnofsky performance status scale

<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>100</td>
<td>Normal no complaints; no evidence of disease.</td>
</tr>
<tr>
<td>90</td>
<td>Able to carry on normal activity; minor signs or symptoms of disease.</td>
</tr>
<tr>
<td>80</td>
<td>Normal activity with effort; some signs or symptoms of disease.</td>
</tr>
<tr>
<td>70</td>
<td>Cares for self; unable to carry on normal activity or to do active work.</td>
</tr>
<tr>
<td>60</td>
<td>Requires occasional assistance, but is able to care for most of his personal needs.</td>
</tr>
<tr>
<td>50</td>
<td>Requires considerable assistance and frequent medical care.</td>
</tr>
<tr>
<td>40</td>
<td>Disabled; requires special care and assistance.</td>
</tr>
<tr>
<td>30</td>
<td>Severely disabled; hospital admission is indicated although death not imminent.</td>
</tr>
<tr>
<td>20</td>
<td>Very sick; hospital admission necessary; active supportive treatment necessary.</td>
</tr>
<tr>
<td>10</td>
<td>Moribund; fatal processes progressing rapidly.</td>
</tr>
<tr>
<td>0</td>
<td>Dead</td>
</tr>
</tbody>
</table>

Able to carry on normal activity and to work; no special care needed.

Unable to work; able to live at home and care for most personal needs; varying amount of assistance needed.

Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly.
### WHO/ECOG Performance score

<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Asymptomatic (Fully active, able to carry on all predisease activities without restriction)</td>
</tr>
<tr>
<td>1</td>
<td>Symptomatic but completely ambulatory (Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature. For example, light housework, office work)</td>
</tr>
<tr>
<td>2</td>
<td>Symptomatic, &lt;50% in bed during the day (Ambulatory and capable of all self care but unable to carry out any work activities. Up and about more than 50% of waking hours)</td>
</tr>
<tr>
<td>3</td>
<td>Symptomatic, &gt;50% in bed, but not bedbound (Capable of only limited self-care, confined to bed or chair 50% or more of waking hours)</td>
</tr>
<tr>
<td>4</td>
<td>Bedbound (Completely disabled. Cannot carry on any self-care. Totally confined to bed or chair)</td>
</tr>
<tr>
<td>5</td>
<td>Death</td>
</tr>
</tbody>
</table>
19 References


