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Introduction

Primary brain tumours account for 1.6% of all tumours diagnosed in the UK. It has been estimated that the lifetime risk of developing brain and other central nervous system (CNS) cancer is 1 in 133 for men and 1 in 185 for women in the UK, and the incidence rates are rising slightly. In adults, most brain tumours are supratentorial and high-grade gliomas and meningiomas predominate. Brain tumours can develop at any age in adults but are most common in people aged between 50 and 70 (Brain and central nervous system tumours – UK incidence statistics, Cancer Research UK).

Survival from brain tumours depends on many factors such as the type of tumour, its grade, position in the brain, shape and size. Overall, for all types of malignant brain tumours in adults, more than 4 out of 10 people diagnosed (41.5%) live for at least a year. About 15 out of every 100 people (15%) live for more than 5 years after diagnosis. Just under 10 out of every 100 people diagnosed (10%) live for more than 10 years after diagnosis (Cancer Research UK).

CNS malignancy accounts for approximately 2% of primary tumours, or about 6,500 cases per year in the UK (6–7/100,000 per year). The catchment population for the LCA neuroscience centres (which includes Kent and parts of Surrey and Sussex) is approximately 10 million.

The classification of brain tumours is complex and is being constantly reviewed. There are many subgroups and the treatment approach differs for each. The WHO classification of brain tumours includes:

- astrocytic tumours
- oligodendroglial tumours and mixed gliomas
- ependymal tumours
- choroid plexus tumours
- neuroepithelial tumours of uncertain origin
- neural and mixed neuronal-glial tumours
- pineal parenchymal tumours
- embryonal tumours
- peripheral neuroblastic tumours
- tumours of the cranial and peripheral nerves
- meningeal tumours
- tumours of the haematopoietic system (lymphoma and histiocytic tumours)
- germ cell tumours
- tumours of the sella region (pituitary and craniopharyngioma)
- metastatic tumours of the CNS.

CNS tumours can arise in any of the tissues within the CNS but are broadly grouped into intrinsic tumours, tumours of the meninges and tumours of the pituitary and pineal glands. In the latest data available from Cancer Research UK, 58% of all CNS tumours arose in the brain itself; 23% arose in the meninges; 11% in the intracranial endocrine glands; and the remaining 8% in the other parts of the CNS (e.g. spinal cord).
The incidence of CNS malignancies is related to age, with highest overall rates being in the older population with a relatively equal sex distribution. There is a small peak in incidence during childhood where CNS malignancies are the second most common group of cancers (after leukaemia), accounting for more than a quarter (27%) of all tumours diagnosed in children. Figure 1 below demonstrates the incidence across the different age groups.

**Figure 1: Brain, CNS and intracranial tumours: average number of new cases per year and age-specific incidence rates per 100,000 population, UK.**

Prepared by Cancer Research UK – original data sources are available from www.cancerresearchuk.org/cancer-info/cancerstats/


There are several pathological sub-types of CNS malignancy, dependent upon the cell of origin. Astrocytomas (34%) are the most common.

Referrals of primary tumours to neuro-oncologists consist of approximately:

- Gliomas – astrocytoma/oligodendroglioma 25%
- Glioblastoma (WHO Grade 4) 30%
- Meningiomas 20%
- Pituitary tumours/craniopharyngioma 10%
- CNS lymphoma 5%
- Others (rarities including primitive neuroectodermal tumour) 10%

These figures and guidelines presented below exclude cerebral metastases and metastatic spinal cord disease, which may be managed by the relevant site-specific team.

A TNM classification system for brain tumours exists but is rarely used in clinical practice.

See the imaging section of the guidelines for appropriate scans for patients with primary brain tumours.
For those patients with suspected metastases, the appropriate clinical examination, blood tests and cross-sectional imaging (usually a CT of chest abdomen and pelvis) are carried out. An 18FDG positron emission tomography scan may be useful in some patients.

The management of patients with CNS tumours will discussed at multidisciplinary meetings and treatment may include a combination of some form of surgery, radiotherapy (conventional or stereotactic) and possibly chemotherapy.

The LCA Brain/CNS Cancer Clinical Guidelines encompass guidance from *Improving Outcomes for People with Brain and Other CNS Tumours* (2006) and from the guidelines produced by the previous north west London, south west London and south east London cancer networks. The *Manual for Cancer Services: Brain and CNS Measures* (National Peer Review Programme, March 2014) was also taken into consideration.

The objective of these guidelines is to ensure that patients referred to any of the neuroscience multidisciplinary team meetings throughout the London Cancer Alliance (LCA), with its existing integrated cancer system, will be treated appropriately and in a timely manner. These guidelines are designed to prevent or reduce any inequality of care within the LCA. All patients who live within the LCA should be managed in an LCA centre to improve compliance with the LCA guidelines.

The LCA guidelines are designed to be used by all healthcare professionals in Trusts within the LCA who are involved in the care of the brain and CNS cancer patient. They have been developed to take into account the wide range of clinical experience of the user and the different clinical settings in which they work. The guidelines are intended to assist in the initial assessment, investigation and management of patients. Adoption of the LCA guidelines will allow widespread implementation of up-to-date and evidence-based management of brain and CNS cancer patients, and will assist in the provision of a consistently high standard of care across the LCA.

All Trusts are expected to be able to provide the standard of care detailed in these guidelines. These guidelines will be reviewed on an annual basis in line with guidance from the National Institute for Health and Care Excellence, the British Neuro-Oncology Society and other national and international guidance, as well as significant new research publications, to ensure that they continue to reflect best practice.

With respect to the more rare forms of brain tumours, rather than use our ‘local’ guidelines we have adopted the nationally agreed British Neuro-Oncology Society (BNOS) publications as a guide ([www.bnos.org.uk](http://www.bnos.org.uk)). The LCA has also developed operational policies for pituitary, anterior and lateral skull base tumours, and which accompany this document.

I would like to thank the LCA Brain/CNS Pathway Group members who contributed greatly to the development of these guidelines.

Dr Ron Beaney
Chair, LCA Brain/CNS Pathway Group
Consultant clinical oncologist, Guy’s and St Thomas’ NHS Foundation Trust
Executive Summary

The LCA Brain/CNS Cancer Clinical Guidelines combine the best features of earlier network protocols and have been developed in agreement with clinicians across the LCA. The guidelines combine evidence-based and best practice recommendations with the aim of ensuring that there are equitable, high-quality services across the LCA. The guidelines are multidisciplinary and cover early diagnosis, imaging, pathology, surgery, radiotherapy, rehabilitation and survivorship.

Chapter 1 aims to reduce the time to diagnosis of primary brain tumours. This chapter outlines referral criteria to the neuro-oncology multidisciplinary team (MDT) and emergency medicine department as well as onward referrals from GPs and emergency medicine. It also provides guidance on increasing awareness of brain tumours and access to imaging.

Chapter 2 provides guidance for imaging of brain tumours, including protocols for initial diagnosis of primary and secondary brain and spinal tumours, follow-up and guidelines on metastatic spinal cord compression.

Chapter 3 deals with neuropathology services, molecular and genetic markers, turnaround times and provisional agreement between neuropathological services.

Chapters 4–7 set out the MDT structure in line with peer review requirements. This section also outlines the role of the key worker and the neuro-oncology consultant therapeutic radiographer, essential components of ensuring high-quality patient experience.

The patient information section in Chapter 8 provides a list of key areas to be discussed with each patient and also looks at breaking bad news.

Chapters 9–12, on surgery, radiotherapy and chemotherapy, set out key generic principles for treating brain and central nervous system (CNS) tumours as well as detailing tumour-specific treatment protocols.

Rehabilitation of brain/CNS patients is outlined in Chapter 13 and survivorship described in Chapter 14, detailing the ongoing care for patients living with their condition during and beyond treatment.

Palliative care is presented in Chapter 15 and improving patient experience is outlined in Chapter 16.

Chapter 17 provides information for managing paediatric, teenage and young adult patients.

Alongside this, Chapter 18 stresses that there should be a continued emphasis on national clinical trial leadership, proven to improve the standard of care for all patients.

Some of the recommendations in these guidelines will be challenging to implement, but as the role of the LCA is to ensure that world-class quality of care is delivered for its patients with cancer, it is anticipated that provider organisations within the LCA will use these guidelines as a tool to support change improvement. During the coming months the clinicians will develop standards and measures against which organisations can be assessed.
1 Early Diagnosis

There is an intention to reduce the time to diagnosis of primary brain tumours. This would offer the opportunity to:

- intervene earlier in the disease progress and reduce the risk of acquired neurological disability due to tumour-related brain injury
- improve prognosis with early and more extensive intervention
- reduce the number of initial operations conducted as urgent or emergency procedures with associated raised intracranial pressure and thus enhanced mortality and morbidity risks
- reduce patients’ and their families’ anxieties about the consequences of avoidable delays in diagnosis, whether they are due to patient and family delays, or physician and health system delay
- enhance the public’s confidence in the health services.

1.1 Criteria for referral

1.1.1 Suspected brain tumour

Following is the guideline for the referral of adults admitted via their local A&E department or of patients attending their GP with the symptoms listed below for imaging and onward referral to the neuro-oncology multidisciplinary team (MDT):

- patients with non-migrainous headaches of recent onset, accompanied by features suggestive of raised intracranial 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, or with any focal neurological symptoms
- patients who do not normally complain of headaches, now presenting with headache (particularly if over 45 years)
- patients presenting with a first fit.

Patients with the following should be referred via A&E or the on-call neurology or neurosurgical service for immediate assessment and for urgent imaging:

- acute/subacute neurological deficit developing over days and at most a few weeks (e.g. weakness, sensory loss, dysarthria, ataxia)
- new onset seizures characterised by one or more of the following:
  - prolonged and repetitive focal seizures with or without secondary generalisation
  - prolonged post-ictal focal deficit
  - status epilepticus
  - associated inter-ictal focal deficit
  - patients with headache, vomiting and papilloedema
  - cranial nerve palsies (e.g. double vision, visual failure including optician-defined visual field loss).
Patients not fitting these criteria or with other neurological symptoms should be referred to the local neurology outpatient department.

1.1.2 Suspected spinal tumour

Refer to the LCA Acute Oncology Clinical Guidelines (September 2013, updated May 2014), section 9 Metastatic Spinal Cord Compression.

1.2 Onward referral

There will be protocols to ensure that patients with imaging showing a tumour who are referred by GPs, A&E departments and radiologists will be incorporated into the neuro-oncology service, with a named neuro-oncology clinical nurse specialist and consultant.

1.2.1 GPs

The intention is to increase the number of GPs with a specialist interest (GPwSIs) in neurology to act as a referral source for local GPs for patients with suspected brain tumours. They would have additional expertise in headache, first fit management and subacute neurological deficit so as to provide a filter mechanism for the radiology service and be able to refer on appropriate cases to the neuro-oncology team or to the local neurologist, as appropriate.

Patients should ideally be referred to their local GPwSI or into the neuro-oncology service by their GP following local examination and clinical assessment. For the specific symptoms listed above, GPs should have access to imaging (preferably through their local GPwSI if available) and then direct access either to the local consultant neurologist (who can make the onward referral to the regional neuro-oncology MDT) or directly to the regional neuro-oncology MDT. If there are acute symptoms, as listed above, then referral should be through A&E or, alternatively, via the on-call neurosurgical or neurology service, where available.

If a patient is found to have a suspected tumour, and a scan has been performed in the patient’s local hospital or region, then the images will be transferred through the Image Exchange Portal (IEP) for review by the neuro-oncology MDT or by the on-call neurosurgical service in acute cases.

1.2.2 A&E departments

Any patient presenting to A&E with the specific symptoms listed above, particularly a first fit, should have imaging while the patient remains in the A&E department; if the patient is found to have a suspected tumour, then the A&E team should make the onward referral to the neuro-oncology MDT (ensuring that the GP is informed and that the GP’s details are forwarded to the MDT) or, for patients with acute symptoms, referral should be made to the on-call neurosurgical team.

First fit patients with negative imaging would then be referred to a ‘First Fit’ clinic or to the general neurology or epilepsy clinic (depending on the availability of such clinics at the local hospital).

A standard protocol for imaging of first fits and patients with concerning acute and subacute neurological symptoms will be devised by the LCA Brain/CNS Pathway Group and circulated to all A&E departments.

Increased awareness

Currently, only 1% of adult brain tumours are diagnosed following fast-track GP referral for suspected cancer, according to the National Cancer Intelligence Network (2010); most present with an acute
presentation via A&E. The LCA Brain/CNS Pathway Group is collaborating with The Brain Tumour Charity to help raise awareness of brain tumour symptoms in adults for the general public and for GPs, similar to the HeadSmart campaign which was devised for the improved diagnosis of paediatric brain tumours.

**Access to imaging**

Of paramount importance is increased access to imaging by primary care and improved imaging through A&E departments. The Department of Health has recently published a paper calling for increased direct access to imaging for brain tumours by GPs.¹

2 Radiology – Guidelines for Imaging

2.1 Imaging protocols

Neuroimaging is necessary in all patients with symptoms suggestive of intracranial or spinal tumour unless deemed inappropriate on clinical grounds.

For intracranial tumours, magnetic resonance imaging (MRI) is superior to computerised tomography (CT) for tumour detection, delineation, characterisation and differentiation from non-neoplastic lesions.

CT is frequently more readily available and convenient in acute presentations. It is usually sufficient for excluding immediately life-threatening complications such as hydrocephalus, acute haemorrhage or cerebral herniation. CT may also show tumour calcification or characterise bone involvement and thus aid differential diagnosis.

For tumours of the spinal cord, MRI is necessary. CT myelography may be substituted if MRI is contraindicated. MRI is required for full assessment of tumours of the vertebral column, unless contraindicated. However, CT may give some indication of spinal canal compromise and may be useful for assessment of bony integrity and surgical planning.

Contrast medium should be used in accordance with local protocols in patients with renal impairment, history of allergy or other contraindications.

The following protocols are recommended:

2.1.1 Initial diagnosis of intracranial tumour (primary or secondary)

Patients with symptoms that may be due to an intracranial tumour should undergo MRI with a degree of urgency according to clinical need. A non-contrast examination may be sufficient unless metastatic disease is suspected, in which case the addition of contrast-enhanced scans increases sensitivity. If a tumour or other mass is demonstrated, contrast-enhanced images are necessary unless contraindicated. Diffusion weighted imaging should be acquired in all cases. It may contribute information about tumour grade and is useful in differentiation from non-neoplastic lesions such as abscess, demyelination and infarcts.

CT may be used if MRI is unavailable or contraindicated, or if CT is deemed safer in an emergency setting. Unenhanced scans should be acquired in the first instance, supplemented by post-contrast imaging if a mass is confirmed or metastatic disease is suspected.

It is acknowledged that, in accordance with local resources, CT may be considered acceptable for early diagnostic screening of patients with a low a priori likelihood of intracranial tumour (e.g. patients with headaches uncomplicated by neurological signs or symptoms). However, CT incurs a small radiation dose and offers lower sensitivity and specificity than MRI for smaller lesions and metastases. Therefore, where possible, local services should work towards replacing CT with MRI in these pathways.

In patients newly diagnosed with intracranial metastatic disease, further imaging to identify a primary site should be undertaken according to suspected primary diagnosis and clinical state, and guided by acute oncology advice.
Contrast-enhanced diagnostic MRI should be performed in all patients prior to surgery or other active treatment for intracranial tumour unless contraindicated or deemed otherwise inappropriate on clinical grounds.

CT or MRI may be used for neurosurgical navigation according to local preference and availability.

According to local availability and practice, physiological and functional techniques such as perfusion imaging, MR spectroscopy, diffusion tensor imaging (DTI), functional MRI (fMRI) and positron emission tomography (PET) are sometimes used to inform treatment stratification or to assist surgical planning.

Intracranial MRI should be supplemented by whole spine imaging if a tumour known to disseminate through cerebrospinal fluid (CSF) pathways such as a primitive neuroectodermal tumour (PNET) or germinoma is diagnosed, or if there are spinal symptoms in patients with lymphoma, glioma or cerebral metastases. For convenience, spinal imaging may be performed after intravenous (IV) contrast administration when performed in conjunction with brain imaging and should include both T1 and T2 weighted sequences.

2.1.2 Follow-up imaging for intracranial tumour

MRI with contrast-enhanced sequences is necessary unless contraindicated, in which case CT pre- and post-contrast may be substituted. Protocols may be tailored to diagnoses, for instance a limited protocol is acceptable for monitoring of meningiomas. Physiological and quantitative MRI protocols including perfusion and MR spectroscopy are sometimes incorporated in glioma follow-up protocols although local practice varies and some techniques are currently partly investigational.

Following radical resection of high-grade (WHO Grade 3 and 4) glioma, patients should undergo an initial contrast-enhanced MRI scan within 72 (ideally, 48) hours of surgery to determine the extent of resection prior to the development of reactive enhancement of the surgical cavity margins. Early post-operative scans may also be done following resection of other tumours on a case-by-case basis according to surgical findings and local practice.

Frequency of subsequent follow-up imaging should be determined according to primary diagnosis and multidisciplinary team (MDT) advice.

2.1.3 Skull base, pituitary fossa/sellar region, internal auditory canal/cerebellopontine angle, orbits

Dedicated protocols should be used including thin sections to increase anatomical resolution, and in some cases contrast-enhanced and fat-attenuated sequences to optimise lesion conspicuity.

Skull base

Imaging of skull base tumours may include fat-suppressed sequences according to local preference. CT is frequently useful to characterise bone involvement and may assist in surgical planning.

Pituitary fossa/sellar region

Imaging of the sellar region should include unenhanced T1 weighted sequences in coronal and sagittal planes, the latter to assess for the normal hyperintense appearance of the posterior pituitary lobe and integrity of the pituitary stalk. T2 weighted sequences are often also employed. Contrast-enhanced sequences may be helpful in the detection of microadenomas causing Cushing’s disease or acromegaly.
Contrast enhancement is not essential in the investigation of hyperprolactinaemia but may be performed according to local practice.

On first examination of a pituitary macroadenoma, contrast-enhanced imaging may be helpful in delineating anatomy and differentiating from mimics such as sellar meningioma.

Contrast enhancement is not usually necessary for follow-up imaging of pituitary adenomas. It is sometimes useful for surgical follow-up if post-operative anatomy is distorted or in the early post-operative period if it is necessary to differentiate residual tumour from haematoma.

CT may be helpful to demonstrate calcification in suspected craniopharyngioma. CT may also be used for diagnosis or monitoring of pituitary fossa tumours if MRI is contraindicated. A spiral technique is usually employed with multiplanar reformats.

Diabetes insipidus (DI) may be caused by lesions of the pituitary stalk or hypothalamus that are occult on unenhanced MRI. Therefore, contrast-enhanced images should always be acquired for the investigation of DI unless contraindicated. Whole head sequences should also be acquired if the differential diagnosis includes disseminated conditions such as sarcoidosis. It is often necessary to do repeated follow-up imaging if initial scans for DI are normal, as lesions such as germinoma may become symptomatic before they are detectable on imaging.

**Internal auditory canal/cerebellopontine angle**

Outpatient screening examinations for tumours of the internal auditory canal/cerebellopontine angle (IAC/CPA) are usually negative. Therefore, contrast-enhanced scans are not routinely required and heavily T2 weighted 2D or 3D sequences are sufficient for screening purposes. If a tumour is demonstrated, it should be characterised further using thin section T1 weighted sequences before and after IV contrast administration. If MRI is contraindicated, high-resolution contrast-enhanced CT may be substituted although it is inferior for detection of smaller tumours, in particular within the internal auditory canal.

Follow-up of non-operated vestibular tumours can be done using T2 weighted imaging alone. Following surgery, contrast-enhanced MRI may be necessary for proper delineation of small volume residual disease.

**Orbits**

For orbital masses, T1 weighted imaging is used to exploit the natural contrast provided by orbital fat. T2 weighted sequences and post-contrast imaging should be performed with fat suppression.

CT may be used for the diagnosis and assessment of orbital masses and associated calcification or bone involvement. It is the preferred modality in some centres but incurs a radiation dose that is avoided by using MRI.

### 2.1.4 Initial diagnosis of spinal tumour

**Spinal cord (primary or secondary)**

MRI is required for proper delineation of intrinsic tumours of the spinal cord and differentiation from mimics such as transverse myelitis or vascular malformations. Whole spine imaging should be performed including pre- and post-contrast sequences. CT myelography may be substituted if MRI is absolutely contraindicated but is less sensitive for intramedullary lesions.
Vertebral column (primary or secondary)

MRI is the preferred imaging modality and whole spine imaging should be performed. Sagittal T1 and T2 weighted sequences are usually sufficient to rule out spinal cord compression or threatened structural integrity, particularly in an acute setting. Short T1 inversion recovery (STIR) or other fat-suppressed T2 weighted imaging may be helpful to demonstrate small deposits if time and patient compliance allow. Where possible, axial images should be acquired through levels of actual or threatened neural compression or vertebral collapse. Contrast-enhanced images are not usually necessary for vertebral infiltration but should be obtained in suspected intradural disease, infection, primary tumour (of bone, nerve sheath or meninges) or where the diagnosis is unclear.

CT may be required to assess bony integrity prior to surgery and if MRI is contraindicated.

Metastatic spinal cord compression (MSCC)

Patients with a known primary diagnosis of cancer who present with spinal pain suggestive of spinal metastases should undergo MRI within a week. Imaging should be performed within 24 hours in the case of spinal pain suggestive of spinal metastases and neurological signs or symptoms suggestive of metastatic spinal cord compression (MSCC), and occasionally sooner if there is a pressing clinical need for emergency surgery (see NICE (2008) Metastatic spinal cord compression, CG75).

MRI of the whole spine should be performed unless contraindicated. Sagittal T1 and T2 weighted sequences are usually sufficient in the acute setting, supplemented by axial images through levels of neural compression. Where time and patient compliance permit, STIR or other fat-suppressed T2 weighted sequences may be helpful in detecting small metastases in disseminated disease.

If MRI is contraindicated, CT may be substituted. Spiral CT with multiplanar reformats may confirm spinal tumour and spinal canal compromise. CT may be supplemented with myelography if necessary.

If MRI is unavailable on site at the time of presentation, the decision to transfer for urgent imaging or wait until local imaging is available should be made on the basis of clinical findings and discussion with the regional MSCC service.

2.1.5 Follow-up imaging for spinal tumour

MRI is preferred for follow-up imaging of tumours of the spinal cord or vertebral column. Frequency is determined by primary diagnosis and individual patient management plan. CT may be used to follow up vertebral tumour if MRI is contraindicated. CT is also useful to assess the instrumented spine.

2.2 Referral pathways

Patients presenting as an emergency with symptoms of raised intracranial pressure, depressed conscious level, progressive neurological deficit or other pressing clinical features should undergo immediate intracranial imaging, usually CT unless MRI is immediately available and considered safe. If tumour or other life-threatening lesion such as acute hydrocephalus or abscess is suspected on imaging, the patient should be discussed urgently with the regional on-call neurosurgical service according to local protocol.

CT scanning with radiology reporting (local or remote) should be available 24/7 in any hospital admitting patients with possible intracranial tumour.
All patients with confirmed or suspected primary intracranial or spinal primary tumour should be referred to the regional brain/CNS MDT according to local protocol.

Patients with brain metastases should be referred to the brain/CNS MDT by the specialty MDT for the primary cancer site (e.g. breast, lung) where advice is required on neurosurgical intervention, stereotactic radiotherapy or other aspects of the management of brain metastases.

Suspected MSCC patients should be referred to the regional MSCC service via the MSCC coordinator according to local protocol. MSCC patients should be discussed in the regional spinal or MSCC MDT, which may be retrospective depending on the clinical urgency at the time of referral.

Image transfer via the Image Exchange Portal (IEP) to the regional neurosurgical centre should be available 24/7 to facilitate discussion of emergency patients. For non-emergency patients, IEP image transfer should be done in timely fashion to allow adequate time for preparation of regional MDT meetings.
3 Pathology – Guidelines for Reporting Tumours

3.1 Purpose of neuropathology services

- To standardise the classification and grading of tumours according to the current system of World Health Organization (WHO) classification.
- To provide adequate histological data for prognosis and planning treatment.

Standardised histological data is important in the communication between cancer centres, clinical audit and stratification of patients in clinical trials.

The diagnosis of brain tumours has to be conducted by a medically qualified consultant neuropathologist according to the National Institute for Health and Care Excellence (NICE) improving outcomes guidelines. The guidelines define neuropathologists as accredited pathologists, registered as neuropathologists, or histopathologists with specialist expertise in neuro-oncology who take part in the national external quality assurance (EQA) scheme of neuropathology, organised by British Neuropathological Society.

3.2 Required neuropathological services

3.2.1 Intra-operative diagnosis (frozen sections and smear preparations)

The intra-operative diagnosis shows a good prediction of final histology. Although there is increasing benefit from current imaging techniques, the intra-operative diagnosis is a well-established procedure and valued by neurosurgeons to give an indication of the presence of diagnostic material, type of tumour and possible grading. It can also be used to guide intra-operative adjuvant therapy in placement of local chemotherapy wafer. Therefore, it is recommended by NICE to be available in neurosurgical centres. The intra-operative diagnosis should be taken as provisional assessment but the final diagnosis, treatment and planning and patient counselling should be based on the final record of paraffin histology.

3.2.2 Pathological specimen

Fresh specimen is necessary in cases where intra-operative diagnosis is needed or a specific molecular or genetic analysis is recommended. However, most specimens are recommended to be received in fixative (usually 10% neutral peppered formalin) and should be in an adequately sized specimen pot.

3.2.3 Clinical information

Clinical information is required on the specimen request form submitted by neurosurgeons or clinicians and also recorded in the pathology report. Adequate clinical history is essential to ensure proper interpretation of histological findings. Clinical information should include type of specimen-procedure, previous diagnosis biopsy and therapy including radiotherapy, radiosurgical intervention, chemotherapy and others, site of tumour and neuroradiological findings, and duration and nature of symptoms. Different containers should be used if multiple specimens from different areas are taken.

3.2.4 Macroscopic examination of the specimen

Estimate of tumour size in three dimensions or volume of tumour tissue (if submitted piecemeal) or provided tumour weight should be undertaken.
3.2.5 Microscopic examination and histological classification

Central nervous system tumours are classified and graded according to the WHO grading system (currently 2007) but updated criteria should be followed if further WHO classification becomes available in the future. The scheme is used in all neuropathology centres in the UK and its classification and grading scheme of brain tumours is endorsed by the British Neuropathological Society and its national EQA scheme. It is also widely used internationally, allowing comparison of data from European, North American and other centres. Haematoxylin and eosin stained sections remain the cornerstone of histological evaluation but should be further supplemented by immunohistochemical stains, the use of which, in general, aids the classification. The use of immunohistochemistry should be subject to appropriate internal and external quality control. This should involve the use of appropriate controls and the laboratory should be participating in UK National External Quality Assessment Service for Immunocytochemistry (NEQAS-ICC).

Lymphomas may be presented as central nervous system disease and occur as primary tumour. Guidelines on lymphoma reporting are available in the Royal College of Pathologists’ database for pathologists reporting on lymphoma.\(^1\)

Pituitary tumours are now classified according to sub-type based on hormone production with tumour cells. This is generally determined by immunohistochemistry to conventional adenohypophyseal hormones including adrenocorticotropic hormone (ACTH), luteinising hormone (LH), follicle-stimulating hormone (FSH), alpha subunit, thyroid-stimulating hormone (TSH), prolactin and growth hormone. Ki-67 should also be added to further characterise pituitary adenomas. In some cases, electron microscopy may contribute to the diagnosis.

It is recommended that the report includes sections on the description of the pathological features of tumour, in addition to sections of comment and then final conclusion and diagnosis. The latter should include the tumour type, tumour sub-type relevant to grading and prognosis, tumour grade (WHO 2007) and, for extra-axial tumours (particularly meningiomas), presence of brain invasion.

3.2.6 Molecular and genetic markers

These markers have become important and improve understanding and pathogenesis of brain tumours. They have contributed towards classification of brain tumour, predicting prognosis and assisting in treatment and management. The following are the recommended markers to be used in neurosurgical centres. This list will certainly expand in the near future as more markers become available.

- **Co-deletion of chromosome arms 1p/19q.** This is important in classifications of oligodendrogliomas and other gliomas and can be assessed by fluorescent in-situ hybridisation (FISH), the polymerase chain reaction based method for loss of heterogeneity or other methods (such as MLPA). A large number of studies have suggested that loss of these chromosomal arms predict a better prognosis and better response to chemotherapy and radiotherapy, suggesting that this is both a prognostic and predictive factor. Testing for 1p/19q has become widely available and is the standard test for care of histological analysis in brain tumours.

- **06 methylguanin-DNA methyltransferase (MGMT).** This is a DNA repair enzyme which can repair the damage induced by chemotherapeutic alkylating agents leading to chemo-resistance. Epigenetic silencing of the MGMT gene by promoter methylation plays an important role in regulating MGMT expression in gliomas. MGMT promoter methylation has shown value as a predictive marker for temozolomide sensitivity and correlates with better progression-free and overall survival in glioblastomas and anaplastic gliomas. Assessment of the percentage of methylation of MGMT is...
recommended by pyrosequencing or other method. Immunohistochemical evaluation of MGMT should be also be done as a complementary test and discrepancies between methylation-sensitive PCR and immunostain should be noted in the report.

- **Mutation of isocitrate dehydrogenase 1 gene (IDH1 and the related IDH2).** These gene mutations are found in clinically and genetically distinct sub-types of gliomas, particularly astrocytoma and oligodendroglioma of WHO Grade 2 and 3 and in secondary glioblastomas which evolved from lower-grade tumours. Patients with mutation in these genes have a better outcome than those without mutation. Assessment of IDH1 mutation is very reliable with the immunohistochemistry method which should be available in all participating centres. Further tests for IDH1 and IDH2 gene sequencing are recommended in glioma Grade 2 and 3 in which the IDH1 immunohistochemistry is negative.

- **KI1549-BRAF fusion gene.** This gene occurs in over 70% of pilocytic astrocytomas and is emerging as an important diagnostic marker and therapeutic target. This is easily identified by interface FISH but can also be demonstrated in DNA from frozen tumour tissue. The identification of these genetic aberrations may help to differentiate other tumour forms from pilocytic astrocytoma in difficult cases which have significant implications for the prognosis and treatment of patients.

Molecular analysis should be carried out in laboratories participating in appropriate EQA schemes. A pilot EQA for brain tumour molecular markers is now available in the UK.

Further molecular markers are predicted to be available in the future, and neuropathological centres should follow and update their procedures accordingly.

### 3.2.7 Turn-around times

The turn-around times for diagnosing brain tumours and providing results for immunohistochemistry and molecular markers should be agreed in each centre between neuropathologists, neurosurgeons and neuro-oncologists. The following is the Royal College of Pathologists’ recommendation:

- Reporting central nervous system tumours (brain biopsies, surgical): 5 days (2 days if no special stains are required)
- Pituitary biopsies: 4 days
- Epilepsy surgery: 15 days
- 1p/19q co-deletion: 15–20 days
- MGMT methylation and BRAF-600 mutation: 10 days.

### 3.2.8 Multidisciplinary team meetings

Cases from brain tumours are recommended to be discussed in the context of multidisciplinary team (MDT) meetings which are regarded in NICE guidelines as central to patient management. This forum should allow for reviews of biopsies with clinical and neuroradiological information. This may be of particular value in the assessment of small biopsies to ensure that the tissue is likely to be representative of the lesion. The clinical, surgical, pathological and radiological findings can be compared and integrated for clinical management purposes. In some cases, the final neuropathological report may need to be revised to interpret the histological findings in the light of additional information. This may be useful in situations where difficulties are encountered in finally categorising patients. In practice, assessment of borderline tumours for prognostic and therapeutic purposes may be aided by discussion in MDT meetings where
additional clinical and radiological factors such as patient’s age, tumour size, presence of contrast enhancement, and rate of growth on serial scans provide additional information.

3.3 Provisional agreement between neuropathological centres for south and west London

Discussion has been conducted by the three neuropathological centres at King’s College Hospital, St George’s Hospital and Charing Cross Hospital regarding provision of neuropathology services for brain tumours across the LCA. The following are points of agreement:

- The centres agreed that neuropathology services should follow and be co-located with the neurosurgical services. This is important to provide intra-operative diagnosis, close discussion with the neurosurgeons, neuroradiologists and neuro-oncologists and to conduct critical discussion in MDT meetings. For these reasons it was felt that maintaining neuropathological services in each individual centre is essential. It was recommend that each Trust should support neuropathology services and provide sufficient cover for neuropathologists to provide the recommended neuropathology services.

- The centres agreed to suggest a scheme of audit across all centres to ensure that the standard criteria for neuropathological assessment are followed.

- The centres agreed that clinical research activities should be conducted across all centres in combination with activities of neurosurgery, neuro-oncology and neuroradiology.

- The centres recommended that further funding and support should be targeted towards developing state-of-the-art molecular biology services, as with other international centres, for the importance of this subject in the current and future practices in classification, prognosis and directing of treatment of brain tumours. It was recommended that the molecular biology services be integrated with the neuropathology services.

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4 Multidisciplinary Team Membership and Function

All adult patients with suspected primary brain and spinal tumours should be referred to the neurosurgical multidisciplinary team (NS MDT) for discussion. The brain/CNS MDT should meet weekly.

Patients will be reviewed at the NS MDT meeting at the following points in the patient pathway:

- post-initial radiological diagnosis, pre-histological confirmation
- post-histological confirmation and/or post-definitive surgical procedure.

All patients with recurrent tumours managed by a neuro-oncology service will be reviewed at the NS MDT. Brain metastases will be discussed at the NS MDT only if a surgical or radiosurgical opinion is required.

There is a single named lead clinician for the MDT, who is a core team member and has responsibilities agreed by the lead clinician of the host Trust. The lead clinician is responsible for chairing the weekly meeting or agreeing a rotating chair.

The MDT meets on a weekly basis (as a minimum) and discusses all patients with suspected brain and CNS tumours who are formally referred via the neuro-oncology MDT coordinator.

The core members of the Brain and CNS MDT include:

- two neurosurgeons
- a neuroradiologist
- two neuropathologists (Note: For the purpose of peer review, the neuropathologist is defined at minimum as a consultant pathologist who is taking part in the external quality assurance (EQA) scheme for neuropathology, organised by the British Neuropathological Society, or, for a pathologist acting only as the pituitary tumour pathologist for a team, an EQA scheme for endocrine pathology)
- a clinical oncologist
- a neurologist with specified Direct Clinical Care PAs for the care of patients with the neurological consequences of a CNS tumour and of its treatment
- a clinical nurse specialist
- a clinical neuropsychologist
- a healthcare professional who is a core member of a specialist palliative care team
- an allied health professional who is agreed to have responsibility for liaison with neuro-rehabilitation services
- a therapeutic radiographer
- the team may choose to have specific allied health profession (AHP) representatives and liaise with only one or some of the AHP subspecialties
- an MDT coordinator/secretary.

Within the MDT there is a nominated member responsible for users’ and carers’ issues and information, and a nominated member responsible for ensuring that recruitment into clinical trials and other well-designed studies is integrated into the function of the MDT.

All patients who are discussed must have recent, relevant imaging. Patients who have suspected metastatic disease from an unknown primary or an established diagnosis of cancer with new suspected metastatic disease should undergo a computerised tomography (CT) scan of their chest, abdomen and pelvis to assess the extent of disease. Details of other staging investigations that have been undertaken should be supplied to the MDT to assist in appropriate treatment planning.

The MDT should provide specialist neuroradiology advice on patients with suspected brain/CNS tumours but should not be used to provide specialist neuroradiology reporting.

During the meeting, the pathology for every patient who has undergone surgery should be discussed. In some cases, additional molecular testing may be requested and should be brought back to a subsequent meeting for discussion once the result has been formally agreed.

Clinicians will consider the potential entry of each patient into a trial.

The MDT is also an important forum in which to establish the specific needs of a patient. These needs include input from hospital or community palliative care, inpatient therapies, formal cognitive assessment and management, ongoing rehabilitation needs and community therapies. It is also an opportunity to identify psychological, social and spiritual needs which need ongoing management through the network MDT.

An agreed minimum dataset should be formally recorded during the MDT to reflect clinical workload, accurate patient numbers and a breakdown of tumour types.

It is the responsibility of the referrer to communicate the outcome of the MDT to the patient and their GP within 24 hours of the discussion and to ensure that a formal ongoing referral is instigated as instructed by the MDT.

It is good practice for patients who require surgical intervention to be seen in an MDT clinic to discuss the outcome of the meeting, to review scans and agree a treatment plan.

Patients who are not suitable for surgery but may benefit from oncological management should be discussed with the oncologist and booked into the next available clinic.

The suitability of different radiotherapy modalities (e.g. 3D, intensity-modulated radiotherapy (IMRT), helical modalities, stereotactic radiosurgery/stereotactic radiotherapy (SRS/SRT), protons) and proximity to critical structures should be discussed so that dose and fractionation considerations can be planned for within the radiotherapy service. The imaging reviewed at the MDT should also be evaluated to consider whether this can be incorporated into the radiotherapy planning (fusion) or whether an additional imaging referral is required.

An evaluation is required of patient-specific considerations, disease-specific considerations and treatment modality options. This is the role of the neuro-oncology consultant radiographer/advanced practitioner so that all referrals to radiotherapy modalities are dealt with in a timely manner to ensure a seamless pathway.

All members of the team who have contact with patients at this point in the pathway should have formal training in advanced communication skills.
5 Inter-professional Communication between Secondary and Primary Care

5.1 General principles

Communication needs to be timely and concise.

Use fax-back route/electronic means for urgent communications (meaning those that need to be with the GP within 24 hours) and follow up with a call to confirm receipt.

Communications at key points along the patient journey must include:

- what the patient has been told
- who told the patient
- who was there with the patient (e.g. named partner/friend)
- what written/other information was offered
- next steps – when the patient is being seen or their treatment started
- actions for the GP – for information only or suggesting specific GP actions (including information for Macmillan or district nursing colleagues)
- named key worker in secondary/tertiary care and any planned changes in key worker
- intent of treatment (curative/palliative)
- any additional information required from the GP (e.g. co-morbidities status)
- summary of medication and alterations to medication
- contact details for further information/discussion
- specialist assessment and intervention summary (e.g. allied health profession input)
- treatment plan summary when created and when amended
- written correspondence to be copied to all appropriate team members who have actions to be undertaken.

5.2 Key communication points

- Diagnosis
- Multidisciplinary team (MDT) discussions
- Clinic appointment reviews
- On treatment reviews
- Decision points for changes in care planning
- Decision point for end of life care planning.

The LCA Survivorship Group has recommended the adoption of the National Cancer Survivorship Initiative (NCSI) Treatment Summary. A copy of this document can be found at Appendix 2.
It is recommended that all LCA providers refer to *Improving Outcomes: A Strategy for Cancer. Third Annual Report* (Department of Health, 2013) for details about the MDT set-up.
6 Neuro-oncology Clinical Nurse Specialist/Key Worker

The LCA has produced a key worker policy document which should be read in conjunction with this guidance. This document can be found at Appendix 3. A list of competencies for the key worker role can be found at Appendix 4.

All patients seen within the LCA with a diagnosis of a brain or spinal tumour will be given the name and contact details of a key worker. It is the responsibility of this key worker to refer on to a new key worker when:

- a patient’s care and follow-up is taken over by another hospital
- a patient’s care is handed over to a community or hospital palliative care team.

All neurosurgical and cancer centres should have one or more trained neuro-oncology cancer clinical nurse specialists to see patients before and after diagnosis, to provide continuing support, and to facilitate communication between the secondary and tertiary care teams (including the MDT), the patient’s GP, the community team and the patient. Patients may have joint key workers (one in the treating Trust and one in the community).

All patients newly diagnosed with brain and spinal tumours should have access to a neuro-oncology clinical nurse specialist who may act as the main key worker.

The neuro-oncology clinical nurse specialist is involved in all aspects of the disease journey, from diagnosis to end of life care, in both out- and inpatient settings. The clinical nurse specialist has a pivotal role in the MDT, ensuring that appropriate professionals are involved and working across boundaries in an effort to provide seamless care and support for patients and carers.

The neuro-oncology clinical nurse specialist will play a key role in the following aspects of care:

- the delivery of holistic care
- coordination of care across sectors
- onward referrals to appropriate allied health professions and local services
- nurse-led outpatient care
- information giving
- holistic needs assessment
- communicating significant news
- pain control and symptom management in close collaboration with palliative care
- carer support and assessment
- referral for benefits and financial advice
- end of life choices.
7 Therapeutic Radiographer

The transition points between primary, secondary and tertiary care, including radiotherapy, are recognised as impeding continuity and are particular areas of concern. Improving Outcomes: A Strategy for Cancer states that the emphasis needs to be placed on patient-centred care carried out by appropriate highly skilled teams. Radiotherapy requires highly specialist staff, including clinical oncologists, therapeutic radiographers, medical physicists, medical scientists and technicians.

It is recommended that therapeutic radiographers are present in Trusts to enhance patient care. This is the only profession to specialise in radiotherapy from initial training and is therefore best positioned to provide care from referral to follow-up within the radiotherapy pathway. It is recommended that all Trusts consider employing neuro-oncology consultant therapeutic radiographers/advanced practitioners that have a specialist understanding of the planning principles and the radiotherapy treatment modalities and are therefore able to incorporate their clinical knowledge and skills into considering and evaluating disease management issues.

The skills mix report published by the Department of Health identified the advanced and consultant tiers of the skills mix model as reflecting “the requirements of clinical governance in respect of their contribution to the continuous improvement of the service”. The Report from the National Radiotherapy Advisory Group made recommendations for commissioners and service employers to fund implementation of advanced and consultant-level posts because “where these roles have been introduced they have demonstrated the potential to drive efficiency, reduce waiting times and refocus radiotherapy services around the needs of patients”.

The neuro-oncology consultant therapeutic radiographer/advanced practitioner strategically manages the patient pathway from referral to post-radiotherapy and long-term follow-up, and refines the patient pathway according to both service provision and patient needs. The neuro-oncology patient’s management plan within radiotherapy is often complex. Therapeutic radiographers have a unique role in supporting patients throughout the journey. However, radiotherapy appointments are often short and under time restraints; site-specific dedicated therapeutic radiographers are therefore important to ensure that the needs of the patients are met and that service aims of individualised care are achieved.

The expectation is that the neuro-oncology consultant/advanced practitioner role would nominally comprise 50% clinical work as well as work on research and development, audit, the education and training of others, and policy and practice development. The practitioner performs an important and integral part in the case management, providing an expert service for individual patients and ensuring a seamless service, with continuity throughout the active treatment period.

Therapeutic radiographers working at consultant and advanced practitioner level provide:

- an ‘expert practice’ function, delivering technical and cancer-site-specific expert knowledge
- professional leadership and consultancy
- an education and training role
- development of the practice and the service
- research and evaluation.
The role crosses traditional boundaries and improves the quality of patient care. It brings “strategic direction, innovation and influence through practice, research and education, based on specialised knowledge and skills”.

Other sources of information include:


Society of Radiographers (2008), *Learning and Development Framework for Clinical Imaging and Oncology*.


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4 The Royal College of Radiologists/The Society and College of Radiographers/The Institute of Physics and Engineering in Medicine, *Commissioning arrangements for radiotherapy: A response*. York/London: RCR/SCOR/IPEM.


8 Patient Information

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

Information must be given in the most accessible format based on the patient’s cognitive/communication needs. If there is concern about the patient’s cognition, there should be close liaison with allied health professions, such as the occupational therapist, to facilitate a formal cognitive assessment. Speech and language therapists should be involved to assist patients with cognitive and communication difficulties. If a patient demonstrates cognitive impairment which may affect their capacity to understand and process the information that is to be given, then the person responsible for giving that information should refer to the Mental Capacity Act 2005.

Information may need to be sourced in the patient’s native language if English is not their first language and delivered using the intervention of a translator. In some cases (with the exception of the communication of bad news), Language Line may represent a useful tool and is widely available within NHS Trusts. Audio and videotaped formats will also be considered.

Information to be given to the patient and families/carers should cover:

- description of the disease
- management of the disease
- diagnostic procedures
- treatment options and their effects (including potential adverse effects)
- predicted outcome – any discussion of this with patients should take account of their requirements and requests
- drugs and other treatments
- self-management and care
- dietary and nutrition information
- contact details of the patient’s allocated key worker
- support organisations or internet resources recommended by the clinical team.

The National Cancer Action Team introduced information prescriptions (IPs) across the country to provide standardised, personalised information for patients and their carers. This is a national resource accessed via the NHS Choices website (although this initiative is not available for all rare brain and spinal tumours). In those Trusts across the LCA which have access to IPs, this should be considered the written information of choice. Individual Trusts will use leaflets when giving information for local procedures. Patients with brain and spinal tumours should be provided with or signposted to local sources of support and written information from appropriate brain and spinal tumour or cancer charities such as The Brain Tumour Charity or Macmillan Cancer Support where IPs are not available.
9 Surgical Guidelines

9.1 Guidelines for low-grade glioma


9.1.1 Background

Low-grade gliomas (LGGs) represent up to 30% of gliomas and affect patients at a younger age than high-grade gliomas. LGGs are commonly located in or close to eloquent areas, i.e. those areas of the brain involved in motor, language, visuospatial and memory function.

The 5-year overall and progression-free survival rates in randomised studies range from 58% to 72% and 37% to 55%, respectively.

Patients with LGGs may survive for up to 20 years, but these tumours grow continuously and tend to progress to a higher grade, leading to neurological disability and ultimately to death.

9.1.2 Clinical features

Seizures are the most common presentation and may be partial or generalised. They occur in over 90% of patients and are intractable in 50%. Seizures are more frequently associated with cortically based tumours, particularly in frontal, temporal and insular/parainsular locations.

There is no clear association between severity of epilepsy and the behaviour of the tumour. Focal neurological deficits are unusual, developing over many years.

Raised intracranial pressure is rare in patients with supratentorial tumours and is typically seen in posterior fossa and intraventricular tumours. Intratumoural haemorrhage can occur.

9.1.3 Diagnostic pathway

Imaging

- Diagnosis and staging includes imaging of the brain, ideally with conventional magnetic resonance (MRI) including contrast enhancement.

Multimodal advanced imaging can be used to augment conventional MRI in specific circumstances:

- guidance of stereotactic biopsy to the most aggressive regions of large lesions, especially those with little or no contrast enhancement

- treatment stratification in mass lesions of uncertain pre-surgical nature or grade
  - in selected cases, functional MRI (fMRI, using motor and language tasks) and diffusion tensor MRI may be used to assess the relation of tumour to and invasion of functionally eloquent cortex and white matter tracts; these can be fused with structural datasets for neurosurgery planning and intra-operative neuronavigation to guide resection
  - planning radiotherapy and monitoring treatment response.
9.1.4 Treatment pathway

Anti-epileptic therapy

- Patients with no history of seizures have no benefit from anti-epileptic drugs (AEDs).
- In patients with single seizures, immediate treatment with AEDs increases time to recurrent seizures compared with delayed treatment, without differences with respect to quality of life or serious complications.
- AEDs should be individualised according to seizure type, co-medication, co-morbidity and patient preferences.
- In patients who need treatment with chemotherapeutics, non-enzyme inducing anti-epileptic drugs are to be preferred.

9.1.5 Multidisciplinary team discussion

- Patients are evaluated by a specialised multidisciplinary team (MDT) in the neurosciences brain/CNS MDT meeting.
- Special consideration is given to performance status and neurological function.

9.1.6 Surgery for newly diagnosed patients with suspected low-grade glioma

- Surgery can provide tissue for distinguishing between the histological types, grading the malignancy and assessing the molecular status of tumours using advanced molecular diagnostic profiling.
- Total resection improves seizure control, particularly in patients with a long epileptic history and insular tumours.
- The use of brain mapping techniques, including awake surgery, should be available as an adjunct to conventional surgery to maximise safe resection.
- The use of visualisation technologies, including modern neuronavigation systems utilising advanced image guidance, can improve the accuracy and extent of resection.
- The extent of resection and determination of residual disease should be assessed using post-operative MRI within 72 hours after surgery.
- When resective surgery is not feasible (because of tumour location, extension or co-morbidities), a biopsy (either stereotactic or open) should be considered to obtain a histological diagnosis.
- Awake surgery has increased the safety of re-operation owing to mechanisms of brain plasticity.
- The timing of surgery is controversial in patients who are young, present with an isolated seizure (medically well controlled) and with small tumours.

Recurrent tumours

Patients with tumour recurrence should be discussed at the MDT and consideration be given to further surgical intervention and second-line therapy.

9.2 Guidelines for high-grade glioma

These guidelines are based on Stupp et al. on behalf of the ESMO Guidelines Working Group (2010), ESMO Clinical Practice Guidelines, Annals of Oncology 21 (Supplement 5): v190–v193.
9.2.1 Diagnostic pathway

Imaging

Diagnosis and staging includes imaging of the brain, ideally with conventional MRI including contrast enhancement.

Multimodal advanced imaging can be used to augment conventional MRI in specific circumstances:

- guidance of stereotactic biopsy to the most aggressive regions of large lesions, especially those with little or no contrast enhancement
- treatment stratification in mass lesions of uncertain pre-surgical nature or grade
- in selected cases, functional MRI (fMRI, using motor and language tasks) and diffusion tensor MRI may be used to assess the relation of tumour to and invasion of functionally eloquent cortex and white matter tracts; these can be fused with structural datasets for neurosurgery planning and intra-operative neuronavigation to guide resection
- planning radiotherapy and monitoring treatment response.

9.2.2 Initial treatment pathway: concurrent medication

Corticosteroids

- High doses of corticosteroids (usually dexamethasone 8–16mg/day) allow rapid reduction of tumour-associated oedema and improve clinical symptoms; corticosteroid dose can be tapered according to individual needs. The patient’s glucose levels must be monitored.
- Steroids are not necessary in patients without increased intracranial pressure and absence of neurological deficits.
- There is no routine need for prolonged steroid therapy after tumour resection or prophylaxis during radiotherapy but patients should be assessed on an individual basis according to needs.

Anti-epileptic therapy

- Anti-epileptic therapy is indicated in patients presenting with an initial seizure; however, prophylactic anti-epileptic therapy before or after surgery is not routinely needed.
- After tumour resection, the indication for anti-seizure therapy should be revisited.
- First-generation AEDs (phenytoin, carbamazepine, phenobarbital and their derivatives) are strong inducers of the hepatic metabolism, and may interfere with medications including many commonly used chemotherapy agents (but not with temozolomide). Third-generation agents such as lamotrigine, levetiracetam or pregabalin are preferred.

9.2.3 Co-morbidities

- Patients undergoing neurosurgery need to fulfil general fitness and anaesthetic criteria.
- Any metabolic, haematological (particularly platelet) and clotting abnormalities should be corrected.
- Anti-platelet drugs (e.g. aspirin, clopidogrel and dipyridamole) should be stopped at an appropriate time before surgery except in high-risk cases (if in doubt discuss condition with cardiologist/haematologist).
- Anti-coagulants such as warfarin should be stopped except in high-risk patients such as those with intracardiac thrombus, metallic heart valve or a pulmonary thrombus in the previous 6 months. In such high-risk patients warfarin should be substituted for a suitable alternative as per local haematological advice.

### 9.2.4 Multidisciplinary team discussion
- Patients are evaluated by a specialised MDT in the neurosciences brain/CNS MDT meeting.
- Special consideration is given to performance status and neurological function.

### 9.2.5 Surgery for newly diagnosed patients with suspected high-grade glioma
- Surgery is commonly the initial therapeutic approach for tumour excision and obtaining tissue for diagnosis, including the use of advanced molecular diagnostics.
- Tumour resection is of prognostic value; it is beneficial to attempt maximal tumour resection provided that neurological function is not compromised by the extent of resection.
- The use of brain mapping techniques, including awake surgery, should be available as an adjunct to conventional surgery to maximise safe resection.
- The use of visualisation technologies, including modern neuronavigation systems utilising advanced image guidance, can improve the accuracy and extent of resection. This can be further augmented with the use of field visualisation techniques such as blue light fluorescence with or without the administration of agents that increase tumour fluorophores such as porphyrins with 5-aminolevulinic acid (S-ALA).
- When microsurgical resection is not safely feasible (e.g. due to location of the tumour or impaired clinical condition of the patient), a stereotactic biopsy can be considered to guide further treatment.
- The extent of resection and determination of residual disease should be assessed using post-operative MRI within 72 hours after surgery.
- Implantation of chemotherapy-impregnated wafers (carmustine polymers, Gliadel) into the resection cavity before radiotherapy has been shown to marginally improve median survival compared with radiotherapy alone in patients who have radical tumour resection. However, subgroup analysis did not show significant benefit for patients with glioblastoma.
- The suitability for Gliadel wafer insertion should be discussed in the brain/CNS MDT. They are now approved for use by NICE (TA121; [www.nice.org.uk/TA121](http://www.nice.org.uk/TA121)) for selected patients provided the following criteria are satisfied:
  - pre-operative MRI suggestive of high-grade glioma
  - the case is discussed before surgery in a neuro-oncology MDT meeting
  - surgery is performed by a specialist neuro-oncology surgeon
  - the surgeon is able to remove more than 90% of the tumour
  - the pathologist confirms that the tumour is high-grade glioma during surgery
  - the ventricle (fluid space) in the brain is not widely opened.

### Recurrent tumours
Patients with tumour recurrence should be discussed at the MDT and consideration be given to further surgical intervention and second-line therapy.
10 Radiotherapy – Generic

10.1 Basic principles

In view of the varied types of tumours within the skull, the radiation treatment regimens vary. Nevertheless, the basic principles – delivering a tumoricidal dose of radiation to the tumour and limiting the dose to the normal, unaffected surrounding structures – are of paramount importance. This means that immobilisation, whether by thermoplastic mask or another fixation device, is used to keep the patient’s head steady during treatment. Cross-sectional imaging computerised tomography (CT), magnetic resonance imaging (MRI) and, occasionally, positron emission tomography (PET) are important in radiotherapy planning. In some cases, two or more co-registered imaging modalities are required for optimum delineation of the tumour. For the more common intrinsic brain tumours, treatment is given in several fractions – typically 25–33 fractions over approximately 6 weeks.

Some tumours and indeed benign lesions, for example arising from the skull base and pituitary region, or some intra-cerebral tumours that are particularly resistant to conventionally fractionated radiotherapy, may require stereotactic radiosurgery (SRS) or stereotactic radiotherapy (SRT). The term SRS is normally reserved for single fraction treatment and SRT for a fractionated treatment – usually between 2 and 5 treatment fractions.

Stereotactic treatments, by virtue of their high individual fraction size, have to be delivered very accurately. In principle there is little difference whether the radiation is delivered by Gamma Knife or CyberKnife or indeed a linear accelerator-based system. There is, however, some difference in the intra-lesion dose and the dose-rate delivered.

There may be a role for proton therapy in patients with clival chordomas and chondrosarcomas. Suitable patients may be referred to the proton panel. At the moment a clinical oncologist must make this referral. Prior to commencing any radiotherapy, the patient should be provided with information on the need for this type of treatment along with the risks and benefits, and informed written consent should be obtained.

Any patient eligible for a National Cancer Research Network, European Organisation for Research and Treatment of Cancer (EORTC) or locally approved clinical trial should be offered the chance to participate.

At this stage, the clinical nurse specialist should ensure that the support required for the patient and family has been assessed and the patient is given the name and contact number of the key worker.

The patient’s signs and symptoms are determined by the size and location of primary tumour within the central nervous system (CNS), and have been discussed in the early diagnosis section (see Chapter 1). In some patients when there may be a need for assessment of vision, the following should be recorded: visual acuity, formal visual field, colour vision and an assessment of the optic disc (either clinically, photographically or by OCT).

10.2 Radiotherapy planning

Radiotherapy departments will have different hardware (linear accelerators), each requiring its associated software. For this reason, local planning systems should be used.
10.2.1 Position and immobilisation

- The standard treatment position is supine with the head immobilised in a thermoplastic shell. The use of head tilt angle may be discussed with the pre-treatment radiographer, dosimetrist or mould room staff to ensure the optimum position for planning.

- When appropriate, the MRI scan should be accurately fused with the CT scan.

- These co-registered images will aid the delineation of the tumour and organs at risk. The MRI should have as a minimum T1 preferably with contrast, T2 and FLAIR sequences. Diffusion weighted images are sometimes helpful.

- Most tumours are dealt with by 6–10MV photons.

- Each department should be cognisant with ISO 9000 RT guidelines.

- Craniospinal radiotherapy should be delivered preferably with a rotational or helical means, thereby avoiding the need for matched spinal fields.

10.2.2 CT planning scan

The CT scan should be performed with the patient’s head in the appropriate position. The scan should be done with 3mm slices from vertex to angle of mandible or to the C3 vertebral body if matched spinal fields are to be applied.

Intravenous (IV) contrast is not necessary except where MRI co-registration is not possible. This will be clearly indicated on the radiotherapy request form.

Target definition

See site-specific sections.

10.2.3 Tolerances/organs at risk

See QUANTEC (Quantitative Analysis of Normal Tissue Effects in the Clinic). As a rough guide, the tolerances given below relate to a point max/0.3cc volume unless otherwise specified and the dose to these structures will be displayed on a dose volume histogram:

- Lens <7Gy
- Lacrimal glands <20Gy (mean) will be outlined by clinician if appropriate
- Optic nerves <50Gy–54Gy
- Optic chiasm <55Gy
- Spinal cord <50 Gy (0.2% risk; 60Gy – 6% risk)
- Brainstem <54Gy
- Pituitary <50Gy to 54Gy
- Vestibulo-cochlear apparatus <45Gy less after cisplatin chemotherapy

Calculation of equivalent biological equivalent doses (BEDs) will be performed when doses higher than 2Gy/# are prescribed. Any member of the clinical team may order thermoluminescence dosimetry (TLD) or diode measurements to record the actual lens dose if required.
10.2.4 Field arrangement

Fields should be angled to avoid organs at risk. Segmented fields may be used to provide dose compensation as required. Non co-planar beam arrangements may also help to avoid organs at risk, but beware of exit doses through the mouth, parotids or lens.

Consider intensity-modulated radiotherapy (IMRT) for lower-grade tumours close to critical structures.

Consider tomotherapy for patients requiring whole CNS radiotherapy.

Table 10.1: Dose fractionation

<table>
<thead>
<tr>
<th>Site</th>
<th>Dose (Gy)</th>
<th>Fractions (#s)</th>
<th>Duration</th>
<th>RCR evidence level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Glioma – radical</td>
<td>40</td>
<td>15</td>
<td>5 times/week</td>
<td>*</td>
</tr>
<tr>
<td></td>
<td>45</td>
<td>20</td>
<td></td>
<td>–</td>
</tr>
<tr>
<td></td>
<td>55–60</td>
<td>30–33</td>
<td></td>
<td>A</td>
</tr>
<tr>
<td>Glioma – palliative</td>
<td>40</td>
<td>15</td>
<td>5 times/week</td>
<td>C</td>
</tr>
<tr>
<td></td>
<td>30</td>
<td>6</td>
<td>2 to 3 weekly</td>
<td></td>
</tr>
<tr>
<td>Pituitary (standard)</td>
<td>45–54</td>
<td>25–33</td>
<td>5 times/week</td>
<td>C</td>
</tr>
<tr>
<td>(if indicated)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cranio-pharyngioma</td>
<td>50–54</td>
<td>25–33</td>
<td>5 times/week</td>
<td>A</td>
</tr>
<tr>
<td>Meningioma WHO 1</td>
<td>50–54</td>
<td>30–33</td>
<td>5 times/week</td>
<td>A</td>
</tr>
<tr>
<td>Malignant meningioma</td>
<td>54–60</td>
<td>30</td>
<td>5 times/week</td>
<td>–</td>
</tr>
<tr>
<td>Whole CNS</td>
<td>35–40</td>
<td>20–23</td>
<td>28–29 days</td>
<td>see PNET</td>
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<tr>
<td>Involved fields boost</td>
<td>+ 15 to 20</td>
<td>9 to 12</td>
<td>11–14 days</td>
<td>–</td>
</tr>
<tr>
<td>Spinal tumours</td>
<td>45–54</td>
<td>28–33</td>
<td>5 times/week</td>
<td>–</td>
</tr>
</tbody>
</table>

Note: Depending on the location and size of the tumour, 1.67Gy, 1.8Gy or 2Gy per fraction may be selected as the most appropriate dose fractionation.

Verification

When appropriate, the local portal imaging protocol should be used.

10.3 Patient management during radiotherapy

10.3.1 On-treatment review

All patients, except those undergoing pituitary radiotherapy, ideally should be seen weekly during their radiotherapy treatment by the clinical nurse specialist, treatment review radiographer or clinician. Pituitary
patients may be seen once at the end of treatment if they have no other concerns during their course of treatment.

During the on-treatment review the following should be checked: appropriate clinical assessment, blood tests if indicated and review of medication. Weekly full blood counts (FBCs), liver function tests (LFTs) and urea and electrolytes (U&Es) are required for patients having concomitant temozolomide.

### 10.3.2 Treatment interruptions

Patients with medulloblastoma (primitive neuroectodermal tumour – PNET) are classed as Category 1 and should therefore have all treatment interruptions accounted for. All other CNS patients being treated with palliative intent are classed as Category 2 and should ideally have no more than two treatment interruptions.

### 10.3.3 Patient follow-up

Patients are seen between 4 and 6 weeks after completing their radiotherapy.

Those patients undergoing adjuvant chemotherapy will be seen after 4 weeks, preferably with an up-to-date MRI scan.

High-grade glioma patients are scanned every 3 months for the first year.

Low-grade glioma patients are scanned every 3 to 6 months for the first year.

The scan intervals are usually increased in subsequent years depending on the patient’s status.

### 10.3.4 Clinical audit and quality review meeting

Regular audit and review of incident reports and variance forms should be undertaken and is presented in the quality review meeting. This is done in accordance with local guidelines.
11 Chemotherapy – Generic

Valid consent and initiation of treatment (1st cycle) ideally should be performed by a consultant or appropriately qualified specialty registrar (StR)/fellow. The commencement of each cycle will be based upon clinical examination, full blood counts (FBCs, including differential white blood cell (WBC) biochemistry) and any other test results specific to the regime in question. Subsequent cycles can be authorised either by any clinician at StR level in the team or an appropriately trained and qualified clinical nurse specialist who has passed the physical assessment and Independent Nurse Prescribers course.

11.1 First-line treatment

11.1.1 Temozolomide in newly diagnosed patients with glioblastoma multiforme

- Concomitant with radiotherapy:
  - temozolomide 75mg/m^2 PO daily for 6 weeks
  - (+ co-trimoxazole as PCP prophylaxis)
  - discontinue concomitant temozolomide and co-trimoxazole if platelets less than 75 x 10^9/l.

- Adjuvant temozolomide:
  - 150mg/m^2 daily for 5 days every 28 days for 1st cycle and commence 4–6 weeks post end of radiotherapy
  - if adequate haematological recovery, increase to 200mg/m^2 for the remaining 5 cycles
  - total of 6 cycles as per NICE guidance TA121.

11.2 Chemotherapy treatment of recurrent disease

11.2.1 PCV (MRC protocol) for recurrent disease

PCV is the first line of choice in patients of good performance status (ECOG 0–2) with high-grade glioma (HGG) who progressed on or after first-line treatment (either radiotherapy alone or radiotherapy and temozolomide). It has been the gold standard regimen for anaplastic oligodendrogliomas.

<table>
<thead>
<tr>
<th>Drug</th>
<th>Dose</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lomustine</td>
<td>100mg/m2 PO day 1</td>
</tr>
<tr>
<td>Vincristine</td>
<td>1.5mg/m2 IV day 1 (max 2mg)</td>
</tr>
<tr>
<td>Procarbazine</td>
<td>100mg/m2 PO daily for days 2–11 in 2 divided doses</td>
</tr>
</tbody>
</table>

Cycle repeated every 6 weeks (up to 6 cycles, stop if progressive disease).

Dose modification

- If day 1 neutrophil count <1.5 x 10^9/l or platelets <100 x 10^9/l: delay for 2 weeks and then give full dose if count fully recovers.
- If FBC low after initial 2-week delay: wait further 2 weeks and reduce dose by 25%.
- If delay required for two consecutive cycles due to haematological toxicity: reduce dose by further 25%.
- If LFTs >5 x ULN: reduce or omit vincristine and procarbazine.
11.2.2 Single agent alternatives to PCV at first recurrence

**Lomustine**  
100–120mg/m² PO once/cycle  
q 6/52  
Dose modifications as per PCV

**Carmustine**  
80mg/m² IV daily for 3 days or 200–240mg/m² IV once  
q 6/52  
Dose modifications as per PCV

11.2.3 Temozolomide for recurrent disease

Indicated as per NICE guidance (TA23) after failure of a nitrosourea-based chemotherapy regime and good performance patients (ECOG 0–1) or in patients with a contraindication to a nitrosourea-based chemotherapy regime:

Standard dose: 200mg/m² PO daily for 5 days (if no previous chemotherapy); 150mg/m² PO daily for 5 days at 1st cycle (if previous chemotherapy). If adequate haematological recovery after 4 weeks (neutrophil count $\geq 1.0 \times 10^9/l$ and platelets $\geq 100 \times 10^9/l$), increase to standard dose of 200mg/m² for the remaining cycles.

11.2.4 Carboplatin/etoposide

Carboplatin and etoposide can be used in combination or etoposide can be used as a single agent as third- or fourth-line treatment.

**Carboplatin**  
AUC 5 IV day 1 of 21

**Etoposide**  
100mg/m² IV day 1 of 21

**Etoposide**  
200mg/m² PO day 2, 3 of 21

Or

**Etoposide**  
50mg/m² PO (max 100mg) day 1 to 21 (inclusive)

11.2.5 Bevacizumab

Bevacizumab may be given as a single agent or in combination with irinotecan. Currently, this is not being funded. We acknowledge that some patients may benefit with a marked reduction in perifocal oedema and the ability to come off high-dose steroids.

**Bevacizumab**  
5–7.5mg/kg can be administered every 2 or every 3 weeks

**Bevacizumab**  
5mg/kg/week can be administered every 2 or every 3 weeks

**Irinotecan/CPT11**  
340mg/m² (enzyme inducing AEDs) day 1 of 21

**Irinotecan/CPT11**  
125mg/m² (non-enzyme inducing AEDs) day 1 of 21

11.2.6 Carboplatin as a single agent

Carboplatin may be used (AUC 4 to 6) depending on renal function and bone marrow reserve.
12 Tumour-specific Pathways

12.1 High-grade gliomas

12.1.1 Treatment policy

Unless there are exceptional (clinically indicated) circumstances, patients should only be offered active treatment following tumour biopsy or debulking surgery.

Resection of a glioma may give rapid relief from symptoms (e.g. raised intracranial pressure – ICP), especially if the tumour is in a non-eloquent area. A transient neurological deficit will occur in 10% of cases post-operatively, and there is recovery of the neurological deficit in up to 50% of cases. The extent of surgery (biopsy vs gross debulking) has been shown in a number of studies to affect the length of survival. In a study by Ammirati et al., patients with high-grade gliomas who had a gross total resection had a 2-year survival rate of 19%, while those with a subtotal resection had a 2-year survival rate of 0%.

Bis-chloroethylnitrosourea (BCNU)-polymer wafers (Gliadel wafers) may be used by neurosurgeons in selected patients with either primary or recurrent tumours, where a 90% tumour debulking is achievable. Dural closure must be possible and peri-ventricular regions are best avoided. A phase III randomised trial that included 240 patients compared surgery with the implantation of polymer wafers with BCNU into the tumour bed, and demonstrated significant prolongation of survival compared with a placebo wafer. Both groups received radiotherapy. The median survival was 13.9 months in the group treated with Gliadel wafers and 11.6 months in the group treated with placebo. Level 1a

Age, performance status and the extent of surgery are strong predictors of survival, so radical radiotherapy should be offered to patients <70 years and with good performance status of World Health Organization (WHO) Grade 0–1. More frail or elderly patients may be suitable for palliative radiotherapy. Older patients over 70 years of age who are fit with a good performance status should be considered for radical chemo-radiotherapy.

12.1.2 Delineation of target volumes

The gross tumour volume (GTV) is delineated on the contrast-enhancing edge of the tumour, preferably on the post-operative gadolinium-enhanced T1-weighted magnetic resonance imaging/computerised tomography (MRI/CT) fused images.

Clinical target volume (CTV) = GTV + 15mm to 25mm depending on the nature of the tumour.

The CTV may be modified to take into account the natural barriers to spread (e.g. bone, tentorium and falx) as tumours tend to grow along the lines of least resistance, e.g. white matter tracts.

Gliomas generally do not grow across to the opposite hemisphere except via the corpus callosum; therefore the CTV volume can often be trimmed up to 1cm over midline superiorly or inferiorly to this, in order to reduce the treatment volume. In certain instances, for example where there is massive midline shift, the tumour will cross the midline although it remains confined to one hemisphere.

Planning target volume (PTV) = CTV + 3mm to 5mm.

This 5mm margin is added to the CTV taking into account the departmental measurements for set-up accuracy.
Our current understanding is that tumour recurrence after focal brain radiation therapy occurs within 2cm of the original site in 90% of patients, supporting the use of focal radiation therapy.

**12.1.3 Dose prescription**

6MV photons are appropriate for most patients. (See the table at section 10.2.4 for dose fractionation schedules.) Usually, 60Gy in 30 fractions is given.

**Chemotherapy**

Concomitant phase:
- Temozolomide 75mg/m\(^2\) PO daily for 42–49 days with concomitant radiotherapy. Well motivated patients with good performance status are to take temozolomide preferably 1–2 hours before radiotherapy. Some patients for a variety of reasons may find this timing difficult – this will not prevent continuing with concomitant chemo-radiation.
- Full blood counts (FBCs), urea and electrolytes (U&E) and liver function tests (LFTs) should be undertaken weekly.
- If radiotherapy is interrupted for technical or medical reasons unrelated to temozolomide, then the daily temozolomide should continue.
- If radiotherapy is permanently interrupted, then treatment with daily temozolomide should stop.

The following concomitant and adjuvant chemotherapy regimen should be used, based on the phase III trial of Stupp et al.\(^3\). Temozolomide with radiation was associated with significant improvements in median progression-free survival (6.9 vs 5 months), overall survival (14.6 vs 12.1 months), and the likelihood of being alive in 2 years (26% vs 8%). **Level 1a**

Patients with oligodendrogliomas that exhibit chromosomal changes at band 1p/19q are known to have improved responses to the procarbazine, CCNU, vincristine (PCV) regimen of chemotherapy. The 1p/19q chromosome deletion test is routinely available. Adjuvant PCV may be considered following radiotherapy in good performance status (PS) patients with high-grade oligodendroglial tumours after full discussion with the patient. The role of neo-adjuvant chemotherapy in these patients is being investigated.

For patients with no co-deletion and the diagnosis of anaplastic oligodendroglioma, anaplastic oligoastrocytoma or anaplastic astrocytoma, then entry into the BR14 (EORTC26053-22054) trial should be considered.

**Table 12.1: Dose modifications**

<table>
<thead>
<tr>
<th>Toxicity</th>
<th>Value</th>
<th>CTC Grade</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>Absolute neutrophil count</td>
<td>≥0.5 and &lt;1.5</td>
<td>2, 3</td>
<td>Delay until normalisation</td>
</tr>
<tr>
<td>Platelet count</td>
<td>≥10 and &lt;100</td>
<td>1, 2, 3</td>
<td>Delay until normalisation</td>
</tr>
<tr>
<td>CTC non-haematological toxicity (except alopecia, N&amp;V)</td>
<td>2</td>
<td></td>
<td>Delay until normalisation</td>
</tr>
<tr>
<td>Absolute neutrophil count</td>
<td>&lt;0.5</td>
<td>4</td>
<td>STOP</td>
</tr>
<tr>
<td>Platelet count</td>
<td>&lt;10</td>
<td>4</td>
<td>STOP</td>
</tr>
<tr>
<td>CTC non-haematological toxicity (except alopecia, N&amp;V)</td>
<td>3, 4</td>
<td></td>
<td>STOP</td>
</tr>
</tbody>
</table>
Other prescriptions

**Ondansetron** 8mg (or equivalent anti-emetic) prior to first dose – then domperidone 10mg 8 hourly PRN

**Co-trimoxazole Forte** 960mg 3x per week (PCP prophylaxis) during the concomitant phase

**Adjuvant temozolomide chemotherapy**

Commence after a 4-week gap from the end of concomitant chemo-radiation.

Dose cycle 1: 150mg/m\(^2\) PO daily for 5 days out of 28 days. If this dose is tolerated, increase to 200 mg/m\(^2\) PO daily for cycle 2 to cycle 6. Further cycles may be given (at the discretion of the clinician) if there is continued clinical and radiological improvement.

12.1.4 **Recurrent high-grade gliomas**

Options include:

- best supportive care
- further debulking surgery/Gliadel wafers
- PCV chemotherapy if not received in the primary setting
- temozolomide chemotherapy if not received in the primary setting or a re-challenge if appropriate time interval
- CEV chemotherapy (second-/third-line) – carboplatin, etoposide, vincristine or modified CEV (omitting the vincristine)
- a single nitrosourea may be used
- carboplatin as a single agent may be used
- bevacizumab single agent or in combination with irinotecan for individual patients may be funded via individual funding requests
- referral for phase I/II trials (discuss with the clinical trials unit) EGFR inhibitors, imatinib, etc., only for patients with WHO PS 0–1. Malignant gliomas often have amplification of the EGFR gene, amplification of c-kit, and loss of PTEN.\(^4\)
- There is no proven role for stereotactic radiosurgery or Gamma Knife radiosurgery in recurrent high-grade glioma. Nevertheless, in exceptional circumstances with a truly localised recurrence, stereotactic radiosurgery/radiotherapy may be used. Partial brain radiotherapy re-treatment may be considered in exceptional circumstances on an individual basis.

12.2 **Low-grade gliomas**

Patients with low-grade gliomas can receive radiotherapy either upfront after primary surgery, or at relapse following a surveillance policy. Both options have a similar overall survival rate, although time to relapse is greater with early radiotherapy. If indolent, and the patient is asymptomatic, a surveillance follow-up policy is preferred with serial scanning. If symptomatic, a maximal safe resection and/or radiotherapy should be offered. Delayed radiotherapy is preferred if resection is complete; however, in cases where only a biopsy can be performed or resection is incomplete, or where there are atypical histological features, early
radiotherapy is preferred. Each case should be considered on its merits, and patient preference noted, before deciding on early versus delayed radiotherapy.

12.2.1 Delineation of target volumes

The pre-operative GTV seen on T2 weighted MRI is outlined on the fused CT/MRI images.

CTV = GTV + 5mm to 25mm.

PTV = CTV + 3mm to 5mm.

Chemotherapy

There is no convincing evidence yet of a significant benefit to concomitant or adjuvant chemotherapy in low-grade astrocytomas. Chemotherapy may have an adjuvant role in oligodendroglioma if incompletely resected, and can be an alternative to radiotherapy in these patients. Choice of regimen is as for high-grade glioma. 1p/19q and methylation status may be useful in decision making. With regard to neo-adjuvant chemotherapy, currently there is no convincing evidence for its use but in exceptional cases it may be considered with knowledge of the 1p/19q and methylation status.

12.2.2 Ependymoma

Maximal safe resection should be attempted if at all possible. These usually occur in posterior fossa or spinal cord, but also supratentorially. The cure rate is approximately 50%. Craniospinal axis radiotherapy (CSA-RT) does not improve the local control of ependymoma, therefore localised radiotherapy is the preferred option in most cases.

Supratentorial, infratentorial or spinal (low grade)

If a complete resection has been achieved and brain and spinal MRI are clear and cerebrospinal fluid (CSF) cytology is clear, limited field radiotherapy or observation (sub-ependymomas) can be used. If resection is subtotal but MRI and CSF are clear, then offer local radiotherapy (50Gy to 55Gy). If MRI or CSF show evidence of seeding, CSA-RT should be considered (for technique, see medulloblastoma, section 12.3).

Supratentorial (high grade)

If a complete resection has been achieved and post-operative brain and spinal MRI are clear and CSF cytology is clear, local radiotherapy (55Gy/30#) may be used. If resection is subtotal but MRI and CSF are clear, then local radiotherapy is probably sufficient. If MRI or CSF show evidence of seeding, CSA-RT should be strongly considered (for technique, see medulloblastoma, section 12.3).

Note: Check for organs in exit beams, especially kidneys in lower T/upper L tumours. Whole kidney dose must not exceed 15Gy. If clinically indicated, sperm banking or oophoropexy should be considered.

Chemotherapy

Chemotherapy can be used for ependymomas for inoperable cases recurrent after radiotherapy or for metastatic disease. The regimens are generally derived from the paediatric studies and are cisplatin based.  

12.3 Medulloblastoma: craniospinal radiation

Medulloblastoma is a highly cellular malignant embryonal neoplasm classified as a primitive neuroectodermal tumour (PNET). It accounts for 15% to 20% of all childhood primary central nervous
system (CNS) neoplasms. It is rare in adults. Standard management consists of complete or near complete surgical resection followed by post-operative CSR-RT. (See British Neuro-oncology Society guidelines.)

12.3.1 Chemotherapy

The benefit of post-radiation chemotherapy, although not proven in a randomised controlled trial, has now been generally accepted for all paediatric patients with medulloblastoma and should be discussed for all young adult and adult patients. The standard treatment is the ‘Packer’ regimen. It consists of weekly vincristine during treatment; commencing 6 weeks after radiation, patients receive cycles of CCNU, cisplatin and vincristine. It is standard for 8 courses to be delivered but this is often modified because of cisplatin toxicity.

12.3.2 Staging and pre-planning investigations

For patients to be ‘standard risk’ medulloblastoma, they must be non-metastatic and must meet the following criteria:

- histologically proven medulloblastoma
- no CNS metastases on MRI or brain and spine (preferably performed before surgery)
- no clinical evidence of extra-CNS metastases
- no tumour cells on cytospin of lumbar CSF obtained at least 15 days following surgery.

Patients with metastases fall into the high-risk group. This includes Chang stage M1 disease in which tumour cells are found free in the CSF without radiological evidence of metastasis; these patients have a worse prognosis than those without evidence of such tumour spread and they are therefore included in the high-risk group.

Residual posterior fossa disease

The patient would have to be discussed at the multidisciplinary team (MDT) meeting and the surgeons asked to consider further surgery.

12.3.3 Radiotherapy principles

The aim of this treatment is to achieve homogenous irradiation to the whole CSF volume so as to eradicate malignant cells free within the cerebrospinal fluid. In the cranium care must be taken to include:

- the cribriform plate
- the temporal lobe
- the posterior orbit.

Patient position and immobilisation

Patients will be immobilised in a thermoplastic shell. Care must be taken to determine if the patient is to have treatment on the tomotherapy unit or a conventional linear accelerator as this may determine the patient’s position. The local guidelines should be followed.

CT Planning

The planning dataset is acquired from the CT scanner and if the patient is to have conventional whole CNS radiotherapy it is then transferred into the planning system (see local guidelines).
If the patient is to have whole CNS radiotherapy on the tomotherapy unit, the CT dataset is transferred to the tomotherapy planning system.

12.3.4 Normal tissue tolerances/gonad doses (see QUANTEC)

A dose volume histogram will be provided for the following structures and will require the clinician’s approval.

In addition to the normal brain and brainstem organs at risk (e.g. supratentorial brain, posterior fossa, cochlea, hypothalamus, pituitary and optic chiasm), the following should be considered:

- kidneys
- heart
- lungs
- gonads (consideration will be given to the location of these organs for dose estimation).

**Posterior fossa boost**

The CTV for the posterior fossa is determined from a planning CT and encompasses the entire posterior fossa as follows:

- superiorly – the tentorium
- inferiorly – at least 2cm below the lower limit of the tumour and including at least the outer table of the skull at the foramen magnum with a minimum 1cm margin
- anteriorly – the posterior clinoid processes
- posteriorly – the posterior extension of the meninges as far as the inner table of the skull; the CT should include any herniation of the meninges through the craniotomy defect
- laterally – the lateral extension of the meninges around the cerebellum.

PTV = CTV + 3mm to 5mm.

No attempt will be made to include the internal auditory meatus in the high-dose volume by extending the CTV to include it.

Posterior fossa contents should be outlined on an MRI using image fusion or on a post-operative enhanced CT scan.

It should be noted that some trials define posterior fossa target differently (e.g. HIT-SIOP PNET 4) and for patients in studies the trial protocol should be studied. In addition, it is essential to have a pre-operative scan available to ensure adequate margin.

12.3.5 Radiotherapy prescription

Localised disease

Brain – 35Gy in 21 daily fractions of 1.67Gy

Spine – 35Gy in 21 daily fractions of 1.67Gy

Primary tumour boost – 20Gy in 12 daily fractions of 1.67Gy

Total dose to primary – 55Gy in 33 fractions of 1.67Gy.
Modifications due to haematological toxicity

It is rare to have to interrupt radiotherapy but weekly FBCs need to be taken and patients reviewed in a weekly on-treatment clinic. Patients will be monitored daily if their platelet count falls to 40 and radiotherapy will be interrupted if the platelet count falls below 25 or the neutrophil count below 0.5. If either of these occurs, then the craniospinal part of radiotherapy is interrupted and the posterior fossa boost is commenced early. Granulocyte colony stimulating factor (G-CSF) should be given in consultation with the pharmacologists to assist neutrophil recovery and platelet support may be required. Haemoglobin levels should be maintained above 10gm/l by transfusion if necessary.

Portal images and lithium fluoride or diode dosimetry of the eyes

Patients being treated on a conventional linear accelerator will be imaged according to local guidelines. Thermoluminescence dosimetry (TLD) or diodes are completed within the first two fractions of radiotherapy to assess the eye dose. This is to be carried out via individual departmental policies.

12.4 Spinal cord tumours

Ependymomas, astrocytomas and meningiomas receive localised radiotherapy.

12.4.1 Spinal ependymoma

Surgical debulking should usually take place first. Complete resection is rare. For certain tumours, e.g. Grade 1 myxopapillary ependymoma, surgery may be curative.

High grade (anaplastic) usually requires radiotherapy.

Initial investigations and assessment

Baseline tests as for glioma plus gadolinium-enhanced staging MRI of the spine.

Treatment policy

- Completely excised myxopapillary ependymoma: no further treatment, surveillance only.
- Incompletely excised myxopapillary ependymoma: discuss options of surveillance or local radiotherapy.
- Residual or recurrent myxopapillary ependymoma with adjacent metastases: local radiotherapy.
- Incompletely excised subependymoma (usually brain): surveillance.
- Completely excised low-grade ependymoma: local radiotherapy/discuss.
- Incompletely excised low-grade ependymoma and high-grade ependymoma: local radiotherapy.
- Disseminated spinal ependymoma: craniospinal irradiation and boost to sites of macroscopic disease.

12.4.2 Spinal astrocytoma

Initial investigations and assessment

Baseline tests for glioma plus gadolinium-enhanced staging MRI of the spine.

Treatment policy

- Low grade: surveillance or involved field radiotherapy.
- High grade: involved field radiotherapy.
Treatment volume

The GTV is the extent of residual tumour on the post-operative MRI. Cover the spinal canal and/or nerve roots with proximal and distal extension based on pre-operative MRI.

CTV = GTV + 20mm margin superiorly and inferiorly and 10mm laterally.

PTV = CTV + 5mm.

For lumbar tumours the CTV may need to be extended laterally to include the nerve roots.

Note: Check for organs in exit beams, especially kidneys in lower T/upper L tumours. Whole kidney dose must not exceed 15Gy. If clinically indicated sperm banking or oophoropexy should be considered.

12.5 Germ cell tumours

12.5.1 Initial investigations and assessment

In addition to standard assessments, if not already performed:

- serum tumour markers – αFP, βHCG
- MRI spine
- CSF cytology and tumour markers (αFP, βHCG) if no evidence of raised ICP
- full endocrine assessment
- formal visual assessment if clinically indicated.

12.5.2 Germinoma

Treatment policy

Post-pubertal male (localised or bifocal)

In fully staged patients with confirmed localised disease in typical locations (pineal/suprasellar):

- whole ventricular system (all ventricles including 4th) + 1cm margin (WVRT) to 24Gy/15 #
- boost to primary site plus 1cm margin 16Gy/10# (total dose 40Gy).

In incompletely staged patients or patients with non-typical primary locations (e.g. brainstem, thalamic):

- craniospinal axis: 24Gy/15#
- boost to primary site: 16Gy/10# (total dose 40Gy).

All females/pre-pubertal males (localised or bifocal)

Treatment should be individualised. The options include:

- whole ventricular radiotherapy (24Gy in 15#) and boost to primary tumour (16Gy in 10#) (preferred option)
- carbo-PEI chemotherapy and WVRT and boost as per SIOP CNS GCT 96 protocol7 and the Children’s Cancer and Leukaemia Group (CCLG) GCT group interim guidelines8
- CSA-RT and boost to primary site (as for post-pubertal males above).

Metastatic
Craniospinal radiotherapy:
- boost to primary and sites of macroscopic metastases (to total dose of 40Gy).

12.5.3 Non-germinomatous germ cell tumours

Treatment policy
- Primary chemotherapy: PEI (cisplatin, etoposide and ifosfamide) as per SIOP CNS GCT 96 protocol (12 weeks).
- Then focal radiotherapy in localised disease and CSA-RT and conformal boost in patients with metastatic disease at diagnosis.

Allow for a 4–6 week gap between the end of chemotherapy and beginning of radiotherapy.

Chemotherapy – PEI protocol (used at The Royal Marsden)
- Pre-hydration: NaCl 0.9% at 2L/m² daily + 20mmol KCl/l + 12g mannitol/l for 3 hours.
- Cisplatin 20mg/m² in 500ml 5% dextrose over 60 minutes, days 1–5.
- Etoposide 100mg/m² IV, days 1–3.
- Ifosfamide 1,500mg/m² IV over 3 hours, days 1–5.
- MESNA 1,875mg/m² over 15 hours as a continuous infusion.
- Post-hydration: NaCl 0.9% at 2L/m² daily + 20mmol KCl/l + 12g mannitol/l for 9 hours.

Mannitol should only be administered to patients who exhibit no signs of diabetes insipidus.

Repeat every 3 weeks for a total of 4 cycles.

Notes
- Ethylenediaminetetraacetic acid (EDTA) clearance before start of chemotherapy and repeat if EDTA <100 after cycle 2.
- MRI scan post-chemotherapy/pre-radiotherapy.
- Consider surgical resection of residual disease in secreting germ cell tumour post completion of chemotherapy.
- Monitor tumour markers at each cycle of chemotherapy and at the start and end of radiotherapy.
- Regular (at least twice daily) electrolyte measurements during chemotherapy.
- Ensure and maintain regular review/input of endocrinology team during inpatient and outpatient phases.

Table 12.2: Post-chemotherapy radiotherapy dose

<table>
<thead>
<tr>
<th>Localised disease</th>
<th>Primary tumour</th>
<th>54Gy/30F with conformal 3–6 field technique or IMRT/VMAT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Metastatic disease</td>
<td>Whole brain</td>
<td>30Gy/20# (supine)</td>
</tr>
<tr>
<td></td>
<td>Whole spine</td>
<td>30Gy/20# (supine)</td>
</tr>
<tr>
<td></td>
<td>Boost to primary</td>
<td>24Gy/15# (total dose 54Gy)</td>
</tr>
<tr>
<td></td>
<td>Boost to macroscopic metastatic disease</td>
<td>24Gy/15# (20Gy if spine)</td>
</tr>
</tbody>
</table>
Radiotherapy technique

Phase I craniospinal axis – technique as in medulloblastoma/PNET.

Phase II GTV = tumour as visible on planning CT scan.

PTV = GTV + 0.8cm–1cm margin.

Patients needing CSA-RT should be referred for radiotherapy to a centre with a paediatric service.

Management at relapse

Given the rarity, treatment at relapse has to be individualised.

For these relatively rare tumours see BNOS guidelines, [www.bnos.org.uk](http://www.bnos.org.uk)

- CNS lymphoma
- tumours of pineal region
- optic pathway gliomas
- adult PNET

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7 Calaminus G et al. (2013), SIOP CNS GCT 96: final report of outcome of a prospective, multinational nonrandomized trial for children and adults with intracranial germinoma, comparing craniospinal irradiation alone with chemotherapy followed by focal primary site irradiation for patients with localized disease, *Neuro-Oncology*, [http://neuro-oncology.oxfordjournals.org/content/early/2013/03/03/neuonc.not019.full](http://neuro-oncology.oxfordjournals.org/content/early/2013/03/03/neuonc.not019.full).

13 Rehabilitation

Cancer rehabilitation attempts to maximise patients’ ability to function, to promote their independence and to help them adapt to their condition. It offers a major route to improving their quality of life, no matter how long or short the timescale.\(^1\)

Considerable medical advances in the treatment of primary brain and spinal tumours have translated into a marked increase in the number of survivors who present with impairments and functional limitations.\(^2,3\) Learning to compensate for these deficits with a holistic rehabilitative approach that encompasses medical, physical, social and psychological aspects of the disease is an important factor in improving the patient’s quality of life.\(^4\)

13.1 Evidence

- Patients with brain tumours make significant functional gains after a course of rehabilitation.\(^5,6,7,8,9,10\)
- Inpatient multidisciplinary rehabilitation results in marked reduction in disability as measured by various functional measurement tools (Functional Independence Measure, Barthel Index, Karnofsky Performance Status Scale).\(^5,11,12\)
- The same principles of neuro-rehabilitation used in patients with traumatic brain injury and stroke are equally applicable to patients with brain and spinal cord tumours.\(^13\)
- Treatments such as exercise and other therapy interventions that enhance physiological and functional outcomes are known to improve the quality of life of cancer survivors.\(^14,15,16,17\)

13.2 Prognosis and rehabilitation

- Key elements, alongside generic principles of neuro-rehabilitation, should be considered in the rehabilitation of brain and spinal tumours, such as:
  - consideration of disease related functional fluctuations
  - progressive decline
  - difficult psychological adjustments to changing functional abilities
  - uncertain prognosis
  - depression, fatigue and medical fragility.\(^13\)
- Access to rehabilitation services should be offered to patients at curative stage, in long-term remission, receiving active treatment, or requiring support at the end of life.\(^1\)
- The approach in the rehabilitation of patients with a good long-term prognosis should focus on reducing deficits over a medium to longer timeframe.\(^18,19,20\)
- It should be recognised that patients with a poor prognosis have a limited window of opportunity for recovery of function and therefore should receive urgent access to rehabilitation services, including inpatient settings, where goals should be clearly defined around maximising function and optimising the quality of their remaining life.\(^20\)
- For other patients with poor prognosis, a compensatory rehabilitation approach may be more appropriate to maintain a meaningful level of function for as long as possible.\(^1\)
13.3 Access and timing of rehabilitation

- Referral to rehabilitation and supportive care services should not be dependent on diagnosis, but on patient need.\(^{20,21}\)
- The patient’s wishes in the rehabilitation referral process should be considered.
- Rehabilitation should begin as early as possible to optimise rehabilitation opportunities and functional participation in society.\(^{21}\)
- Clinicians must recognise that the principles of neuroplasticity and associated gains also apply to patients with brain tumours.\(^{22,23,24,25}\)
- Consideration should be given to an individual’s diagnosis, prognosis and ongoing medical management.
- Patients receiving adjunct medical treatment such as radiotherapy or chemotherapy should still be considered for rehabilitation.\(^{7,19}\)
- The timeliness of rehabilitation referral will be facilitated by comprehensive communication between allied health professionals.\(^{20}\)

13.4 Rehabilitation assessment

- Assessment and interventions in rehabilitation should consider the impact of the disease at different levels of the International Classification of Functioning, Disability and Health (ICF) framework such as impairments, activity limitation, restriction in participation and contextual factors (environmental or personal).\(^{26}\)
- Assessment areas should include: patients’ ideas, concerns and expectations; social history; levels of function (including work, leisure, activities of daily living); impairments (including physical, cognitive, perceptual, psychological, communication and nutritional status); and assessment of the carer’s ability to actively participate in ongoing management.
- Reassessment should be considered at any stage of the patient’s disease trajectory dependent on clinical presentation of symptoms.\(^{1,20,27}\)

13.5 Rehabilitation intervention

- It is recommended that rehabilitation treatments be structured around the ICF framework to ensure a holistic approach. For example, the activity and participation domain will address mobility, self-care and domestic life; and environmental factors will consider transport, community access and so on.\(^{26}\)
- The intensity, frequency and content of therapy in multidisciplinary rehabilitation will vary and goal setting should be individualised based on clinical needs.\(^{28}\)
- Rehabilitation approaches may be restorative or compensatory in nature and the content can include functional training, physical reconditioning, task reacquisition strategies, cognitive and behavioural therapy, psychological support, environmental adaptations, and vocational and recreational programmes.\(^{20,29}\)
- Self-supported management is an important aspect in the rehabilitation of cancer patients applicable to all settings.\(^{30}\)
- Education and counselling should be available at various point of the journey to address adjustment issues such as self-worth, self-image and role reversal within the family.\(^{28,30}\)
• The emotional and spiritual needs of the patient, family and carers must be recognised and appropriate services accessed.¹,²⁰

• Access to and reliable information about complementary therapy services should be available.¹

• Brain and spinal cancer patients should have access to vocational rehabilitation or a similar form of work support.³⁰

• Patients should be signposted to dedicated brain tumour-specific charities and non-profit organisations at a time that is appropriate for them.

• Patients discharged to the community are confronted with various adjustment issues. Ongoing monitoring, education and counselling of the patient and family are therefore essential.²⁸

• Highly responsive community services to support rapid or significant changes in a patient’s condition are key.

13.6 Cancer/treatment secondary side effects and rehabilitation

• Rehabilitation should not be excluded where concurrent medical treatment such as chemotherapy or radiotherapy is taking place²,²⁰ as there is no proven detrimental effect on functional gains⁶,¹⁰,¹⁹ and no significant difference in length of stay.³¹

• Flexibility in rehabilitation in this population is important to promote the patient’s tolerance and optimise rehabilitation outcomes.³²

• Rehabilitation should aim to improve the patient’s perception of cancer-related symptoms and treatment side effects such as steroid-induced proximal myopathy, general deconditioning,¹³,³² poor appetite, fatigue, insomnia, pain, anxiety, constipation and poor overall sense of wellbeing.³⁴,³⁵

13.7 Multidisciplinary rehabilitation

• Rehabilitation should be delivered by a structured and coordinated multidisciplinary team (MDT).¹,²⁰,²⁷,³⁶,³⁷,³⁸

• The MDT’s goal should include improving patient symptoms, and optimising functional independence and participation.²⁶

• The MDT should use a holistic model of care such as the ICF.²⁶

• The multidisciplinary approach should provide patients with the skills required to manage their own care, to develop coping strategies and to maintain quality of life.³⁹

Multidisciplinary rehabilitation should be provided, according to patient’s needs, by the following professionals.²⁰

• specialist neuro-oncology medical team

• physiotherapists

• occupational therapists

• speech and language therapists

• dietitians

• nurses

• primary healthcare team/GPs
- neuropsychologists, neuropsychiatrists and counsellors
- social worker and social care team
- orthotists
- wheelchair and assistive technology teams
- chaplaincy and bereavement services
- complementary therapy services.

13.8 Outcome measures
- The use of outcome measures is imperative in continuing to demonstrate the value of rehabilitation.
- There is currently no agreed standard outcome measure that should specifically be used in the rehabilitation of brain and spinal tumour patients. The clinician should therefore choose relevant outcome measures based on the individual’s needs and goals.
- In the literature, the following validated outcome measures were used in brain tumour research and may be considered in the clinical setting:
  - the Functional Independence Measure (FIM)\textsuperscript{40}
  - the Barthel Index\textsuperscript{41}
  - the Cancer Rehabilitation Evaluation System (CARES)\textsuperscript{42,43}
  - the Cancer Survivor Unmet Needs measure (CaSUN)\textsuperscript{44}
  - the Perceived Impact of Problem Profile (PIPP)\textsuperscript{45}
  - the Fatigue Impact Scale\textsuperscript{46}
  - the Depression Anxiety Stress Scale\textsuperscript{47}
  - the Work Instability scale\textsuperscript{48}

13.9 Rehabilitation settings
- Rehabilitation and supportive intervention should be delivered in the most appropriate setting for each individual.
- Rehabilitation may be delivered by:
  - specialist neuro-rehabilitation centres
  - local inpatient rehabilitation units
  - neuro-outpatient services
  - community services
  - hospice services with access to specialist neurological expertise.
- Patients discharged to the community are confronted by various adjustments issues; families and carers also often struggle to cope with the new demands associated with increased care needs and the general limitation in the patient’s function. Ongoing monitoring, education and counselling of the patient and family are therefore essential.\textsuperscript{28} Multidisciplinary rehabilitation in the community may consist of integrated care delivered by health, social services and the voluntary sector. Highly responsive community services to support rapid or significant changes in a patient’s condition are key.
13.10 Service improvement, training and education

- Regular liaison and discussion between the clinical providers, specialists and local commissioners of rehabilitation services are recommended in order to identify and meet the needs of patients with brain and spinal tumours.

- Inclusion of the rehabilitation needs of this patient group should be considered in the joint strategic needs assessments of the local commissioning group.

- Rapid access for advice and guidance on the rehabilitation needs and management from the specialist teams should be available for the community services.

- Regular meetings and discussions between specialist centres and local services are recommended to improve links and develop skills, and to improve patient experience and outcomes.

- Regular training and education days between the specialist service providers and local services, including inpatient and community settings should be available.

- The staff delivering rehabilitation to this patient group should be trained in the key principles of rehabilitation identified in this document.

- Monitoring of the progress of the referral and waiting times to access services is recommended.

- Auditing of any gaps in rehabilitation services is recommended to inform commissioners and providers.

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2 NICE (National Institute for Health and Care Excellence) (2004), *Improving Supportive and Palliative Care for Adults with Cancer.*


NICE (2006), *Improving Outcomes for People with Brain and other CNS Tumours*.

NCAT (2010) *Rehabilitation Care Pathway: Brain CNS*.


NCAT (National Cancer Action Team)/Peer Review Team (2008), *Cancer Rehabilitation Measures*.

Khan F, Amatya B, Ng L, Drummond K, Olver J (2013), Multidisciplinary rehabilitation after primary brain tumour treatment (Review), *Cochrane Database of Systematic Reviews* 1.


Tay SS, Ng YS, Lim PA (2009), Functional outcomes of cancer patients in an inpatient rehabilitation setting, *Annals, Academy of Medicine, Singapore* 38:197–201.


14 Survivorship

The LCA has produced a comprehensive document on survivorship (see Appendix 6). This should be read in conjunction with these guidelines.

This section highlights the symptom management that health and social care services should specifically consider when supporting people living with a brain and CNS cancer.

14.1 Symptom management

The duration of the survivorship period for people with brain/CNS cancers may be significantly shorter than for other tumour sites. In non-malignant tumours it may be significantly longer than other tumour sites.

Brain/CNS tumour survivors may suffer from significant changes in their movement control, cognitive abilities, communication and behaviour. They may also suffer from seizures, paralysis and headaches.

The consequence of a combination of some or all of these impairments on independence varies greatly. Access to multidisciplinary teams (MDTs) across the acute, primary, social care services and home environment is recommended.

Robust referral pathways to MDTs should be available. Information on who can refer and how to refer and details of roles and remits should be made available to referring teams by provider teams.

Access to neurological rehabilitation specialty teams, both inpatient and outpatient, should be available for those people who would benefit.

The table below is summary of possible impairments and input.

### Table 14.1: Common symptoms and possible interventions

<table>
<thead>
<tr>
<th>Symptom/sign</th>
<th>Referrals/assessments/interventions to be considered</th>
</tr>
</thead>
<tbody>
<tr>
<td>Headaches/pain</td>
<td>Referral to doctor&lt;br&gt;Medical assessment&lt;br&gt;Assess pain: increase/start dexamethasone if signs of raised intracranial pressure (ICP); regular analgesics (avoid opiates if possible)</td>
</tr>
<tr>
<td>Nausea and vomiting</td>
<td>Referral for advice from palliative care team&lt;br&gt;Clinical nurse specialist review&lt;br&gt;Assess potential causes and manage reversible factors, e.g. constipation, chemotherapy, radiotherapy&lt;br&gt;Regular anti-emetics&lt;br&gt; Increase dexamethasone if signs of raised ICP&lt;br&gt;Consider syringe driver if appropriate</td>
</tr>
<tr>
<td>Seizures</td>
<td>Consult neurologist/epilepsy nurse specialist for advice&lt;br&gt;Prescribe appropriate seizure-terminating medication&lt;br&gt;Increase current anti-convulsants as appropriate&lt;br&gt;Increase dexamethasone as appropriate</td>
</tr>
<tr>
<td>Symptom/sign</td>
<td>Referrals/assessments/interventions to be considered</td>
</tr>
<tr>
<td>----------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Dysphagia</td>
<td>Referral to speech and language therapist/referral to dietitian Assessment by speech and language therapy Assess weight loss Dietary modification and dietary advice Monitor and review</td>
</tr>
<tr>
<td>Mobility/ataxia/limb weakness</td>
<td>Referral to physiotherapy/occupational therapy Assess for other causes, e.g. urine infection, deranged bloods Consider secondary proximal myopathy due to steroid use Assess movement and function Treatment strategies/equipment review/compensatory strategies</td>
</tr>
<tr>
<td>Difficulty with word finding or comprehension of written or verbal information</td>
<td>Referral to speech and language therapist Assess for other causes Increase dexamethasone if signs of ICP Consider use of communication aids Review strategies for communication</td>
</tr>
<tr>
<td>Visual disturbances</td>
<td>Referral to medical team. Increase dexamethasone if signs of ICP Referral to optician/ophthalmology/orthoptist Referral to physiotherapist/occupational therapist</td>
</tr>
<tr>
<td>Cognitive changes e.g. memory loss, difficulty planning and completing tasks, difficulty with attention and problem solving</td>
<td>Referral to occupational therapist for assessment Identify treatment strategies, compensatory strategies Support patient’s family/carers</td>
</tr>
<tr>
<td>Behavioural changes e.g. disinhibition, aggression or withdrawal</td>
<td>Referral to MDT for assessment and management strategies Refer to neuropsychologist/psychologist Support patient’s family/carers</td>
</tr>
<tr>
<td>Excessive fatigue</td>
<td>Refer to occupational therapy/physiotherapy for fatigue management strategies Support patient’s family/carers; offer training on management strategies</td>
</tr>
<tr>
<td>Weight changes</td>
<td>Consider if steroid-related and reduce/increase dose if clinically indicated Referral to dietitian If weight loss related to nausea and vomiting, consider anti-emetics If weight gain, consider reducing dietary intake</td>
</tr>
<tr>
<td>Raised blood sugars</td>
<td>Referral to diabetic nurse specialist/GP Start medication if appropriate Monitor blood sugars regularly Encourage low sugar diet Referral to dietitian for dietary advice</td>
</tr>
<tr>
<td>Symptom/sign</td>
<td>Referrals/assessments/interventions to be considered</td>
</tr>
<tr>
<td>----------------------------------</td>
<td>-----------------------------------------------------</td>
</tr>
<tr>
<td>Constipation</td>
<td>Regular laxatives</td>
</tr>
<tr>
<td></td>
<td>Encourage oral fluid intake</td>
</tr>
<tr>
<td></td>
<td>Referral to dietitian</td>
</tr>
<tr>
<td>Insomnia/sleep disturbances</td>
<td>Consider contributing factors, e.g. physical discomfort, anxiety, depression, steroids, post-radiotherapy</td>
</tr>
<tr>
<td></td>
<td>Relaxation and sleep hygiene techniques</td>
</tr>
<tr>
<td></td>
<td>Hypnotic</td>
</tr>
<tr>
<td></td>
<td>Ensure dexamethasone given in the morning and lunchtime</td>
</tr>
<tr>
<td>Anxiety/depression</td>
<td>Non-pharmacological techniques: counselling, cognitive behaviour therapy, psychologist</td>
</tr>
<tr>
<td></td>
<td>Prescribe antidepressants</td>
</tr>
<tr>
<td></td>
<td>Consider psychiatric referral if depression unresponsive to treatment or if suicide risk identified</td>
</tr>
<tr>
<td>Confusion/disorientation</td>
<td>Assess for causes, e.g. urine infection, drugs, constipation, tumour progression, raised ICP, worsening dysphasia</td>
</tr>
<tr>
<td></td>
<td>Montreal Cognitive Assessment (MOCA)/Mini Mental State Examination (MMSE)/Abbreviated Mental Test (AMT)</td>
</tr>
<tr>
<td></td>
<td>Ensure 24-hour supervision</td>
</tr>
<tr>
<td></td>
<td>Referral to occupational therapist/social services</td>
</tr>
</tbody>
</table>

14.2 Holistic needs assessment

The LCA’s holistic needs assessment (HNA) form (see Appendix 5) is a helpful tool, providing key questions relating to patients’ emotional, personal and social support needs.

This resource is available to download through: [www.londoncanceralliance.nhs.uk/information-for-healthcare-professionals/pathway-groups/survivorship/](http://www.londoncanceralliance.nhs.uk/information-for-healthcare-professionals/pathway-groups/survivorship/).

The LCA Survivorship Group recommends the adoption of the HNA and has chosen to measure its use within 31 days of diagnosis and within 6 weeks of primary treatment. All patients should be provided with an HNA as part of their initial information pack so that they are given a choice whether they wish to complete this. The care plan developed following the completion of an HNA must be shared with appropriate health and social care professionals after consent from the patient or carer if acting in best interests.

For patients with brain and CNS tumours, the key worker will identify the most appropriate time and place to introduce this assessment. Patients who present with cognitive and or communication deficits will require support to complete the HNA.

All patients should have the opportunity to have a relative/carer with them when information is being communicated.
14.3 Additional support for brain tumour patients and carers

Patients and carers may substantially benefit from early contact (as soon after diagnosis as possible) with brain/spinal tumour-specific charities and not-for-profit organisations which offer face-to-face, telephone and/or online support opportunities as well as a wide range of comprehensive, practical information regarding brain and spinal tumours. Talking through the challenges of brain and spinal tumours with other patients and carers who are on the same journey can provide a unique level of emotional support and hope.

It is recommended that all brain/CNS centres set up local patient and user support groups. In addition, patients may wish to access pan-London organisations or national charities. Some examples can be found in the box below.

<table>
<thead>
<tr>
<th>National organisations relating to brain tumours</th>
</tr>
</thead>
<tbody>
<tr>
<td><a href="http://www.patient.co.uk/support/British-Brain-Tumour-Association.htm">www.patient.co.uk/support/British-Brain-Tumour-Association.htm</a></td>
</tr>
<tr>
<td><a href="http://www.thebraintumourcharity.org/">www.thebraintumourcharity.org/</a></td>
</tr>
<tr>
<td><a href="http://www.braintumor.org/">www.braintumor.org/</a></td>
</tr>
<tr>
<td><a href="http://meningiomauk.org/groups.html">http://meningiomauk.org/groups.html</a></td>
</tr>
</tbody>
</table>
15 Palliative Care

15.1 Definition

‘Palliation’ and ‘palliative treatment’ refer to interventions designed to relieve specific symptoms, not merely to treatments that are not expected to be curative.

The World Health Organization (WHO) has defined palliative care as:

“an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. [Palliative care] is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.”

This philosophy is endorsed in the NHS Cancer Plan, the NICE Improving supportive and palliative care for adults with cancer document and the Improving Outcomes for People with Brain and Other Central Nervous System Tumours document.

15.2 Role and remit

Palliative care specialists have a particular role in the management of ‘difficult-to-control’ symptoms, the planning and provision of end of life care and supporting teams and patients in advanced care planning. The remit of specialist palliative care services is discussed in detail in Improving supportive and palliative care for adults with cancer, while the Department of Health’s guidance on end of life care is set out in detail in the End of Life Care Strategy document. Other initiatives to improve end of life care planning include:

- The Gold Standards Framework
- Coordinate My Care, a national initiative
- Advanced Care Planning

Palliative care of the patient should be provided by general teams and specialist palliative care providers in accordance with the NICE guidance.

Patients who would benefit from specialist palliative care services should be identified and seen without delay (see Appendix 8 for LCA specialist palliative care referral form). Neuroscience and neuro-oncology centres should have access to palliative care specialty staff for advice about symptom management, end of life care and advanced care planning. A robust referral system to access palliative care is required. The referral process should identify who can refer to the service and how. The palliative care service should have clear descriptions of its role in symptom management, end of life care and advanced care planning.

15.3 Assessment

The management of difficult-to-control symptoms involves adequate assessment, appropriate treatment and adequate reassessment (i.e. review of the efficacy and tolerability of the treatment). The objective of assessment is to determine the aetiology of the symptom. Thus, many of the symptoms associated with
brain/CNS cancers are non-specific (e.g. headache, nausea and vomiting), and patients may also experience these symptoms as a consequence of the anti-cancer treatment, the supportive care treatment, or a co-existing medical condition.

15.4 Consideration of palliative care needs

There are key points in a patient’s illness when their palliative care needs may need to be specifically considered and this may stimulate referral to multiprofessional specialist palliative care services. These key points include:

- pre-diagnosis if advanced disease is suspected
- diagnosis
- at commencement of definitive treatment of the disease
- on completion of the primary treatment plan
- on disease recurrence or relapse
- at the point of recognition of incurability
- end of life care
- other times requested by a patient.

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1 See [www.who.int/cancer/palliative/definition/en/](http://www.who.int/cancer/palliative/definition/en/).
5 Department of Health (2012), *End of Life Care Strategy*.
7 Coordinate My Care, see [www.coordinatemycare.co.uk/](http://www.coordinatemycare.co.uk/).
8 Royal College of Physicians, National End of Life Care Programme, 2012.
16 Patient Experience/Satisfaction

"Patient experience is only as good as the weakest point in the patient pathway."

Cancer services should be patient-centred and should respond to patient and carer feedback. Excellent communication between professionals and patients is particularly important to improve patient satisfaction.

Positive patient experience is central to meeting the holistic care needs of neuro-oncology patients and their families/carers. All neuro-oncology services should conduct an annual patient experience exercise. Services could consider collecting feedback on the patient experience using patient focus and support groups, one-to-one interviews and patient stories.

Key themes to explore include the patient pathway from first contact with the service through to onward referral as appropriate. These should include:

- pre-diagnosis
- diagnosis
- surgical
- oncology
- key worker
- rehabilitation
- community support
- supportive and palliative care.

All health and social care staff working with patients, families and carers need training in communication skills. The NICE guidelines\(^2\) identify four levels of communication training. There is evidence that all staff involved benefit from level 1 training and this can have a positive impact on the patient’s experience, for example by using the Sage and Thyme model for assisting people in distress.\(^3\)

It is recommended that all key workers have level 2 advanced communication skills training.\(^4\)

All services should ensure that they provide the following:

- a local mechanism for collecting information from their patients regarding every aspect of the patient pathway
- a mechanism for reviewing and reflecting any information about the patient experience from local and or national data
- evidence of responding to patients’ feedback.

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1. NHS (2010), *A Model of Care for Cancer Services, Clinical paper.*
2. NICE (2004), *Supportive and palliative care for adults with cancer.*

17 Management of Children, Teenagers and Young Adults with Diagnosed or Suspected Brain and Central Nervous System Cancer

Children below the age of 16 years with a diagnosis of cancer or suspected cancer must be referred to the paediatric oncology team at the principal treatment centre (PCT) and must not be managed exclusively by adult site-specific teams.

- The joint PTC for children aged 1–16 years for South Thames is The Royal Marsden (Sutton)/St George’s Hospital.
- The PTC for North Thames (including North West London) is Great Ormond Street Hospital/University College London Hospitals.
- All patients <1 year should be referred to Great Ormond Street Hospital.

**South Thames Principal Treatment Centre contacts**

<table>
<thead>
<tr>
<th>The Royal Marsden NHS Foundation Trust</th>
<th>Lead Clinician – Dr Julia Chisholm</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><a href="mailto:Julia.chishom@rmh.nhs.uk">Julia.chishom@rmh.nhs.uk</a></td>
</tr>
<tr>
<td></td>
<td>020 8661 3549</td>
</tr>
<tr>
<td></td>
<td>Paediatric oncology oncall registrar (new referrals)</td>
</tr>
<tr>
<td></td>
<td>020 8915 6248 (24h line)</td>
</tr>
</tbody>
</table>

**North Thames Principal Treatment Centre contacts**

<table>
<thead>
<tr>
<th>Great Ormond Street Hospital (patients aged &lt;13 years)</th>
<th>Lead Clinician – Darren Hargrave</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><a href="mailto:darren.hargrave@nhs.net">darren.hargrave@nhs.net</a></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>University College London Hospitals (patients aged &gt;13 years)</th>
<th>Lead Clinician – Dr Sara Stoneham</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><a href="mailto:sara.stoneham@uclh.nhs.uk">sara.stoneham@uclh.nhs.uk</a></td>
</tr>
<tr>
<td></td>
<td>020 3447 9950</td>
</tr>
</tbody>
</table>

Teenagers aged 16–18 should be managed at a PTC for teenager and young adult (TYA) cancers. Young adults aged 19–24 should be given the choice of being managed at a PTC or TYA designated hospital.

- The PTC for TYA for South Thames is The Royal Marsden (Sutton).
- The PTC for North Thames (including North West London) is University College London Hospitals.

All patients within this age range, regardless of place of care, should be referred to the TYA MDT at the relevant PTC. Referral to the MDT should be made using the TYA referral form (see Appendix 7) which can be found on the LCA website: www.londoncanceralliance.nhs.uk/media/68982/TYA%20MDT%20proforma%20March%20202014.doc.

Discussion at the TYA MDT is in addition to the SSMDT; key functions of the TYA MDT are to agree the treatment plan of the SSMDT, ensure cancer registration and provide a psychosocial care plan. Members of the SSMDT or TYA service at the PTC or TYA designated hospitals are invited to attend the TYA either remotely or in person.
### LCA TYA designated centres contacts allied to The Royal Marsden Hospital PTC

| Joint Centre (Guy’s and St Thomas’ NHS Foundation Trust/King’s College Hospital NHS Foundation Trust) | Guy’s and St Thomas’ Lead Clinician – Dr Robert Carr Robert.carr@gstt.nhs.uk Lead Nurse – Gavin Maynard-Wyatt Gavin.maynard-wyatt@gstt.nhs.uk |
| Joint Centre (Guy’s and St Thomas’ NHS Foundation Trust/King’s College Hospital NHS Foundation Trust) | King’s College Hospital Lead Clinician – Dr Donal McLornan donal.mcclornan@nhs.net Lead Nurse – Gavin Maynard-Wyatt Gavin.maynard-wyatt@gstt.nhs.uk |
| St George’s Healthcare NHS Trust | St George’s Hospital Lead Clinician – Dr Jens Samol jens.samol@stgeorges.nhs.uk Lead Nurse – Linda Shephard Linda.shephard@stgeorges.nhs.uk |

### LCA TYA designated centres contacts allied to University College London Hospitals PTC

| Chelsea and Westminster Hospital NHS Foundation Trust | Chelsea and Westminster (HIV and skin only) Lead Clinician – Dr Mark Bower (interim) Mark.Bower@chelwest.nhs.uk Lead Nurse – Kate Shaw (interim) Kate.Shaw@chelwest.nhs.uk |
| Imperial College Healthcare NHS Trust | Charing Cross Lead Clinician – Dr Josu de la Fuente (deputy) j.delafuente@imperial.ac.uk Lead Nurse – Sinead Cope sinead.cope@imperial.nhs.uk |
| East and North Hertfordshire NHS Trust | Mount Vernon Cancer Centre Lead Clinician (MVCC) – Dr Gordon Rustin grustin@nhs.net Lead Nurse (MVCC) – Laura Miles laura.miles@nhs.net |
18 Research and Innovation

Patients with brain tumours continue to have a poor outcome, and there is recognition that research into brain tumours is small, relative to their impact on patients.\(^1\)

Given this, it seems logical to suggest that active research programmes remain key to improving patient outcomes. In addition, there is some evidence that patients enrolled in clinical trials may have better outcomes, regardless of the treatment they receive. In addition, the LCA provides an opportunity for units to collaborate and coordinate research interests to improve recruitment and reduce duplication.

In order to achieve this, the LCA Brain/CNS Pathway Group will ensure that each centre provides and maintains up-to-date lists of trials open to recruitment, and provides a list of patient groups for whom they were unable to offer a clinical trial. In addition, the pathway group will ask the LCA informatics team to help assemble data measuring trial recruitment across the LCA. The trial register will be held as a separate document to allow for easy updating.

However, research in brain tumours cannot be limited to ensuring an optimal trial portfolio alone. In addition to trial recruitment, the pathway group expects each neuro-oncology centre to provide plans, with evidence of timelines, funding and outputs, for three other areas of research:

- basic science/translational
- quality of life and functional outcomes
- non-glioma research.

The pathway group also expects each unit to submit a list of its academic publications on an annual basis, so that it can present an LCA-wide neuro-oncology research output portfolio on an ongoing basis.

---

\(^1\) Burnet NG et al. (2005), Years of life lost (YLL) from cancer is an important measure of population burden – and should be considered when allocating research funds, *British Journal of Cancer* 92:241–245.
Appendix 1: Urgent Suspected Brain and Central Nervous System Cancers Referral Forms

South West London Referral Form

<table>
<thead>
<tr>
<th>SOUTH WEST LONDON CANCER NETWORK</th>
<th>Suspected Brain and CNS Cancers Referral Form (NICE 2006)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Urgent Referrals Criteria</strong></td>
<td>(Please tick category)</td>
</tr>
<tr>
<td>CNS 1</td>
<td>Patients with CNS symptoms where a brain tumour is suspected.</td>
</tr>
<tr>
<td>History/Symptoms:</td>
<td></td>
</tr>
<tr>
<td>Signs on Examination:</td>
<td></td>
</tr>
<tr>
<td>Possible Diagnosis:</td>
<td></td>
</tr>
</tbody>
</table>

**Date of GP Decision to Refer:**

**No of Pages Faxed:**

**GP DETAILS**

- **GP Name and Initials:**
- **GP Practice Code:**
- **Address:**
- **Post Code:**
- **Telephone No:**
- **Fax No:**

**PATIENT DETAILS**

- **Last Name:**
- **First Name:**
- **Address:**
- **Post Code:**
- **Daytime Tel or Mobile:**
- **Gender:** M | F
- **Date of Birth:**
- **Age:**
- **Interpreter Required?** Y/N
- **Language:**
- **Ethnicity:**
- **Hospital No:**
- **NHS No:**

**COMMENTS/OTHER REASONS FOR URGENT REFERRAL**

**PARENT AWARENESS QUESTIONS**

1. Has the patient been made aware of the nature of their referral? Yes | No
2. Has the patient been supplied with supportive information about the Urgent Suspected Cancer referral process? Yes | No
3. Have you asked the patient if they will be available to attend an appointment within the next two weeks? Yes | No
4. Has the patient indicated to you that they would be available to attend an appointment within the next two weeks? Yes | No

---

**SOUTH WEST LONDON CANCER NETWORK**

How to make urgent referrals for suspected brain and CNS cancers

Please FAX this form to the Cancer Office at the relevant hospital, with or without an accompanying letter. You should receive acknowledgement by fax that your referral has been received. Please ensure that the referral reaches the hospital within 24 hours of the GP’s decision to refer.

<table>
<thead>
<tr>
<th>Epsom and St Helier NHS Trust</th>
<th>St George’s Healthcare NHS Trust</th>
</tr>
</thead>
<tbody>
<tr>
<td>Epsom General Hospital</td>
<td>St George’s Hospital</td>
</tr>
<tr>
<td>Dorking Road, Epsom</td>
<td>Wrythe Lane, Epsom</td>
</tr>
<tr>
<td>KT18 7EG</td>
<td>Surrey SM5 1AA</td>
</tr>
<tr>
<td>FAX: 020 8296 2741</td>
<td>FAX: 020 8296 2741</td>
</tr>
<tr>
<td>TEL: 020 8296 2742</td>
<td>TEL: 020 8296 2742</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Croydon University Hospital NHS Trust</th>
<th>Kingston Hospital NHS Trust</th>
</tr>
</thead>
<tbody>
<tr>
<td>Croydon University Hospital</td>
<td>Kingston Hospital</td>
</tr>
<tr>
<td>London Road, Croydon</td>
<td>Galsworthy Road</td>
</tr>
<tr>
<td>CR7 7YE</td>
<td>Kingston KT2 7OB</td>
</tr>
<tr>
<td>FAX: 020 8401 3337</td>
<td>FAX: 020 8934 3306</td>
</tr>
<tr>
<td>TEL: 020 8401 3986</td>
<td>TEL: 020 8934 3305</td>
</tr>
<tr>
<td></td>
<td>E-mail: <a href="mailto:cancemreferral@chsft.stgeorges.nhs.uk">cancemreferral@chsft.stgeorges.nhs.uk</a></td>
</tr>
</tbody>
</table>
**APPENDIX 1: URGENT SUSPECTED BRAIN AND CENTRAL NERVOUS SYSTEM CANCERS REFERRAL FORMS**

**SECTION 1 - PATIENT INFORMATION**

<table>
<thead>
<tr>
<th>SURNAME</th>
<th>FIRST NAME</th>
<th>Scottish</th>
<th>English</th>
<th>GPs</th>
<th>NHS Number</th>
<th>Number of parents</th>
<th>Address</th>
<th>Post Code</th>
<th>Daytime Telephone</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Gender</th>
<th>M / F</th>
<th>D.O.B.</th>
<th>Patient aware the referral is urgent?</th>
<th>Y / N</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Address</th>
<th>Post Code</th>
<th>Daytime Telephone</th>
</tr>
</thead>
</table>

**SECTION 2 - PRACTICE INFORMATION**

**SECTION 3 - CLINICAL INFORMATION**

**Progressive focal deficit**

- Weakness
- Unsteadiness
- Unilateral sensory loss
- Number / tingling
- Visual disturbance
- Cranial nerve palsy

**Progressive focal deficit**

- Unilateral sensory loss
- Number / tingling
- Visual disturbance
- Cranial nerve palsy

**Raised intracranial pressure**

- Headache
- Nausea
- Vomiting
- Double vision
- Intermittent dizziness

**Seizures / blackout**

- Date of onset:
- Focal onset
- Postictal deficit
- Associated (inter-ictal) focal deficit
- Unpredictable status epilepticus

**Mental state change - short history of**

- Cognitive decline or memory loss
- Behavioural change
- Personality change

**Prior cancer diagnostic**

**Other referrals**

**Use this proforma to refer urgently (2 Week Wait)**

**Investigations in Primary Care**

In a patient with new, unexplained headaches or neurological symptoms, undertake a neurological examination guided by the symptoms, but including examination for papilloedema. Note that the absence of papilloedema does not exclude the possibility of a brain tumour.

When a patient presents with a seizure, take a detailed history from the patient and an eyewitness to the event. Carry out a physical examination, including cardiac, neurological and mental state, and developmental assessment, where appropriate.

**Approved by the South East London Cancer Network in November 2006.**

For comments, additional copies, or patient information resources for GPs, to contact the Network on Tel: 020 7188 7020 / Fax: 020 7188 7101, or visit our website: www.selcn.nhs.uk.
### URGENT SUSPECTED BRAIN/CNS CANCER REFERRAL FORM

Please ensure this form is attached to your Choose and Book referral.

<table>
<thead>
<tr>
<th>Hospital to which patient is being referred:</th>
</tr>
</thead>
<tbody>
<tr>
<td>West Middlesx University Hospital NHS Trust</td>
</tr>
<tr>
<td>Fax: 020 8321 5157 Tel: 020 8321 6776</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Patient details</th>
<th>GP Details</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>NHS No:</strong></td>
<td>Dr:</td>
</tr>
<tr>
<td><strong>Surname:</strong></td>
<td>Address:</td>
</tr>
<tr>
<td><strong>First Name:</strong></td>
<td>Tel:</td>
</tr>
<tr>
<td><strong>Age / D.O.B:</strong></td>
<td>Fax:</td>
</tr>
<tr>
<td><strong>Address:</strong></td>
<td>Email:</td>
</tr>
<tr>
<td><strong>Postcode:</strong></td>
<td>Date of decision to refer:</td>
</tr>
<tr>
<td><strong>Tel/day:</strong></td>
<td><strong>Signature:</strong></td>
</tr>
<tr>
<td><strong>Have you informed the patient that you suspect brain/cns cancer?</strong></td>
<td><strong>Y / N</strong></td>
</tr>
<tr>
<td><strong>Have you given the patient the 2WW information leaflet?</strong></td>
<td><strong>Y / N</strong></td>
</tr>
<tr>
<td><strong>Have you told the patient they will be seen within 2 weeks?</strong></td>
<td><strong>Y / N</strong></td>
</tr>
<tr>
<td><strong>Has the patient had a previous diagnosis of cancer?</strong></td>
<td><strong>Y / N (Specify if known)</strong></td>
</tr>
<tr>
<td><strong>Hospital number (if known):</strong></td>
<td>** Interpreter required? Y / N**</td>
</tr>
</tbody>
</table>

#### Symptoms and Clinical Findings

If symptoms/signs brain tumour suspected or if unsure if tumour or other brain pathology e.g. CVA discuss with local specialist

<table>
<thead>
<tr>
<th>Progressive neuro-deficit</th>
<th>Impairment of higher mental functions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nausea/vomiting</td>
<td>Dipsyphasia</td>
</tr>
<tr>
<td>Headache</td>
<td>Limb – Ataxia</td>
</tr>
<tr>
<td>Cranial nerve palsy</td>
<td>Hemisensory loss</td>
</tr>
<tr>
<td>Short history of behaviour or personality change</td>
<td>Hemiparesis</td>
</tr>
</tbody>
</table>

Raised intracranial pressure

<table>
<thead>
<tr>
<th>Nausea/vomiting</th>
<th>Double vision</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intermittent drowsiness</td>
<td></td>
</tr>
<tr>
<td>Short history cognitive decline (memory loss)</td>
<td></td>
</tr>
<tr>
<td>Short history of behaviour or personality change</td>
<td></td>
</tr>
</tbody>
</table>

### EXAMINATION FINDINGS

- Impairment of higher mental functions
- Dipsyphasia
- Limb – Ataxia
- Hemisensory loss
- Hemiparesis
- Cranial nerves – Papilloedema
- Extracranial muscular palsy
- Facial weakness
- Unilateral deafness
- Other neuro examination

Additional information: Include any investigations arranged or results obtained and any other information you think is relevant.
Appendix 2: NCSI Treatment Summary

Dear Dr X

Re: Add in patient name, address, date of birth and record number

Your patient has now completed their initial treatment for cancer and a summary of their diagnosis, treatment and on-going management plan are outlined below. The patient has a copy of this summary.

<table>
<thead>
<tr>
<th>Diagnosis:</th>
<th>Date of Diagnosis:</th>
<th>Organ/Staging</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Local/Distant</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Summary of Treatment and relevant dates:</th>
<th>Treatment Aim:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Possible treatment toxicities and / or late effects:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Advise entry onto primary care palliative or supportive care register</td>
</tr>
<tr>
<td></td>
<td>Yes / No</td>
</tr>
<tr>
<td></td>
<td>DS 1500 application completed</td>
</tr>
<tr>
<td></td>
<td>Yes/No</td>
</tr>
<tr>
<td></td>
<td>Prescription Charge exemption arranged</td>
</tr>
<tr>
<td></td>
<td>Yes/No</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Alert Symptoms that require referral back to specialist team:</th>
<th>Contacts for re referrals or queries:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>In Hours:</td>
</tr>
<tr>
<td></td>
<td>Out of hours:</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Other service referrals made: (delete as nec)</td>
</tr>
<tr>
<td></td>
<td>District Nurse</td>
</tr>
<tr>
<td></td>
<td>AHP</td>
</tr>
<tr>
<td></td>
<td>Social Worker</td>
</tr>
<tr>
<td></td>
<td>Dietician</td>
</tr>
<tr>
<td></td>
<td>Clinical Nurse Specialist</td>
</tr>
<tr>
<td></td>
<td>Psychologist</td>
</tr>
<tr>
<td></td>
<td>Benefits/Advice Service</td>
</tr>
<tr>
<td></td>
<td>Other</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Secondary Care Ongoing Management Plan: (tests, appointments etc)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Required GP actions in addition to GP Cancer Care Review (e.g. ongoing medication, osteoporosis and cardiac screening)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Summary of information given to the patient about their cancer and future progress:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Additional information including issues relating to lifestyle and support needs:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Completing Doctor:</th>
<th>Signature:</th>
<th>Date:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Appendix 2: NCSI TREATMENT SUMMARY
GP READ CODES FOR COMMON CANCERS (For GP Use only). Other codes available if required.  
(Note: System codes are case sensitive so always ensure codes are transcribed exactly as below).

<table>
<thead>
<tr>
<th>System 1 (5 digit codes)</th>
<th>All other systems</th>
<th>Version 3 five byte codes (October 2010 release)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Diagnosis:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lung Malignant Tumour</td>
<td>XaOKG</td>
<td>Diagnosis: Malignant neoplasm of bronchus or lung</td>
</tr>
<tr>
<td>Carcinoma of Prostate</td>
<td>X78Y6</td>
<td>Malignant neoplasm of prostate</td>
</tr>
<tr>
<td>Malignant tumour of rectum</td>
<td>XE1vW</td>
<td>Malignant neoplasm of Rectum</td>
</tr>
<tr>
<td>Bowel Intestine</td>
<td>X78gK</td>
<td>Malignant neoplasm of Colon</td>
</tr>
<tr>
<td>Large Bowel</td>
<td>X78gN</td>
<td>Malignant neoplasm of female breast</td>
</tr>
<tr>
<td>Female Malignant Neoplasia</td>
<td>B34..</td>
<td>Malignant neoplasm of male breast</td>
</tr>
<tr>
<td>Male Malignant Neoplasia</td>
<td>B35..</td>
<td></td>
</tr>
<tr>
<td><strong>Histology/Staging/Grade:</strong></td>
<td></td>
<td><strong>Histology/Staging/Grade:</strong></td>
</tr>
<tr>
<td>Tumour grade</td>
<td>X7A6m</td>
<td>Tumour staging</td>
</tr>
<tr>
<td>Dukes/Gleason tumour stage</td>
<td>XaOLF</td>
<td>Gleason grading of prostate Ca</td>
</tr>
<tr>
<td>Recurrent tumour</td>
<td>XaOR3</td>
<td>Recurrence of tumour</td>
</tr>
<tr>
<td>Local Tumour Spread</td>
<td>X7818</td>
<td></td>
</tr>
<tr>
<td>Mets from 1°</td>
<td>XaFr.</td>
<td>Metastatic NOS</td>
</tr>
<tr>
<td><strong>Treatment Aim:</strong></td>
<td></td>
<td><strong>Treatment Aim:</strong></td>
</tr>
<tr>
<td>Palliative Radiotherapy</td>
<td>5149.</td>
<td>Radiotherapy tumour palliation</td>
</tr>
<tr>
<td>Curative Radiotherapy</td>
<td>Xa1PH</td>
<td>Radiotherapy</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>x71bL</td>
<td>Chemotherapy</td>
</tr>
<tr>
<td>Radiotherapy</td>
<td>Xa851</td>
<td></td>
</tr>
<tr>
<td><strong>Treatment toxicities/late effects:</strong></td>
<td></td>
<td><strong>Ongoing Management Plan</strong></td>
</tr>
<tr>
<td>Osteoporotic #</td>
<td>Xa1TO</td>
<td>At risk of osteoporosis</td>
</tr>
<tr>
<td>Osteoporosis</td>
<td>XaELC</td>
<td>Osteoporosis</td>
</tr>
<tr>
<td>Infection</td>
<td>Xa9ua</td>
<td></td>
</tr>
<tr>
<td><strong>Ongoing Management Plan</strong></td>
<td></td>
<td><strong>Ongoing Management Plan</strong></td>
</tr>
<tr>
<td>Follow up arranged (&lt;1yr)</td>
<td>8H8..</td>
<td>Follow up arranged</td>
</tr>
<tr>
<td>Follow up arranged (&gt;1yr)</td>
<td>XaL..</td>
<td></td>
</tr>
<tr>
<td>No FU</td>
<td>8HA1.</td>
<td>No follow up arranged</td>
</tr>
<tr>
<td>Referral PRN</td>
<td>8HAZ.</td>
<td></td>
</tr>
<tr>
<td><strong>Referrals made to other services:</strong></td>
<td></td>
<td><strong>Referrals made to other services:</strong></td>
</tr>
<tr>
<td>District Nurse</td>
<td>XaBSn</td>
<td>Refer to District Nurse</td>
</tr>
<tr>
<td>Social Worker</td>
<td>XaBSr</td>
<td>Refer to Social Worker</td>
</tr>
<tr>
<td>Nurse Specialist</td>
<td>XaAgq</td>
<td></td>
</tr>
<tr>
<td>SALT</td>
<td>XaBT6</td>
<td></td>
</tr>
<tr>
<td>Actions required by the GP</td>
<td>Actions required by the GP</td>
<td></td>
</tr>
<tr>
<td>---------------------------</td>
<td>---------------------------</td>
<td></td>
</tr>
<tr>
<td>Tumour marker monitoring</td>
<td>Xalqq</td>
<td></td>
</tr>
<tr>
<td>PSA</td>
<td>Xalqh</td>
<td></td>
</tr>
<tr>
<td>Osteoporosis monitoring</td>
<td>XalSd</td>
<td></td>
</tr>
<tr>
<td>Referral for specialist opinion</td>
<td>Xalst</td>
<td></td>
</tr>
<tr>
<td>Advised to apply for free prescriptions</td>
<td>9D05</td>
<td></td>
</tr>
<tr>
<td>Cancer Care Review</td>
<td>Xalyc</td>
<td></td>
</tr>
<tr>
<td>Palliative Care Review</td>
<td>XalG1</td>
<td></td>
</tr>
<tr>
<td><strong>Medication:</strong></td>
<td><strong>Medication:</strong></td>
<td></td>
</tr>
<tr>
<td>New medication started by specialist</td>
<td>XEOhn</td>
<td></td>
</tr>
<tr>
<td>Medication changed by specialist</td>
<td>8B316</td>
<td></td>
</tr>
<tr>
<td>Advice to GP to start medication</td>
<td>XaKbF</td>
<td></td>
</tr>
<tr>
<td>Advice to GP to stop medication</td>
<td>XaJC2</td>
<td></td>
</tr>
<tr>
<td><strong>Information to patient:</strong></td>
<td><strong>Information to patient:</strong></td>
<td></td>
</tr>
<tr>
<td>DS1500 form claim</td>
<td>XaCDx</td>
<td></td>
</tr>
<tr>
<td>Benefits counselling</td>
<td>6743.</td>
<td></td>
</tr>
<tr>
<td>Cancer information offered</td>
<td>XalmL</td>
<td></td>
</tr>
<tr>
<td>Cancer diagnosis discussed</td>
<td>XalpL</td>
<td></td>
</tr>
<tr>
<td>Aware of diagnosis</td>
<td>XaQly</td>
<td></td>
</tr>
<tr>
<td>Unaware of prognosis</td>
<td>XaVzE</td>
<td></td>
</tr>
<tr>
<td>Carer aware of diagnosis</td>
<td>XaVzA</td>
<td></td>
</tr>
<tr>
<td><strong>Miscellaneous:</strong></td>
<td><strong>Miscellaneous:</strong></td>
<td></td>
</tr>
<tr>
<td>On GSF palliative care framework</td>
<td>XaJv2</td>
<td></td>
</tr>
<tr>
<td>GP OOH service notified</td>
<td>Xaltp</td>
<td></td>
</tr>
<tr>
<td>Carers details</td>
<td>9180.</td>
<td></td>
</tr>
</tbody>
</table>

Note: The table shows actions and medications required by the GP, information to patients, and miscellaneous notes.
Appendix 3: LCA Key Worker Policy

Definition

A key worker is a person who, with the patient’s consent and agreement, takes a key role in coordinating the patient’s care and promoting continuity, ensuring the patient knows who to access for information and advice in relation to their cancer diagnosis. In addition, the key worker will facilitate patients making informed decisions about their treatment.

The implementation of the key worker role is a requirement of the National Cancer Peer Review Programme and detailed in the Manual for Cancer Services, originally published by the National Cancer Action Team (NCAT), and related site-specific Improving Outcomes Guidance, issued by the National Institute for Health and Care Excellence (NICE).

Principles and responsibilities

Designation

1. The key worker is a named clinical member of the site-specific multidisciplinary team (MDT), and acts as the point of contact between the patient and MDT.
2. The key worker is a healthcare professional.
3. The key worker is assigned by the core clinical nurse specialist of an MDT, agreed by the MDT and recorded within the patient record and multidisciplinary meeting proforma.
4. The name of the key worker, designation and contact details will also be recorded in the patient handheld record (PHR), if used, and included in all correspondence and in the patient medical records. All entries in the medical notes will comply with the NHS Litigation Authority standards.

Access

5. All cancer patients will be made aware of their allocated key worker, but have the right to ask for an alternative if they prefer. This will usually happen at diagnosis.
6. The key worker will provide a contact number to all the patients for whom they act as the key worker.

Multi-professional communication

7. If a more appropriate person is identified as a key worker at a point in the patient’s pathway, this will be discussed and agreed by the patient and the new key worker, and recorded in the patient’s notes. This situation is most likely to arise with referral to the palliative care team. In such cases the palliative care clinical nurse specialist will check if a key worker has already been identified for the patient by the relevant tumour MDT. The palliative care clinical nurse specialist will then negotiate and document care responsibilities in the patient’s notes.
8. The key worker may change as patients pass through various stages of the care trajectory or when care is transferred to a different Trust. It is the responsibility of the key worker to hand over to the next one, to document this in the patient’s notes and to keep the patient informed.
9. The key worker will lead on patient communication issues and coordination of the pathway for patients referred to the team.

10. The key worker will ensure that the patient pathway is coordinated and that all relevant information is transferred to the appropriate professionals as the patient moves across care boundaries, e.g. on admission to and discharge from institutions, when care is transferred between teams.

11. The key worker has responsibility for ensuring holistic needs assessments (HNAs) are recorded/documented in patient records.

**Patient communication and support**

12. Where possible, the key worker will be available to support the patient on diagnosis to signpost and provide them with information and contacts for the MDT, national information and support services, self-help groups and associated site-specific support.

13. If the key worker is not available at the time of diagnosis, the person who is providing support at the time will ensure that the patient is aware of the key worker role and provide the relevant contact details.

14. The key worker will be accessible to the patient as a constant point of contact, handing over to colleagues when unavailable and making sure that the patient has clear information about alternative contacts and cover arrangements.

15. The key worker will provide information, care and support throughout the patient journey regardless of the patient’s condition, liaising between health professionals to ensure continuity of care and a seamless service.

**Data/audit**

16. The key worker will contribute to the audit of the key worker role in their organisation.

**Annex A**

**NCAT peer review standard**

*There should be an operational policy whereby a single named key worker for the patient’s care at a given time is identified by the MDT members for each individual patient and the name and contact number of the current key worker is recorded in the patient’s case notes. The responsibility for ensuring that the key worker is identified should be that of the nurse MDT member(s).*

The above policy should have been implemented for patients who came under the MDT’s care after publication of these measures and who are under their care at the time of the peer review visit.

**Notes**

- According to the NICE supportive and palliative care guidance, a key worker is a person who, with the patient’s consent and agreement, takes a key role in coordinating the patient’s care and promoting continuity, e.g. ensuring that the patient knows who to access for information and advice. This is not intended to have the same connotation as the key worker in social work.

- It may be necessary to agree a single key worker across both a cancer site-specific MDT and the specialist palliative care MDT for certain patients.
Appendix 4: Competencies for Key Worker Role

- Work as an integral member of the multidisciplinary team (MDT) to ensure continuity of patient care.
- Initiate and participate in case conferences with all professionals involved in the delivery of patient care.
- Communicate and coordinate information to patients and carers, evaluating their levels of understanding and utilising a range of skills/techniques to overcome any communication difficulties.
- Demonstrate ability to verbally summarise patient information to facilitate understanding.
- Act as an advocate for the patient.
- Act as a communication resource and coordinator for other members of the MDT in the care of the key worker’s patient caseload.
- In conjunction with the MDT, provide patients with comprehensive information on the options available to them for treatment and care. Utilise their specialist knowledge and skills regarding disclosure of information.
- Coordinate the onward referral of patient and/or family members to appropriate clinical or support services.
- Ensure accurate follow-up documentation is maintained, including any changes in the named key worker.
- Utilise support strategies and interventions available to care for patients with complex needs, for example patients exhibiting denial/anger following a cancer diagnosis, adverse reactions to alteration in body image or reaching end of life.
- Demonstrate knowledge of holistic care relating to areas across the patient journey such as screening, curative and palliative treatment, spiritual care, aspects of nutrition and pharmacology, rehabilitation, discharge and collaborative working.
- Initiate appropriate referral or access to sources of specialist support for those experiencing, for example, sexual difficulties as a result of their illness or treatment.
- Utilise all forms of patient information to enable the patient to have a better understanding of their diagnosis and treatment plan. This will include the use of specific resources for patient/carers from minority groups.
- Facilitate the development of teaching and learning skills used to educate patients and other personnel.
- Contribute to the monitoring, audit and evaluation of adherence to policy/procedures/guidelines and standards of practice, initiating changes where appropriate to improve delivery of care to patients/carers within the MDT.
- Demonstrate ability to recognise abnormal grief reactions and refer on to appropriate agencies and healthcare professionals.
- Demonstrate a comprehensive knowledge of the assessment, care, management support, training education and information requirements for patients and carers across the care pathway for the particular specialty area.
• Assess and provide support that is appropriate to the context and sensitive to meet the patient/carer and/or family’s needs, facilitating access to additional support from other healthcare professionals or agencies as applicable and with the agreement of the patient and/or carer.

• Understand the ethical issues relating to treatment in advanced disease.

• Have sufficient knowledge and links with national/local support groups and be able to provide/record information relating to these groups to guide and advise patients.

• Provide information, education and relevant telephone contacts to patients and carers regarding the procedures and management of the side effects of treatment associated with the client group encountered in their practice.

• Be aware of local contact arrangements in the event of patients experiencing unwanted side effects.

• Demonstrate knowledge to prepare, inform and educate patients/carers for survivorship and, where applicable, primary care personnel regarding any associated care requirements, symptom management and contact details on discharge.

• Participate in inter-professional/inter-agency evaluation and audit to effect change for the continued improvement of the quality of care and service for patients.
## Appendix 5: LCA Holistic Needs Assessment Tool

### London Holistic Needs Assessment

For each item below, please tick yes or no if they have been a concern for you during the last week, including today. Please also tick discuss if you wish to speak about it with your health professional.

<table>
<thead>
<tr>
<th>Date:</th>
<th>Practical concerns</th>
<th>Yes</th>
<th>No</th>
<th>Discuss</th>
<th>Physical concerns</th>
<th>Yes</th>
<th>No</th>
<th>Discuss</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Caring responsibilities</td>
<td></td>
<td></td>
<td></td>
<td>High temperature</td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td>Housing or finances</td>
<td></td>
<td></td>
<td></td>
<td>Wound care</td>
<td></td>
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<tr>
<td></td>
<td>Transport or parking</td>
<td></td>
<td></td>
<td></td>
<td>Passing urine</td>
<td></td>
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<tr>
<td></td>
<td>Work or education</td>
<td></td>
<td></td>
<td></td>
<td>Constipation or diarrhoea</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Information needs</td>
<td></td>
<td></td>
<td></td>
<td>Indigestion</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Difficulty mixing plans</td>
<td></td>
<td></td>
<td></td>
<td>Nosebleed and/or vomiting</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Grocery shopping</td>
<td></td>
<td></td>
<td></td>
<td>Cough</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Preparing food</td>
<td></td>
<td></td>
<td></td>
<td>Changes in weight</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Bathing or dressing</td>
<td></td>
<td></td>
<td></td>
<td>Eating or appetite</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Laundry or housework</td>
<td></td>
<td></td>
<td></td>
<td>Changes in taste</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Family concerns</td>
<td></td>
<td></td>
<td></td>
<td>Sore or dry mouth</td>
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<td></td>
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<tr>
<td></td>
<td>Relationship with children</td>
<td></td>
<td></td>
<td></td>
<td>Feeling swollen</td>
<td></td>
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<td></td>
</tr>
<tr>
<td></td>
<td>Relationship with partner</td>
<td></td>
<td></td>
<td></td>
<td>Breathlessness</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Relationship with others</td>
<td></td>
<td></td>
<td></td>
<td>Pain</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Emotional concerns

- Loneliness or isolation: Tiling in hands or feet
- Sadness or depression: Hot flushes
- Worry, fear or anxiety: Moving around or walking
- Anger, frustration or guilt: Fatigue
- Memory or concentration: Sleep problems
- Hopelessness: Communication
- Sexual concerns: Personal appearance
- Other medical condition: Other medical condition

### For health professional use

- Spiritual concerns
- Date of diagnosis:
- Diagnosis:
- Pathway point:

### Care Plan

During my holistic needs assessment, these issues were identified and discussed:

<table>
<thead>
<tr>
<th>Example</th>
<th>Possible causes identified</th>
<th>Coping strategies discussed</th>
<th>Printed information provided</th>
<th>Referral to anxiety management programme; CNS to complete by 34th Dec</th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>Breathlessness</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
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<tr>
<td>4</td>
<td></td>
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</tr>
</tbody>
</table>

Other actions/outcomes e.g. a dental information given, itching motion, smoking cessation, ‘My actions’:

Signed (patient): Date:
Signed (healthcare professional): Date:

For health professional use

| Date of diagnosis | Diagnosis | Pathway point |
Appendix 6: Cancer Survivorship Guidelines

As cancer treatments become more effective, more people are living with and beyond cancer with specific needs as a direct result of the cancer and its treatment. The consequences of cancer treatment are dependent on multiple factors and affect each person differently. Consequences may be physical (e.g. cardiovascular conditions, impact on fertility, bone health and gastro-intestinal); emotional and psychological (e.g. anxiety, self-confidence and depression); social; spiritual; or cognitive. They can have an impact on every aspect of a person and on their family’s lives, from the ability to work, through to the ability to have a family or to participate in social activities. It is widely acknowledged that cancer survivors have a multitude of unmet needs following treatment, with a majority still having some needs 6 months later. Good survivorship care enables the person to live as full and active a life as possible.

Survivorship can be defined as:

“cover[ing] the physical, psychological and economic issues of cancer, from diagnosis until end of life. It focuses on the health and life of a person with cancer beyond the diagnosis and treatment phases. Survivorship includes issues related to the ability to get healthcare and follow-up treatment, late effects of treatment, second cancer and quality of life. Family members, friends and caregivers are also part of the survivorship experiences.”

National Cancer Institute, Dictionary of Cancer Terms, definition of ‘survivorship’

The National Cancer Survivorship Initiative (NCSI) vision document (DH 2010) mandated five shifts in care for individuals completing cancer treatment. NCSI advocates cancer being treated as a chronic illness, with patients empowered and supported to take an active role in their care. Improving Outcomes: a Strategy for Cancer (DH 2011) states that people living with and beyond a cancer diagnosis should have their full needs addressed to prevent long-term disability, enabling them to live a full, active, good quality life for as long as possible. Work within the NCSI has to date focused on survivorship from the end of treatment, but its report, Living With and Beyond Cancer: Taking Action to Improve Outcomes (DH 2013), acknowledges that survivorship care from the point of diagnosis is also vital. It challenges services to develop further and focuses on five new areas:

• information and support from diagnosis
• promoting recovery
• sustaining recovery
• managing consequences
• supporting people with active and advanced disease.

The importance of good survivorship care is well known: those who have unmet needs are 20% more likely to visit their GP and twice as likely to attend A&E than their healthy counterparts. They are more likely to be unemployed and many report economic hardship. Much has been achieved both nationally and locally to address this agenda. It is essential that in the LCA our patients have access to high-quality, equitable survivorship services on a par with the best in the country. We will continue to build on the successes to date.
The Consequences of Cancer and its Treatment (CCaT) collaborative group (a Macmillan Community of Interest) produced a ‘10 Top Tips’ guidance document for patients. These cover the key components of good survivorship care, and the LCA expects services to address these areas. The following nine points for professionals are based on the CCaT’s work.

1 Discuss a person’s needs.

The holistic needs assessment (HNA) has been shown to be effective in identifying a person’s areas of concern. It can take many forms and the LCA has developed its own tool, based on the concerns checklist and distress thermometer. The tool allows patients to specify what is of most concern to them, and so directs subsequent discussion and intervention to addressing these needs. It has scope to cover physical, emotional, spiritual, finance and welfare, and practical concerns. It is anticipated that as the HNA becomes embedded within the pathway, patients will start to ask for an HNA and professionals need to be able to respond to this.

**Recommendation:** Every patient should be offered an HNA at key pathway points, including at diagnosis and end of treatment, and whenever a person requests one.

2 Provide a treatment summary and care plan

A treatment summary provides a summary of the cancer treatments received by the end of first treatment, planned follow-ups (including mechanisms for these) and signs and symptoms of which to be aware. Their aim is to provide information not only to the patient, but also to the GP about possible consequences of cancer and its treatment, signs of recurrence and other important information.

A care plan is generated as a result of an HNA and is the agreed plan between the patient and healthcare professional about how the identified areas of concern will be addressed. This may cover provision of information (e.g. through an information prescription), onward referral for specialist assessment and intervention (e.g. breathlessness management), or things which the patient themselves can do (e.g. contact their HR department about graduated return to work options).

**Recommendation:** An end of treatment consultation should be offered to every patient. This should include an end of treatment HNA and associated written care plan, and should also include the discussion and provision of a comprehensive treatment summary.

3 Provide a main contact

Several pieces of UK-wide work have shown the necessity of a key contact, or key worker, not least the national Cancer Patient Experience Survey. It is now agreed that both patients and GPs (and other healthcare professionals) benefit from having a named person to contact if they need help or advice about issues related to the consequences of cancer and its treatment.

**Recommendation:** The treatment summary should include the details of a key worker in addition to details of who to contact out of hours. This should be sent to the GP, the patient and any others whom the patient identifies as necessary.
4 Identify post-treatment symptoms

As discussed above, cancer and its treatments can have far-reaching consequences and people with associated unmet needs are more likely to access healthcare services than their healthy counterparts. Providing information on likely post-treatment symptoms (e.g. neuropathic pain following thoracic surgery or peripheral neuropathy following chemotherapy), and how these can be managed or avoided, allows people to seek the right help from the right people at the right time.

**Recommendation:** Information on anticipated or possible consequences of cancer treatment and what to do if they occur should be routinely provided to all patients. This should be done from the time of discussion of treatment onwards, with the information clearly reiterated during the end of treatment consultation.

5 Provide support about day-to-day concerns

Life changes following a cancer diagnosis. It is recognised that people need help and support to find a ‘new normal’. This may cover any one of a multitude of aspects, from work and education, through to financial worries and needing help with caring responsibilities. Help should be offered at all key points in the pathway, but may be of particular relevance at the end of treatment and may well be highlighted in the HNA. There are various options for written information provision (e.g. Macmillan Cancer Support information leaflets and information prescriptions) as well as some specialist services (e.g. Citizens Advice). Reports published by the NCSI, available on the NCSI website, may be of use to professionals.

**Recommendation:** Patients should be routinely asked about whether they need support with day-to-day issues and referrals made to specialist services when necessary.

6 Talk about how you feel

Having a cancer diagnosis has an emotional impact, and at the end of treatment people experience a wide range of emotions. Sometimes, these can be dealt with by the person alone or with support from the key worker and others, but some people will need referral to psychological support services. This may be true not only for patients but their family and carers too.

**Recommendation:** Use an HNA to identify emotional concerns. Further screening tools (e.g. the Hospital Anxiety and Depression Scale) should be considered, with subsequent referrals made as necessary.

7 Healthy lifestyle

There is a growing body of evidence which supports the adoption of a healthy lifestyle for those who have had a cancer diagnosis.

**Recommendation:** Patients are provided with dietary advice, based on the WCRF recommendations, at the end of treatment with referral to specialist dietitians as needed.

Physical activity

There has been a dramatic rise in the amount of high-quality published research on the role of exercise in cancer in recent years. Physical activity results in improvement in quality of life, fitness and function and
symptoms related to cancer and its treatments. It reduces cancer recurrence, incidence of second cancers and reduces both all-cause and cancer-specific mortality.

There is wide consensus that cancer survivors should exercise to the same level as the general population for health benefits. Research suggests that a combination of cardiovascular and muscular strength training has additional benefits over and above undertaking only one type of exercise.

**Recommendations:** Patients should be encouraged to maintain or increase their level of physical activity both during and after treatment in line with national guidance. They should be referred for specialist assessment by a physiotherapist as necessary.

Patients should also be offered access to a health promotion event, such as a health and well-being clinic, at the end of treatment.

8 Self-managed follow-up

There is a move towards increased self-management and follow-up closer to home. This has clear benefits to patients, including reduced anxiety in the lead-up to routine appointments and less interference in their day-to-day life caused by travelling to hospitals. In addition, research has shown that recurrence is more likely to be detected by the patient themselves between appointments, rather than at the outpatient appointment. By reducing unnecessary appointments, Trusts are able to see new patients more quickly and spend more time with more complex patients.

For self-management to be effective, patients need to be given the right information about the signs and symptoms of recurrence and clear pathways to follow if they have concerns. They should also be guaranteed a fast, explicit route to re-access services if necessary. A telephone helpline is suggested, which should be staffed by senior, experienced staff.

**Recommendation:** In addition to the use of treatment summaries (as described above), services should investigate the feasibility of rolling out self-managed/patient-led follow-up.

9 Encourage survivors to share their experience

Sharing the experience of living with and beyond cancer can be beneficial to the patients themselves, their carers and others who have a cancer experience. Providing feedback on their experience, and volunteering and participation in research can all have a positive impact on the patient.

**Recommendation:** Patients should be offered information about local support groups and where they can access further information on sharing their experiences.

To summarise, these guidelines set out how to best address survivorship care, based on best available evidence, current national policy and guidance and in response to work such as the national Cancer Patient Experience Survey.
Appendix 7: Teenagers and Young Adults: Referral to Multidisciplinary Team Proforma

External referrals to The Royal Marsden TYA MDT: please complete section A and provide copies of site-specific MDT outcome sheet and original pathology report. We are unable to register patient on the TYAC database without this information.

<table>
<thead>
<tr>
<th>Section A: Patient details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name:</td>
</tr>
<tr>
<td>Ethnic origin:</td>
</tr>
<tr>
<td>Referring hospital:</td>
</tr>
<tr>
<td>History &amp; diagnosis:</td>
</tr>
<tr>
<td>Treatment/protocol:</td>
</tr>
<tr>
<td>Referring consultant name and specialty:</td>
</tr>
<tr>
<td>Discussed in site specific MDT?:</td>
</tr>
<tr>
<td>Reason for referral to RM TYA MDT:</td>
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</table>

<table>
<thead>
<tr>
<th>Section B: Record of RMH TYA MDT discussion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date of TYA MDT:</td>
</tr>
<tr>
<td>Place of care:</td>
</tr>
<tr>
<td>Named consultant at RMH (if relevant):</td>
</tr>
<tr>
<td>Named key worker at RMH (if relevant):</td>
</tr>
<tr>
<td>TYA Designated Hospital / Shared care hospital</td>
</tr>
<tr>
<td>Family / social circumstances:</td>
</tr>
<tr>
<td>Education / work:</td>
</tr>
<tr>
<td>Psychosocial issues:</td>
</tr>
<tr>
<td>Site-specific MDT treatment plan accepted by TYA MDT?: Yes / No</td>
</tr>
<tr>
<td>Clinical trial:</td>
</tr>
<tr>
<td>Fertility preservation discussed:</td>
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<tr>
<td>Action points arising from TYA MDT:</td>
</tr>
<tr>
<td>TYA MDT discussion documented by:</td>
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</table>
## Specialist Palliative Care (SPC) Community and SPC Inpatient Unit Referral Form

<table>
<thead>
<tr>
<th>Specialist Palliative Care Community Teams &amp; Inpatient Units across South &amp; West London</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Greenwich &amp; Bexley Community Hospice</strong>&lt;br&gt;Bostall Hill, Abbey Wood SE2 0GB&lt;br&gt;Home Care: Tel: 020 83205837 Fax: 020 83205839&lt;br&gt;Admissions: Tel: 020 83122244 Fax: 020 83124344</td>
</tr>
<tr>
<td><strong>Lewisham Macmillan Community Team</strong>&lt;br&gt;Lewisham High Street SE13 6LH&lt;br&gt;Home Care: Tel: 020 8323 3017&lt;br&gt;Admissions: Fax: 020 8323 3270</td>
</tr>
<tr>
<td><strong>St Christopher’s Hospice</strong>&lt;br&gt;Lawrence Park Rd, London SE26 6DZ&lt;br&gt;Home Care: Tel: 020 8776 5656 Fax: 020 87765798&lt;br&gt;Admissions: Tel: 020 87684582 Fax: 02086595051&lt;br&gt;St Christopher’s Bromley&lt;br&gt;Tele: 01689 825755 Fax: 01689 892999</td>
</tr>
<tr>
<td><strong>Guy’s &amp; St Thomas’ Community Team</strong>&lt;br&gt;Guy’s Hospital, Great Maze Pond&lt;br&gt;SE1 9RT&lt;br&gt;Tel: 020 71884754 Fax: 020 71884748</td>
</tr>
<tr>
<td><strong>Meadow House Hospice</strong>&lt;br&gt;Southall UB1 3HW&lt;br&gt;Tele: 020 89675179&lt;br&gt;Fax: 020 89675756</td>
</tr>
<tr>
<td><strong>St John’s Hospice</strong>&lt;br&gt;Grove End Road, St John’s Wood&lt;br&gt;NW8 9NH&lt;br&gt;Tel: 020 78064040 Fax: 020 78064041</td>
</tr>
<tr>
<td><strong>Harlington Hospice</strong>&lt;br&gt;St Peter’s Way, Harlington UB3 SAB&lt;br&gt;Tel: 020 87559045 Fax: 020 87559060</td>
</tr>
<tr>
<td><strong>Michael Sobell House</strong>&lt;br&gt;Northwood, Middlesex HA6 2RN&lt;br&gt;Telephone: 01923 844531 Fax: 01923 844565</td>
</tr>
<tr>
<td><strong>St Luke’s Hospice</strong>&lt;br&gt;Kenton Road, Harrow HA3 0YG&lt;br&gt;Tel: 020 83852801 Fax: 020 83852808</td>
</tr>
<tr>
<td><strong>Harrow Community Team</strong>&lt;br&gt;Kenton Road, Harrow&lt;br&gt;HA3 0YG&lt;br&gt;Tel: 020 83828084 Fax: 020 83828085</td>
</tr>
<tr>
<td><strong>Pembroke Palliative Care Centre</strong>&lt;br&gt;Exmouth Street, W10 6DZ&lt;br&gt;Tele: 020 8962 4410&lt;br&gt;Inpatient Fax: 020 89624422&lt;br&gt;Community Services Fax: 020 89624413</td>
</tr>
<tr>
<td><strong>St Raphael’s Hospice</strong>&lt;br&gt;London Road, North Cheam&lt;br SM3 9DX&lt;br&gt;Tel: 020 80997777 Fax: 020 8099 1724</td>
</tr>
<tr>
<td><strong>Hillingdon Community Team</strong>&lt;br&gt;Field Heath Road, Uxbridge&lt;br&gt;UB8 3NN&lt;br&gt;Tel: 01895 279412 Fax: 01895 279452</td>
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<tr>
<td><strong>Princess Alice Hospice</strong>&lt;br&gt;West End Lane, Esher&lt;br&gt;KT10 9NA&lt;br&gt;Tele: 01372 461804 Fax: 01372 470937</td>
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<tr>
<td><strong>Trinity Hospice</strong>&lt;br&gt;Clapham Common SW4 0RN&lt;br&gt;Tele: 020 7787 1000 Ref &amp; Admissions: Nurse: 020 77871065&lt;br&gt;Tele: 020 7787 1067</td>
</tr>
</tbody>
</table>

For further information and advice on these services, please visit the Help the Hospices service directory at: [http://www.helpinhospices.org.uk/about-hospice-care/find-a-hospice/uk-hospice-and-palliative-care-services/](http://www.helpinhospices.org.uk/about-hospice-care/find-a-hospice/uk-hospice-and-palliative-care-services/) and enter the postcode provided above.

Every LCA hospital has a Specialist Palliative Care team; if your patient is a hospital inpatient, please contact the team, via the relevant hospital switchboard.

**FAX MESSAGE**

<table>
<thead>
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<th>From:</th>
<th>To:</th>
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<tr>
<td>Fax No:</td>
<td>Date:</td>
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<td>No. of pages (incl cover sheet):</td>
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<tr>
<td>Additional information</td>
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</table>

Confidentiality: The content of this fax and attached documents are confidential and intended for the use of the addressee(s) named above. If you are not the addressee, you are hereby notified that you may not disclose, reproduce or otherwise disseminate or make use of this information for yourself or any third party. If you have received this in error, please notify us on the telephone number given above.

**PLEASE SEND COPIES OF RECENT CLINICAL CORRESPONDENCE WITH THIS FORM – including recent clinic letters, blood tests and most recent imaging**

NB: INSUFFICIENT INFORMATION MAY DELAY PATIENT ASSESSMENT

**PATIENT NAME ................................................................. NHS No: .................................................................**

LCA Palliative Care Group Revised April 2014

82
### Referral Form for SPC Community and Inpatient Units (2/3)

#### Essential Patient Details

<table>
<thead>
<tr>
<th>Field</th>
<th>Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surname</td>
<td>Male/Female Age:</td>
</tr>
<tr>
<td>First Name</td>
<td>DoB</td>
</tr>
<tr>
<td>Address</td>
<td></td>
</tr>
<tr>
<td>Postcode</td>
<td>Marital Status</td>
</tr>
<tr>
<td>Tel</td>
<td>Mob</td>
</tr>
<tr>
<td>NHS number</td>
<td>Hospital No.</td>
</tr>
</tbody>
</table>

#### Communication

<table>
<thead>
<tr>
<th>Field</th>
<th>Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fruent in English? Yes ☐ No ☐ (If ‘no’ proceed with remaining questions)</td>
<td></td>
</tr>
<tr>
<td>First Language, if not English:</td>
<td></td>
</tr>
<tr>
<td>Would interpreter be helpful to patient and Palliative Care staff? Yes ☐ No ☐</td>
<td></td>
</tr>
</tbody>
</table>

#### Next of Kin/Patient Representatives

<table>
<thead>
<tr>
<th>Field</th>
<th>Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name</td>
<td>Name</td>
</tr>
<tr>
<td>Address</td>
<td>Based at</td>
</tr>
<tr>
<td>Telephone</td>
<td></td>
</tr>
<tr>
<td>Relationship to patient</td>
<td>Postcode</td>
</tr>
<tr>
<td>Main Carer (if different from above)</td>
<td>Social Services Yes ☐ No ☐</td>
</tr>
<tr>
<td>Name</td>
<td>Name</td>
</tr>
<tr>
<td>Telephone</td>
<td>Based at</td>
</tr>
<tr>
<td>Relationship to patient</td>
<td>Fax/email</td>
</tr>
</tbody>
</table>

#### Reason for Referral

<table>
<thead>
<tr>
<th>Field</th>
<th>Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain/Symptom centre</td>
<td></td>
</tr>
<tr>
<td>Emotional/psychological support</td>
<td></td>
</tr>
<tr>
<td>Social/Financial</td>
<td></td>
</tr>
<tr>
<td>Assessment for hospice admission</td>
<td></td>
</tr>
<tr>
<td>Care support</td>
<td></td>
</tr>
<tr>
<td>Other reason (please give details below)</td>
<td></td>
</tr>
</tbody>
</table>

#### Service requested

<table>
<thead>
<tr>
<th>Field</th>
<th>Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home assessment and support</td>
<td></td>
</tr>
<tr>
<td>Hospital assessment</td>
<td></td>
</tr>
<tr>
<td>Day Care</td>
<td></td>
</tr>
<tr>
<td>Outpatient service</td>
<td></td>
</tr>
<tr>
<td>Admission (circle)</td>
<td></td>
</tr>
<tr>
<td>Respite / symptom control / terminal care</td>
<td></td>
</tr>
<tr>
<td>Hospice at Home</td>
<td></td>
</tr>
</tbody>
</table>

#### The patient is currently

<table>
<thead>
<tr>
<th>Field</th>
<th>Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>At Home</td>
<td></td>
</tr>
<tr>
<td>In Hospital (area)</td>
<td></td>
</tr>
<tr>
<td>Other e.g. Nursing Home</td>
<td></td>
</tr>
<tr>
<td>Please specify</td>
<td></td>
</tr>
<tr>
<td>Does patient live alone? Yes ☐ No ☐</td>
<td></td>
</tr>
</tbody>
</table>

#### Any access issues (e.g. key safe):

<table>
<thead>
<tr>
<th>Field</th>
<th>Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>MIRS Status Positive ☐ Negative ☐ Not known ☐</td>
<td></td>
</tr>
<tr>
<td>Any other communicable infection:</td>
<td></td>
</tr>
<tr>
<td>Special devices in situ? Yes ☐ No ☐</td>
<td></td>
</tr>
</tbody>
</table>

#### Referrer's Name (please print)

<table>
<thead>
<tr>
<th>Information</th>
</tr>
</thead>
</table>

#### IS REFERRAL URGENT (assess within 2 working days)? Yes ☐ No ☐

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LCA Palliative Care Group Revised April 2014
Referral Form for SPC Community and Inpatient Units (3/3)

In-Patient details
Hospital: 
NHS No: 
Ward: Direct Ward Ext. 
Telephone: 
Key worker: Date of discharge (if known): 
Consultant: Is Palliative Care team involved? Yes ☐ No ☐

Brief History of diagnosis(es) and Key treatments
Date Progression of disease and investigations/treatment Consultant and hospital

Current palliative care problems
1. 
2. 
3. 
4. 
5. 
6. 

Patient Mobility: Bariatric Nursing required? Yes ☐ No ☐

Any other comments/information (including preferences expressed about care or other psychosocial or spiritual issues):

Referrer’s expectation of current treatment (please circle) symptom control / life prolonging / curative
Prognosis: In your opinion, is the patient
Stable? Yes ☐ No ☐ Unstable? Yes ☐ No ☐ Deteriorating? Yes ☐ No ☐ Dying? Yes ☐ No ☐
Is death anticipated within: Months ☐ Weeks ☐ Days ☐

Patient on Coordinate My Care? Yes ☐ No ☐ Unknown ☐ If not please give reason:
On the GSF register? Yes ☐ No ☐ Unknown ☐ DNACPR in place? Yes ☐ No ☐

Past Medical and Psychiatric History Current Medication

Known Drug Sensitivities/Allergies:
Yes ☐ No ☐ Details:

Insight: Has patient been told diagnosis? Yes ☐ No ☐ Is the carer aware of patient’s diagnosis? Yes ☐ No ☐
Does patient discuss the illness freely? Yes ☐ No ☐

Please ensure patients are aware information will be held on computer according to the Data Protection Act.

Referrer’s signature: Name (please print): 
Job title: Contact number: Reput name: 
Surgery or Hospital: Date: 

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