



Complete Summary

GUIDELINE TITLE

Improving outcomes for people with brain and other CNS tumours.

BIBLIOGRAPHIC SOURCE(S)

National Collaborating Centre for Cancer. Improving outcomes for people with brain and other CNS tumours. London (UK): National Institute for Health and Clinical Excellence (NICE); 2006 Jun. 180 p. [23 references]

GUIDELINE STATUS

This is the current release of the guideline.

COMPLETE SUMMARY CONTENT

SCOPE
METHODOLOGY - including Rating Scheme and Cost Analysis
RECOMMENDATIONS
EVIDENCE SUPPORTING THE RECOMMENDATIONS
BENEFITS/HARMS OF IMPLEMENTING THE GUIDELINE RECOMMENDATIONS
QUALIFYING STATEMENTS
IMPLEMENTATION OF THE GUIDELINE
INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT
CATEGORIES
IDENTIFYING INFORMATION AND AVAILABILITY
DISCLAIMER

SCOPE

DISEASE/CONDITION(S)

- Brain tumors, including:
 - Low-grade gliomas
 - High-grade gliomas
 - Meningiomas
 - Metastases
- Pituitary, spinal cord, and skull base tumors
- Primary central nervous system (CNS) lymphoma, medulloblastoma, pineal tumors, and optic gliomas

GUIDELINE CATEGORY

Counseling
Diagnosis

Evaluation
Management
Treatment

CLINICAL SPECIALTY

Endocrinology
Family Practice
Internal Medicine
Neurology
Oncology
Pathology
Psychiatry
Psychology
Radiation Oncology
Radiology

INTENDED USERS

Advanced Practice Nurses
Allied Health Personnel
Health Care Providers
Hospitals
Nurses
Physician Assistants
Physicians
Psychologists/Non-physician Behavioral Health Clinicians
Social Workers

GUIDELINE OBJECTIVE(S)

To describe key aspects of services required to achieve the best outcomes for adult patients with tumours of the brain and central nervous system (CNS)

TARGET POPULATION

- Adults with tumours of the brain (including primary central nervous system [CNS] lymphomas and teratomas), meninges, and other sites in the central nervous system
- Adults with cranial nerve tumours and primary base of skull tumours
- Adults with pituitary tumours
- Adults with brain metastases from tumours at other primary sites in whom complex neurological or neurosurgical intervention is required
- Adults with syndromes where there is a recognised increased lifelong risk of CNS tumour formation
- Adults with nerve root tumours compressing the spinal cord

Groups that are **not** covered:

- Children and adolescents with brain and CNS tumours whose care will be covered by the Child and Adolescent guidance

- Adults and children with tumours of peripheral nerves
- Adults and children with other space occupying brain lesions (for example, arteriovenous malformation)

INTERVENTIONS AND PRACTICES CONSIDERED

Diagnosis

Imaging, including

- Timely access to computed tomography, magnetic resonance imaging
- Establishment of a rapid access system (electronic image transfer system) between local hospital and neuroscience multidisciplinary team
- Establishment of ready access to neurosurgical biopsy or resection service, including image localization and stereotactic techniques

Management/Treatment

1. Surgery
2. Radiotherapy
3. Chemotherapy
4. Intraoperative histopathological evaluation
5. Intraoperative neurophysiological recording
6. Supportive care
 - Open communication with patients and families/carers
 - Provision of information for patients and families/carers
 - Neuropsychiatry and neuropsychological assessment and support
7. Rehabilitation
8. Palliative care

Service Organization

1. Delivery of care by a multidisciplinary team (MDT)
2. Referral guidelines and early referral
3. Specialist teams treatment and follow up for pituitary and pituitary related tumours, intradural spinal cord tumours, skull-based tumours
4. Establishment of national tumour groups for management of rare central nervous system (CNS) tumours (primary nervous system lymphoma, medulloblastoma, pineal tumours, optic pathway gliomas)
5. Specialist care for patients with genetic predispositions to developing CNS tumours
6. Information management

MAJOR OUTCOMES CONSIDERED

- Morbidity, mortality, and diagnostic yield/accuracy associated with biopsies
- Survival
- Treatment related complications
- Patient quality of life
- Patient/carer satisfaction

METHODOLOGY

METHODS USED TO COLLECT/SELECT EVIDENCE

Hand-searches of Published Literature (Primary Sources)
Hand-searches of Published Literature (Secondary Sources)
Searches of Electronic Databases

DESCRIPTION OF METHODS USED TO COLLECT/SELECT THE EVIDENCE

Literature Searching

Systematic search strategies were constructed by the Information Specialist to identify published evidence for the research questions set by the Guideline Development Group (GDG). A sample search strategy is provided (see Appendix A of the Evidence Review, listed in the "Availability of Companion Documents" field). The search period ended at the end of April 2005.

Unlike clinical guidelines which focus on specific clinical questions, the research questions for this service guidance addressed broad issues of service provision. Consequently, there was a wide range of topic areas for consideration. For this reason and, due to the large number of research questions, the questions were prioritised by the Lead Researcher/GDG Chair/GDG Clinical Lead for either full searching (using search strategies as shown in Appendix A of the Evidence Review) or 'high level' searching. High level searching involved identifying evidence from other suitable sources, examples of which are provided in Appendix B of the Evidence Review (see "Availability of Companion Documents" field).

Studies were selected for critical appraisal according to the hierarchy of evidence (Scottish Intercollegiate Guidelines Network 2002; National Institute for Health and Clinical Excellence 2005), relevance to the research questions and applicability to service provision within the National Health Service (NHS) in England and Wales.

Identified titles and abstracts were initially screened for relevance to the clinical question by the Information Specialist and thereafter by the Researcher. Definite inclusion/exclusion criteria were not employed for articles, because of the nature and variability of the literature on service delivery. Only articles in English were selected for critical appraisal. In some instances help from a member of the GDG was enlisted to verify the relevance of selected articles and as a supplementary check on the completeness of the search. In general no formal contact was made with the authors for each paper identified, but occasionally communication was made for clarification of specific points.

Other Sources of Evidence

Key strategic documents pertinent to brain and central nervous system (CNS) tumours were also identified as sources of evidence. Relevant national and international guidelines were accepted as sources of evidence and were appraised for quality using the Appraisal of Guidelines Research and Evaluation tool (AGREE).

GDG Member and Stakeholder Submissions

A small volume of evidence was identified by individual GDG members or by stakeholders during consultation period(s). This evidence, like that from other sources, was critically appraised.

Complementary Paper

One complementary paper was written for this guidance, titled "The role of Neuropsychiatry in the treatment of neuro-oncology patients." This paper sets out current patterns of referral and treatment with regard to the role of neuropsychiatry in brain and CNS cancer, and is attached as Appendix D of the Evidence Review (See "Availability of Companion Documents" field).

NUMBER OF SOURCE DOCUMENTS

Not stated

METHODS USED TO ASSESS THE QUALITY AND STRENGTH OF THE EVIDENCE

Weighting According to a Rating Scheme (Scheme Given)

RATING SCHEME FOR THE STRENGTH OF THE EVIDENCE

Levels of Evidence

1++ High quality meta-analyses, systematic review of randomised controlled trials (RCTs), or RCTs with a very low risk of bias

1+ Well conducted meta-analyses, systematic reviews of RCTs, or RCTs with a low risk of bias

1– Meta-analyses, systematic review of RCTs, or RCTs with a high risk of bias

2++ High quality systematic reviews of case-control or cohort studies. High quality case-control or cohort studies with a very low risk of confounding, bias, or chance and a high probability that the relationship is causal

2+ Well conducted case-control or cohort studies with a low risk of confounding, bias, or chance and a moderate probability that the relationship is causal

2– Case-control or cohort studies with a high risk of confounding, bias, or chance and a significant risk that the relationship is not causal

3 Non-analytic studies (for example, case reports, case series)

4 Expert opinion, formal consensus

Note: Quality grading: ++ = good quality; + = fair; – = poor

METHODS USED TO ANALYZE THE EVIDENCE

Review of Published Meta-Analyses
Systematic Review with Evidence Tables

DESCRIPTION OF THE METHODS USED TO ANALYZE THE EVIDENCE

Synthesising the Evidence

As a general comment, evidence quality for many of the research questions is poor. There were very few randomised controlled trials (RCTs) relevant to the majority of the clinical questions. This is a widely acknowledged problem with health service research and every effort was made to maximise the retrieval of relevant high quality literature. Where available, evidence from good quality systematic reviews and meta-analyses was appraised and included in the evidence tables; not all studies in the reviews were individually appraised.

The evidence tables recommended for use in the National Institute for Clinical Excellence (NICE) methodology manual were modified to accept the type of studies identified for service guidance. In addition to the evidence tables a brief evidence summary was provided with each table titled, "Summary of the supporting evidence for the recommendations." The relevant research questions are included at the beginning of each section and also at the top of each evidence table.

METHODS USED TO FORMULATE THE RECOMMENDATIONS

Informal Consensus

DESCRIPTION OF METHODS USED TO FORMULATE THE RECOMMENDATIONS

Drafting Recommendations

The Guideline Development Group (GDG) members were allocated specific topic areas and asked to review the evidence tables pertaining to the topic and draft recommendations for the service guidance.

Agreeing Recommendations

Once an early draft of the guidance was produced, the GDG members were asked to review the draft document and consider whether:

- a. There appeared to be any major gaps in the synthesised evidence.
- b. The recommendations were justified from the evidence presented and whether they were sufficiently practical and precise so that health service commissioners and the relevant front line healthcare professionals could implement them.

During the development of this guidance no formal consensus methods were used. Consensus was achieved by informal means during GDG meetings and correspondence outside the meetings.

In this guidance, recommendations are not graded.

Writing of the Guidance

The first formal draft version of the guidance was coordinated by the Chair and Clinical Lead of the GDG in accordance with the decisions of the GDG.

RATING SCHEME FOR THE STRENGTH OF THE RECOMMENDATIONS

Not applicable

COST ANALYSIS

Executive Summary of Economic Analysis

The economic consequences of the recommendations of the 'Guidance on Cancer Services: Improving Outcomes in Brain and Other Central Nervous System [CNS] Tumours' in England and Wales are set out in this document. The analysis focuses on those aspects of the key recommendations that are likely to be of greatest consequence in terms of costs.

The summary of economic implications is outlined in Table A2 (Appendix 2) of the original guideline document.

There is uncertainty concerning the estimates presented and there will be variation at the neuroscience centre and cancer network level. Sensitivity analyses were conducted where appropriate in the estimated costs. Further assessments will be needed at cancer network level and/or National Health Service (NHS) trust level to determine the exact cost implications. The calculations for employment costs are based on pay levels at 2005/06, any future pay awards will also need to be taken into consideration. Work is currently being carried out in the NHS in England, in connection with 'Payment by Results', to develop a better understanding of costs of treatment and care. This may help these assessments in the future.

For further details of the economic implications of the guidance, refer to Appendix 4 of the original guideline document and the companion document "Improving outcomes for people with brain and other CNS tumours. Analysis of the potential economic impact of the guidance" (See "Availability of Companion Documents" field).

METHOD OF GUIDELINE VALIDATION

External Peer Review
Internal Peer Review

DESCRIPTION OF METHOD OF GUIDELINE VALIDATION

The guideline was validated through two consultations.

1. The first draft of the guideline (The full guideline, National Institute for Clinical Excellence [NICE] guideline and Quick Reference Guide) was consulted with Stakeholders and comments were considered by the Guideline Development Group (GDG).
2. The final consultation draft of the full guideline, the NICE guideline and the Information for the Public were submitted to stakeholders for final comments.

The final draft was submitted to the Guideline Review Panel for review prior to publication.

RECOMMENDATIONS

MAJOR RECOMMENDATIONS

Multidisciplinary Teams (MDT)

The care of all patients with central nervous system (CNS) tumours should be coordinated through a specific model of multidisciplinary assessment and care:

- A designated lead in every acute trust (see Table below titled "Designated lead")
- A neuroscience brain and other CNS tumours MDT, usually based at a neuroscience centre (see Tables below titled "Neuroscience brain and other CNS tumours MDT – responsibilities" and "Core membership of the neuroscience brain and other CNS tumours MDT")
- A cancer network brain and other CNS tumours MDT (see Tables below titled "The cancer network brain and other CNS tumours MDT – responsibilities" and "Core membership of the cancer network brain and other CNS tumours MDT")
- A key worker

Where the population served by the neuroscience centre and the cancer network are the same, the neuroscience MDT and cancer network MDT may involve many of the same healthcare professionals, but their responsibilities should be distinct (see below). In these circumstances it may be possible for the neuroscience and cancer network MDT meetings to occur at the same time. However, in many places separate MDTs with close working relationships should be in place (see Chapter 1 in the original guideline document).

All bodies that commission services for adults with CNS tumours within each cancer network should work together to ensure that these services function in a coordinated way. As many neuroscience units cover more than one cancer network area, it is important that networks collaborate and pool resources to deliver a full range of services. The establishment of teleconferencing facilities should be considered if geography makes it difficult for core team members to attend MDT meetings in person.

Neuroscience brain and other CNS tumours MDTs and cancer network brain and other CNS tumours MDTs should define their patient pathways.

Designated Lead

In every acute hospital there should be clearly defined mechanisms, coordinated by a designated lead for the trust (see Table below titled "Designated lead"), for referring all patients with suspected primary CNS tumours to the neuroscience MDT. These should ensure that clinical summaries for discussion and imaging scans of all patients with suspected primary CNS tumours are sent as soon as possible for review.

Table. Designated Lead

The designated lead should coordinate care at a trust level for all the hospitals within that trust. It is likely to be the role of the trust cancer lead clinician at the hospital or delegated to an appropriate consultant colleague. He or she is NOT clinically responsible for the individual patients, but should ensure that mechanisms are in place for the following:

- Receipt and management/processing of general practitioner referrals of patients with suspected CNS tumours
- Direct referral of patients to the neuroscience, spinal cord, pituitary or skull base MDTs as appropriate
- Availability of imaging scans and reports concerning suspected CNS tumours to the neuroscience MDT from radiology departments
- Timely communication between hospital clinicians, the neuroscience MDT and the cancer network MDT where these exist as separate teams
- Implementing actions within the trust arising from audits relevant to this component of the patient pathway

Multidisciplinary Teams

Designated Coordinator

Each neuroscience MDT should have a designated coordinator whose responsibilities include obtaining the imaging scans of patients with CNS tumours from radiology departments in their catchment area. In addition, the designated coordinator should obtain clinical summaries requested by the neuroscience MDT lead clinician (see Table below titled "Communication framework").

MDT Lead Clinician

The neuroscience MDT lead clinician should ensure that processes are in place for obtaining information about patients with CNS tumours directly from the clinician who arranged the imaging, if this is not forthcoming.

Neuroscience Brain and Other CNS Tumours MDT

The responsibilities and membership of the neuroscience MDT should be as defined in Tables below titled "Neuroscience brain and other CNS tumours MDT – responsibilities" and "Core membership of the neuroscience brain and other CNS tumours MDT," respectively.

All specialist neurosurgeons treating patients with CNS tumours should be core members of the neuroscience brain and other CNS tumours MDT (see Table below titled "Core membership of the neuroscience brain and other CNS tumours MDT").

The neuroscience MDT (see Tables below titled "Neuroscience brain and other CNS tumours MDT – responsibilities" and "Core membership of the neuroscience brain and other CNS tumours MDT") should review the case history and images and suggest a management plan which should be communicated back to the appropriate consultant. This plan might suggest referral of the patient for neurosurgical or oncological management or continuing care locally.

The neuroscience MDT should meet at weekly intervals to review all new patients and advise on the initial management of their disease in accordance with national cancer waiting times standards. If emergency intervention is necessary on clinical grounds, particularly out of hours, this should proceed according to agreed protocols prior to discussion by the neuroscience MDT. The operating surgeon should present these patients to the next available neuroscience MDT for discussion and referral, if necessary, to an appropriate core member. Patients reviewed and discussed previously should be referred back to the neuroscience MDT by the cancer network MDT for advice on further surgery or specialist interventions on relapse, according to agreed protocols.

The neuroscience MDT, in collaboration with the cancer network MDT, should develop, regularly review and audit evidence-based protocols for the management of patients with CNS tumours.

Following surgery or a decision by the neuroscience MDT that surgery would be inappropriate, continuing management and specialist supportive care should be provided according to protocol under the supervision of the cancer network MDT.

There may be some frail patients in whom active medical intervention is not considered appropriate. After review of the imaging scans and clinical summary at the neuroscience MDT, these patients should not be seen at the neuroscience centre but referred to the cancer network MDT to arrange appropriate assessment locally by a member of the MDT.

Clinical Nurse Specialist

Clinical nurse specialists should be core members of the neuroscience brain and other CNS tumours MDT and the cancer network brain and other CNS tumours MDT, and may need to work across several geographical sites. They are likely to take on the role of key worker for many patients, especially during the early stages of their clinical care, providing supportive care, information and continuity of care with other healthcare professionals.

Key Worker

All patients should have a clearly identified key worker as nominated by the neuroscience or cancer network MDT.

The key worker should promote continuity of care and manage transitions of care. This is achieved by assessing patients' needs, ensuring care plans have been agreed with patients and that findings from assessments and care plans are communicated to others involved in a patient's care. Coordination of care across the patient pathway should also include ensuring referral of patients to the appropriate multidisciplinary services at any time.

The key worker should ensure that patients, their relatives and carers know whom to contact when help and advice is needed. The key worker is likely to be the clinical nurse specialist or allied health professional (AHP) most closely involved with a patient's care.

The key worker role should be transferred to the most appropriate healthcare professional, for example a neurosurgeon, neurologist, General Practitioner (GP), community nurse, AHP or palliative care team member, as the patient's needs change, or at transitional points in the patient pathway, for example a neuroscience centre, oncology/radiotherapy centre or community.

The patient, their relatives and carers, should be informed of who their key worker is and how their key worker may be contacted.

Cancer Network Brain and Other CNS Tumours MDT

The responsibilities and membership of the cancer network MDT should be as defined in Tables below titled "The cancer network brain and other CNS tumours MDT – responsibilities" and "Core membership of the cancer network brain and other CNS tumours MDT", respectively. The cancer network MDT (see Tables below titled "The cancer network brain and other CNS tumours MDT – responsibilities" and "Core membership of the cancer network brain and other CNS tumours MDT") should meet at least monthly to coordinate care for 5–15 new patients and to monitor the ongoing care of approximately 50–100 patients on follow-up.

Table. Neuroscience Brain and Other CNS Tumours MDT – Responsibilities

The neuroscience MDT is the team responsible for the diagnosis and initial management (both surgical and non-surgical aspects of care) of most adult patients with CNS tumours. Membership of this team is summarised in the Table below titled "Core membership of the neuroscience brain and other CNS tumours MDT," and its responsibilities include the following:

- Establish a diagnosis for the optimal clinical management of the patient
- Develop management plans for patients with CNS tumours at first presentation, to include initial supportive care needs, diagnostic and surgical interventions, non-surgical oncology interventions, treatment of symptoms and follow-up
- Nominate and record a key worker to act as point of contact for patients, their relatives and carers. This should be agreed with the patient, their relatives and carers
- Agree who is responsible for implementing the next stage of the management plan

- Inform the diagnostic clinician/team at the local referring hospital and GP of the management plan (see communication below)
- Inform the cancer network MDT of the management plan (usually via a representative who is a member of the neuroscience MDT and also in writing)
- Review and advise on patients referred back from the cancer network MDT on disease progression or relapse
- Develop MDT protocols, in collaboration with the cancer network MDT, to define appropriate follow-up imaging requirements for patients with CNS tumours
- Implement the national management protocols for CNS lymphoma, medulloblastoma, pineal tumours and optic gliomas (see section below titled "Treatment and follow-up: primary CNS lymphoma, medulloblastoma, pineal tumours and optic gliomas")
- Act as an educational resource for local service providers
- Develop and maintain evidence-based local management protocols covering all aspects of the patient pathway
- Participate in regular site-specific group meetings to review care pathways and protocols
- Introduce and maintain systems for data entry across the area of service provision including links to cancer registries
- Audit practice against this guidance and other national guidelines as they are published
- Facilitate the entry of patients into appropriate National Cancer Research Network (NCRN) and local clinical trials
- Liaise with the cancer network MDT

Lead clinician responsibilities

- Ensure that processes are in place for obtaining information about patients directly from the clinician who arranged the imaging, if this is not forthcoming
- Refer onwards patients with spinal cord, pituitary or skull base tumours if inappropriately referred to this MDT

Table. Core Membership of the Neuroscience Brain and Other CNS Tumours MDT*

MDT Member	Description
Neurosurgeon(s)	A specialist neurosurgeon who spends at least 50% of his or her clinical programmed activities in neuro-oncological surgery and is regularly involved in dedicated specialty clinics caring for these patients
Neuroradiologist(s)	A consultant radiologist in a substantive post with at least 50% of clinical programmed activities spent in the practice of neuroradiology
Neuropathologist(s)	An accredited pathologist who is registered as a neuropathologist or histopathologist, has specialist expertise

MDT Member	Description
	in neuro-oncology, and takes part in the national External Quality Assurance scheme for neuropathology organised by the British Neuropathological Society
Neurologist(s)	A consultant neurologist with expertise in neuro-oncology, epilepsy or neuro-rehabilitation
Oncologist(s)	A clinical oncologist with a special interest in tumours of the CNS
Clinical nurse specialist(s)	A nurse with specialist knowledge of CNS tumours and skills in communication as defined by the "Manual for cancer services"***
Palliative care	A healthcare professional (normally a member of the specialist palliative care team) with experience and expertise in the provision of palliative care services for patients with CNS tumours
Neuropsychologist(s)	A clinical neuropsychologist with a special interest in tumours of the CNS
Specialist AHP(s)	Representative(s) of the allied health professions, including occupational therapy, physiotherapy, speech and language therapy, dietetics and others as appropriate, who have knowledge and experience of dealing with this patient group, with responsibility for education and liaison with other local specialist AHPs
Coordinator(s)	An administrative post responsible for coordinating patient registration with the neuroscience MDT and data collection
Others as required (extended MDT members)	For example, representatives from ward nursing, community palliative nursing, psychology/ psychiatry, neuropsychiatry and epilepsy nurse specialists

*Appropriate cross-cover should be available for all MDT members. AHP, allied health professional.

***Department of Health (2004) *Manual for cancer services. Topic 2a The generic multidisciplinary team 2A -122 to 2A - 127*. London: Department of Health. Available from www.dh.gov.uk

Table. The Cancer Network Brain and Other CNS Tumours MDT – Responsibilities

The cancer network MDT is the coordinating team for the nonsurgical management of most adult patients with CNS tumours. Membership of this team is summarised in the Table below titled "Core membership of the cancer network brain and other CNS tumours MDT," and its responsibilities include the following:

- Implement the non-surgical aspects of the management plan produced by the

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

Table. Core Membership of the Cancer Network Brain and Other CNS Tumours MDT*

MDT Member	Description
Neurologist(s)	A consultant neurologist with expertise in neuro-oncology, epilepsy or neuro-rehabilitation
Radiologist(s)	A radiologist with a specialist interest in CNS imaging
Radiographer(s)	A therapy radiographer with a special interest in patients with CNS tumours who has dedicated time allocated to participate in the local MDT
Oncologist(s)	A clinical oncologist with a special interest in tumours of the CNS and who is the designated neuro-oncologist for the cancer network
Clinical nurse specialist(s)	A nurse with specialist knowledge of CNS tumours and skills in communication as defined by the "Manual for cancer services"***

MDT Member	Description
Palliative care	A healthcare professional (usually a member of the specialist palliative care team) with experience and expertise in the provision of palliative care services for CNS tumour patients
Specialist AHP(s)	Representative(s) of the allied health professions, including occupational therapy, physiotherapy, speech and language therapy, dietetics and others as appropriate who have knowledge and experience of dealing with this patient group, with responsibility for education and liaison with other local specialist AHPs, who participate in MDT meetings
Coordinator(s)	An administrative post coordinating the MDT meeting and collecting/collating and recording appropriate information through clinicians, radiology and the neuroscience and cancer network MDTs
Others as required (extended MDT members)	For example, epilepsy nurse specialists, and representatives from ward nursing, community palliative nursing, epilepsy nurse specialist, psychology/psychiatry, neuropsychology/neuropsychiatry

*Appropriate cross-cover should be available for all MDT members. AHP, allied health professional.

**Department of Health (2004) *Manual for cancer services. Topic 2a The generic multidisciplinary team 2A -122 to 2A - 127*. London: Department of Health. Available from www.dh.gov.uk.

Communication between MDTs

Good communication is essential for the smooth and effective provision of services and should be a standard of care. Communication episodes and expected timescales are summarised in the Table below titled "Communication framework".

Table. Communication Framework

Communication Episode	Expected Timescale
Logging of patients with a possible diagnosis of CNS tumour onto neuroscience MDT data base	Within 1 week of imaging report date
Clinical summary from the diagnosing clinician received by the neuroscience MDT	Within 2 working days of the imaging report
Written summary of the proposed management plan produced by the neuroscience MDT sent back to the referring clinician, cancer network MDT and GP	Within 1 working day of the MDT
Informing the patient, their relatives or carers of diagnosis and management plan	Within 1 working day of MDT for inpatients

Communication Episode	Expected Timescale
	Within 5 working days for outpatients
Referral to the rehabilitation and supportive care services and palliative care team where appropriate	Within 1 working day of the decision
Referral to the cancer network MDT for further management	Within 2 working days of discharge from neurosurgical care
Discussion of key worker appointment and their role with patient, their relatives and carers	Within 1 working day of MDT for inpatients Within 5 working days for outpatients
Referral back to the neuroscience MDT for further management	Within 1 working day of decision

CNS, central nervous system; GP, general practitioner; MDT, multidisciplinary team.

Presentation and Referral

Primary care trusts/local health boards should ensure appropriate training is provided for implementation of the National Institute for Health and Clinical Excellence (NICE) clinical guidelines on "Referral guidelines for suspected cancer" as they apply to CNS tumours (see the National Guideline Clearinghouse (NGC) summary of the NICE guideline [Referral guidelines for suspected cancer in adults and children](#)). This provision should include the new forms of primary care contact such as National Health Service (NHS) Direct, walk-in centres, nurse practitioners and health visitors, and the use of relevant information technology (IT) links. The contents of the guidelines should be incorporated into electronic decision support systems/algorithms used in such settings.

Cancer networks should ensure that the trust lead clinician has set up clear and well-publicised mechanisms for the receipt and management/processing of GP referrals of patients with suspected primary brain tumours. There should be similar mechanisms for the management of internal referrals.

Where a brain tumour is identified on imaging requested by the GP, the trust lead clinician should ensure that processes are in place for the GP to be informed quickly, allowing early referral through local arrangements.

Cancer networks should set up robust local mechanisms to ensure that every patient with imaging that suggests a diagnosis of CNS tumour is discussed by the neuroscience MDT without delay (see Table above titled "Communication framework"). This is to ensure that radiological diagnosis is confirmed and advice on further management can be given, regardless of the source of the initial referral or possible need for specialist treatment.

Radiological images sent to the neuroscience MDT should be supplemented by clinical information provided either by the consultant responsible for the patient's care or by a member of the MDT who has seen the patient. There should be prior review of all images by the participating neuroradiologist(s) who should have sufficient time to provide an unhurried professional opinion for the MDT meeting. The opinion given should be annotated on the MDT list and retained for future reference.

Diagnosis: Radiology and Pathology

All acute trusts should have adequate computed tomography (CT) and magnetic resonance imaging (MRI) facilities so that investigations of patients with suspected CNS tumours meet cancer waiting time national targets.

An electronic image transfer system should be in place to ensure timely image transfer between the local hospital and neuroscience MDT (see Section above titled "Presentation and referral"). A function of the MDT meeting should be to determine whether or not further imaging is necessary prior to surgery.

When initial CT imaging is not diagnostic there should be rapid access to adequate MRI resources.

Neuropathology and neuroradiology services should be provided to a level that ensures practitioners in these specialties can deliver appropriate diagnostic investigations in a timely and efficient manner, complying with national cancer waiting times targets, and such that they can be involved in preoperative and postoperative management decisions and intraoperative diagnosis. Neuropathologists should be able to report to the standards detailed in the document "Minimum dataset for the histopathological reporting of tumours of the central nervous system" (Royal College of Pathologists). Neuroradiologists should be able to report and review examinations to the standards detailed in the document "Cancer multidisciplinary team meeting – standards for clinical radiologists" (Royal College of Radiologists).

There should be ready access to a neurosurgical biopsy or resection service, including image localisation and stereotactic techniques. Preoperative discussions should take place at the neuroscience MDT to determine the optimum approach to surgery and the processing of tissue specimens, including intraoperative histological evaluation.

Molecular diagnostic tests will become increasingly important as supplementary investigations to the neuropathological assessment of CNS tumours, informing diagnosis, prognosis and therapeutic decisions. The evaluation, development and implementation of these tests should be supported.

There is a need for improved biological research into CNS tumours; tumour biopsy material, when processed optimally at the time of operation, should be stored for future scientific research, with appropriate consent, as well as for diagnostic purposes.

Treatment and Follow-Up: Brain Tumours

The neuroscience MDT should ensure that there are explicit and widely known mechanisms for the urgent management of patients developing acute problems that might require neurosurgical intervention.

The neuroscience MDT (see Tables above titled "Neuroscience brain and other CNS tumours MDT – responsibilities" and "Core membership of the neuroscience brain and other CNS tumours MDT") should be adequately resourced to ensure that all patients start their definitive treatment without delay.

Members of the neuroscience MDT should be responsible for implementing the surgical aspects of the management plan and adjuvant therapy based on neuropathological diagnosis. All other care including chemotherapy, radiotherapy and coordination of supportive care should be the responsibility of the cancer network MDT (see Tables above titled "The cancer network brain and other CNS tumours MDT – responsibilities" and "Core membership of the cancer network brain and other CNS tumours MDT").

The neuroscience MDT should be responsible for assessing new treatments and relevant NICE technology appraisals and updates. The patient's management plan defined by the neuroscience MDT should take these into consideration. The final recommendations for treatment should apply the relevant patient factors such as comorbidity when considering these treatments.

The cancer network MDT and the neuroscience MDT should develop locally agreed guidelines for follow-up. There should be robust mechanisms in place to ensure that GPs and community palliative care teams are able to communicate efficiently with the specialist teams as the need arises. Patients, their relatives and carers should be given clear information on whom to contact and how if they are concerned about their condition.

After initial treatment, patients should have follow-up as close to home as possible, with a member of either the neuroscience MDT or the cancer network MDT in a multidisciplinary outpatient clinic setting.

There should be ready access to specialist neuropsychology and neuropsychiatry services for assessment and management of complex cognitive, emotional and behavioural problems. There should also be access to specialist healthcare professionals as appropriate for any other problems patients may experience, such as epilepsy, headaches and functional loss, for example speech, language or visual problems.

The neuroscience MDT should advise on the management of patients presenting with metastases in the brain in whom:

- Biopsy is required to clarify the diagnosis
- There is doubt about the imaging findings following neuroradiological assessment
- Neurosurgical intervention is considered appropriate.

Stereotactic radiotherapy should be available as an alternative to surgery in patients with a single, small (<3 cm) metastasis in the brain, or occasionally two small metastases, when the histopathological diagnosis is known.

Novel treatments currently under evaluation should not generally be used outside the context of a clinical trial/research setting.

Treatment and Follow-Up: Pituitary, Spinal Cord and Skull Base Tumours

Table. Pituitary, Spinal cord, and Skull Base MDTs – Responsibilities

The pituitary, spinal cord and skull base MDTs are responsible for the diagnosis and initial management plan (both surgical and non-surgical aspects of care) of most adult patients with these tumours. Membership of these is summarised in Tables 13–15 of the original guideline document and responsibilities include the following:

- Establish as complete a diagnosis as possible for the optimal clinical management of the patient
- Develop management plans at first presentation, to include initial supportive care needs, diagnostic and surgical interventions, non-surgical oncology interventions, treatment of symptoms and follow-up
- Inform the diagnostic clinician/team at the local referring hospital of the management plan
- Inform the cancer network MDT of the management plan
- Review of and advise on patients referred back for disease progression or relapse
- Develop MDT protocols, in collaboration with the neuroscience MDT and the cancer network MDTs, to define appropriate follow-up imaging requirements for patients
- Act as an educational resource for local service providers
- Organise regular site-specific group meetings to review pathways of care and protocols
- Nominate and record a key worker to act as a point of contact for patients, their relatives and carers. This should be agreed with the patient, their relatives and carers
- Develop and maintain evidence-based local management protocols covering all aspects of the patient pathway
- Introduce and maintain systems for data entry across the area of service provision including links to cancer registries
- Audit practice at local, cancer network and supra network levels against national standards of care
- Facilitate the entry of patients into appropriate National Cancer Research Network (NCRN) and local clinical trials
- Liaise with the cancer network MDT

General

Patients with pituitary, spinal cord or skull base tumours should have their management plan decided by a dedicated specialist MDT.

The relationship between these specialist MDTs and the neuroscience MDT should be clearly defined by local protocols.

All patients should have specialist follow-up as defined by the relevant MDT.

Pituitary and Pituitary-Related Tumours

Patients should be followed up by a member of the specialist pituitary MDT at a multidisciplinary clinic. More local follow-up based on protocols may be arranged in conjunction with the specialist pituitary MDT or the cancer network MDT and the relevant endocrinology team.

Specialist histopathological assessment should be available, as should mechanisms for ready access to a second opinion.

Intradural Spinal Cord Tumours

Intradural spinal cord tumours should be managed by teams that deal with other spinal disease that may require surgical management (for example, disc prolapse), including emergency services for patients with suspected cord compression.

There should be a single point of referral into the on-call spinal team for both imaging and specialist referral including urgent MRI scans, CT myelography, spinal angiogram and specialist management.

There should be access to intraoperative histopathological evaluation and intraoperative neurophysiological recording with appropriate neurophysiologist and technical support.

There should be access to appropriate rehabilitation services.

Skull Base Tumours

There should be ready access to MRI, high-resolution CT, MR angiography, CT angiography and conventional angiography. There should be ready access to pre-operative neurophysiological assessment.

An appropriate mix of surgical skills is required for these patients. This will necessitate that those surgeons forming the core or extended surgical team should have sufficient flexibility in their timetable to accommodate joint operating when necessary. There should be access to stereotactic radiotherapy/radiosurgery.

Treatment and Follow-Up: Primary CNS Lymphoma, Medulloblastoma, Pineal Tumours and Optic Gliomas

General

National tumour groups for rare CNS tumours should be established to coordinate the approach to care; this should include developing protocols for the

investigation, management, registration and clinical research into rare tumours. They should also maintain a national register of all these cases.

All patients with rare CNS tumours should be managed within the context of an MDT – usually the neuroscience MDT but, where appropriate, in collaboration with the cancer network MDT.

Primary Central Nervous System Lymphoma (PCNSL)

A national PCNSL tumour group should be established to unify management approaches, develop national standardised guidelines and treatment protocols, and determine research programmes. A multidisciplinary approach to the management and care of patients with PCNSL should be provided by the neuroscience MDT, and the cancer network MDT as described in the Section above titled "Multidisciplinary Teams". It is important that a haemato-oncologist, or medical or clinical oncologist with a special interest, should be involved in the management of lymphomas. Where the neuroscience MDT does not have appropriate expertise in the core membership, there should be a named representative of the lymphoma MDT to act in this capacity.

Facilities for neurosurgery should include stereotactic biopsy, image-guided surgery and an on-site neuropathology service for intraoperative histopathological evaluation. The on-site neuropathology service should have access to specialist lymphoreticular pathology services to distinguish lymphoma from other lymphoid pathologies and to grade and classify the lymphoma.

Chemotherapy services must meet the national guidance on the safe administration of intrathecal chemotherapy and the corresponding measures are given in the "Manual for cancer services" (available from www.dh.gov.uk).

There should be ready access to ophthalmic services as PCNSL often involves the visual pathways, and ophthalmic review is required to complete disease staging.

All patients with human immunodeficiency virus (HIV)-related lymphoma should also be under the care of the local HIV service.

Medulloblastoma

A national adult medulloblastoma tumour group should be established to unify management approaches, develop national standardised guidelines and treatment protocols, and determine research programmes.

Patients with medulloblastoma should be reviewed by the neuroscience MDT and receive further investigations and treatment according to nationally agreed protocols.

All adult patients with medulloblastoma should receive their neuraxis radiotherapy in radiotherapy centres that also treat paediatric medulloblastoma, to utilise their experience and expertise in planning for these tumours.

Pineal Tumours

A national pineal tumour group should be established to unify management approaches, develop national standardised guidelines and treatment protocols, and determine research programmes.

Facilities for the neurosurgical management of patients with pineal lesions should include access to surgical teams with practice in complex pineal approaches and should provide the following procedures:

- Ventricular endoscopy (including third ventriculostomy)
- Stereotactic techniques

There should be access to on-site neuropathology services to provide intraoperative histopathological evaluation.

Patients with low-grade pineocytomas should have access to stereotactic radiotherapy services.

Optic Pathway Glioma

A national optic glioma tumour group should be established to unify management approaches, develop national standardised guidelines and treatment protocols, and determine research programmes.

A multidisciplinary approach to the management and care of patients with optic gliomas should be provided by the neuroscience MDT and the cancer network MDT, as described in the Section above titled "Multidisciplinary Teams".

There should be access to ophthalmic services with regular ophthalmic review.

Endocrine support should be available where required.

There should be access to conformal stereotactic procedures.

Lifelong follow-up and support should be provided for patients with optical pathway glioma.

Genetic Predispositions

Patients with genetic syndromes that confer an increased risk of developing tumours of the CNS require management within the context of a multidisciplinary team, which should incorporate advice from clinical geneticists on diagnosis and screening.

Coordinated follow-up and interval imaging/investigation of patients with neurocutaneous syndromes should be performed, where possible, in combined specialised neurogenetic clinics where there is access to a neurologist and geneticist.

Cases of people with familial predilection to cancer (for example, Li-Fraumeni and Turcot's syndrome) should be coordinated, where possible, via cancer genetic

clinics or by clinicians with the most appropriate clinical skills (for example, Turcot's – gastroenterology; Gorlin – dermatology).

Supportive Care

Communication

Communication skills training, sensitive to the particular needs of patients with CNS tumours, should be provided for healthcare professionals caring for patients with CNS tumours.

Healthcare professionals should have face-to-face communication with patients, their relatives and carers at critical points in the care pathway to discuss diagnosis, prognosis, treatment options (including no treatment), recurrence and end-of-life care.

Patient Information

There should be a nominated CNS tumours information lead at cancer network MDT level. These CNS tumours information leads should consider ways to develop a regularly updated central register of information for patients.

Cancer networks should ensure that patient and carer groups have the opportunity to ask questions of specialist healthcare professionals. Cancer networks should determine the most effective way to facilitate this via their patient and public involvement arrangements.

Information on CNS tumour services should use existing high-quality sources.

Information on CNS tumours should include local and national societies, appropriate websites and other relevant publications.

Information materials containing clear, accurate and relevant information about each CNS tumour type should be made available to patients, their relatives and carers by all healthcare professionals. This material should explain what patients can expect to happen to them at each stage of their disease journey, and when and where each event will occur, with an explanation of the terminology. This should include information concerning any relevant clinical trials and research on a particular treatment.

Information on local specialist palliative care services should be available for professionals, patients, their relatives and carers at each stage of the patient pathway.

Psychological Support Services Including Neuropsychology and Neuropsychiatry

Psychological assessment and support should be an integral part of the MDT management of patients with brain and other CNS tumours.

Neuropsychology and neuropsychiatry services should be adequately resourced to enable referral of patients who require specialist intervention for cognitive, emotional or behavioural problems.

One member of the cancer network MDT should be nominated to maintain links with specialist psychology services.

Ongoing training should be provided for all staff providing psychological support to patients with CNS tumours, their relatives and carers.

The psychological and social well-being of the patient, their relatives and carers should be considered throughout the course of the illness.

Rehabilitation Services

Commissioners should ensure that implementation of the recommendations in the NICE guidance "Improving supportive and palliative care for adults with cancer" includes services for patients with CNS tumours.

There should be rapid access to AHP assessment and rehabilitation services, including specialist neurorehabilitation when appropriate, as a patient's condition changes.

There should be immediate access to specialist equipment, as necessary.

General Palliative Care

Palliative care education and training for healthcare professionals should include when and how to seek advice from, or refer to, specialist palliative care services.

Social Support and Continuing Care

The provision of long-term care arrangements should be in accordance with "Continuing care: NHS and local councils' responsibilities" (available from www.dh.gov.uk).

Younger patients with continuing care needs should also be carefully considered. Procedures should be in place to ensure the continuing care needs of younger patients with CNS tumours are appropriately met.

Needs for social support should be elicited as an integral component of routine assessment, ideally undertaken with or by a social care professional.

Specialist Palliative Care

Palliative care specialists should be included as members of the neuroscience brain and other CNS tumours multidisciplinary team (MDT) and the cancer network brain and other CNS tumours MDT. They should provide advice on palliative and supportive care and the management of symptoms, and contribute to the patient's management plan, including advice on onward referral to local services as appropriate.

Cancer networks should ensure that healthcare professionals in neuro-oncology services and specialist palliative care services work closely together throughout the patient's illness to ensure an appropriate balance between active treatment and palliative care.

Cancer networks should ensure that there are clear mechanisms in place for referral to and from specialist palliative care services for patients with CNS tumours, with referral at the time of diagnosis, when appropriate.

Information on local specialist palliative care services should be available for healthcare professionals, patients, their relatives and carers at each stage of the patient pathway.

Information Management

Data collection systems should be in place that allow entry of information on all patients with a radiological or histopathologically confirmed CNS tumour. Consideration should be given to a web-based information system that will allow easy data sharing between healthcare professionals across services, and complies with data protection legislation.

A local retrieval system that identifies all radiology reports that mention CNS tumours should be developed and maintained until digital, coded reporting systems are universal.

The lead clinician of the neuroscience MDT and the lead clinician of the cancer network MDT should assume overall responsibility for ensuring that complete data are collected, verified and recorded on all patients reviewed by the teams. Strong links with the local cancer registry should be developed to ensure complete and accurate registration of all patients.

The data collection responsibilities of the various MDT members should be clearly defined in local protocols.

Adequate clerical support should be provided for the MDTs to facilitate data collection.

The national minimum datasets for CNS tumours should be adopted in both England and Wales when they become available.

CLINICAL ALGORITHM(S)

None provided

EVIDENCE SUPPORTING THE RECOMMENDATIONS

TYPE OF EVIDENCE SUPPORTING THE RECOMMENDATIONS

The type of evidence supporting each section of the care pathway is specifically stated in the technical companion titled *Improving Outcomes for People with Brain*

and Other CNS Tumours: The evidence review. NICE clinical guideline. 2006 June (See "Availability of Companion Documents" field).

BENEFITS/HARMS OF IMPLEMENTING THE GUIDELINE RECOMMENDATIONS

POTENTIAL BENEFITS

Appropriate management of brain and other central nervous system (CNS) tumors in order to improve patient outcomes

POTENTIAL HARMS

Morbidity and mortality associated with diagnostic biopsies and treatment

QUALIFYING STATEMENTS

QUALIFYING STATEMENTS

The focus of the cancer service guidance is to guide the commissioning of services and is therefore different from clinical practice guidelines. Health services in England and Wales have organisational arrangements in place for securing improvements in cancer services and those responsible for their operation should take this guidance into account when planning, commissioning and organising services for cancer patients. The recommendations in the guidance concentrate on aspects of services that are likely to have significant impact on health outcomes. Both the objectives and resource implications of implementing the recommendations are considered. This guidance can be used to identify gaps in local provision and to check the appropriateness of existing services.

IMPLEMENTATION OF THE GUIDELINE

DESCRIPTION OF IMPLEMENTATION STRATEGY

The Measurement sections of the guidance list "structures," "processes," and "outcomes" directly related to the recommendations and suggest ways in which implementation of guidance can be measured. The topics may feed into any peer review process, may be subjects for regular or ad hoc clinical audit, or be the subject of other forms of assessment such as patient surveys. Resource implications are also provided for each section of "The Care Pathway."

IMPLEMENTATION TOOLS

Patient Resources

For information about [availability](#), see the "Availability of Companion Documents" and "Patient Resources" fields below.

INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT CATEGORIES

IOM CARE NEED

End of Life Care
Getting Better
Living with Illness

IOM DOMAIN

Effectiveness
Patient-centeredness

IDENTIFYING INFORMATION AND AVAILABILITY

BIBLIOGRAPHIC SOURCE(S)

National Collaborating Centre for Cancer. Improving outcomes for people with brain and other CNS tumours. London (UK): National Institute for Health and Clinical Excellence (NICE); 2006 Jun. 180 p. [23 references]

ADAPTATION

Not applicable: The guideline was not adapted from another source.

DATE RELEASED

2006 Jun

GUIDELINE DEVELOPER(S)

National Collaborating Centre for Cancer - National Government Agency [Non-U.S.]

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FINANCIAL DISCLOSURES/CONFLICTS OF INTEREST

All guideline development group (GDG) members made and updated any declarations of interest.

GUIDELINE STATUS

This is the current release of the guideline.

GUIDELINE AVAILABILITY

Electronic copies: Available in Portable Document Format (PDF) format from the [National Institute for Health and Clinical Excellence \(NICE\) Web site](#).

AVAILABILITY OF COMPANION DOCUMENTS

The following are available:

- Improving outcomes for people with brain and other CNS tumours. Analysis of the potential economic impact of the guidance. London (UK): National Institute for Clinical Excellence (NICE); 2006 Jun. 47 p. Available in Portable Document Format (PDF) from the [National Institute for Health and Clinical Excellence \(NICE\) Web site](#).
- Improving outcomes for people with brain and other CNS tumours. The evidence review. London (UK): National Institute for Clinical Excellence (NICE); 2006 Jun. 437 p. Available in Portable Document Format (PDF) from the [National Institute for Health and Clinical Excellence \(NICE\) Web site](#).
- Improving outcomes for people with brain and other CNS tumours. An assessment of need for brain and other CNS tumour services in England and Wales. London (UK): National Institute for Clinical Excellence (NICE); 2006 Jun. 166 p. Available in Portable Document Format (PDF) from the [National Institute for Health and Clinical Excellence \(NICE\) Web site](#).

Print copies: Available from the National Health Service (NHS) Response Line 0870 1555 455. 11 Strand, London, WC2N 5HR.

PATIENT RESOURCES

The following is available:

- Healthcare services for people with brain and other central nervous system tumours. Understanding NICE guidance – information for the public. National Institute for Clinical Excellence (NICE), 2006 Jun. 4 p. Available in Portable Document Format (PDF) from the [National Institute for Health and Clinical Excellence \(NICE\) Web site](#).

Print copies: Available from the National Health Service (NHS) Response Line 0870 1555 455, ref: N1048. 11 Strand, London, WC2N 5HR.

Please note: This patient information is intended to provide health professionals with information to share with their patients to help them better understand their health and their diagnosed disorders. By providing access to this patient information, it is not the intention of NGC to provide specific medical advice for particular patients. Rather we urge patients and their representatives to review this material and then to consult with a licensed health professional for evaluation of treatment options suitable for them as well as for diagnosis and answers to their personal medical questions. This patient information has been derived and prepared from a guideline for health care professionals included on NGC by the authors or publishers of that original guideline. The patient information is not reviewed by NGC to establish whether or not it accurately reflects the original guideline's content.

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