Brain and other CNS tumours – 2nd consultation – stakeholder comments

5 December 2005 – 16 January 2006

National Institute for Health and Clinical Excellence

Organisation	Section number or general	Comments Please insert each new comment in a new row.	Developers' response Please respond to each comment
Addenbrooke's NHS Trust		This organisation was approached but did not respond.	
All Wales Senior Nurses Advisory Group (Mental Health)		This organisation was approached but did not respond.	
Anglesey Local Health Board		This organisation was approached but did not respond.	
Association for Palliatvie Medicine of Great Britain and Ireland		This organisation was approached but did not respond.	
Association of British Neurologists		This organisation was approached but did not respond.	
Association of Hospice and Specialist Palliative Care Social Workers		This organisation was approached but did not respond.	
Association of Neuro-oncology Nurses (ANON)		The Association of Neuro-Oncology nurses are pleased with the alterations made in the 2nd draft which reflects more positively and effectively the work undertaken by Nurse Specialists in Neuro-Oncology. We therefore for this recent 2nd draft have no comments.	Thank you for your comment.
Association of Professional Music Therapists		This organisation was approached but did not respond.	
Association of Surgeons of Great Britain and Ireland		This organisation was approached but did not respond.	
Association of the British Pharmaceuticals Industry (ABPI)		This organisation was approached but did not respond.	
Bard Limited		This organisation was approached but did not respond.	
Barking, Havering & Redbridge NHS Acute Trust		This organisation was approached but did not respond.	

Barts and The London NHS Trust		This organisation was approached but did not respond.	
BASIC (Brain and Spinal Injury Charity)		This organisation was approached but did not respond.	
Bath and North East Somerset PCT		This organisation was approached but did not respond.	
Bayer Healthcare plc		This organisation was approached but did not respond.	
Bedfordshire and Hertfordshire NHS Strategic Health Authority		This organisation was approached but did not respond.	
Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
Boston Scientific Limited		This organisation was approached but did not respond.	
Brain and Spine Foundation		Our comments from the first consultation were addressed adequately. We very much welcome this service guidance and if implemented, it will significantly improve the standard of care for these patients and their carers.	Thank you for your comment.
Brain and Spine Foundation	IFP – General	Overall this document accurately reflects the content of the full version in summary form. The language and terminology is easy to understand.	Thank you.
Brain and Spine Foundation	IFP – 6	Consider changing some of the phraseology in this paragraph. In places it is slightly ambiguous. E.g., The distinction between malignant ('cancerous) and benign ('non-cancerous') tumours is not as important for CNS tumours as it is for tumours at most other sites. CNS tumours can spread (metastasise) outside the CNS, but this is very rare. The problems caused by CNS tumours are almost always due to an increase in pressure in the brain and damage to surrounding tissue. For the most common CNS tumours, called gliomas, the appearance under the microscope is very important. This will show if the glioma is 'high grade' (growing quickly) or 'low grade' (growing slowly).	Sentences reworded: 'The distinction between malignant ('cancerous') and benign ('non cancerous') tumours is not as important for CNS tumours as it is for tumours at most other sites in the body. CNS tumours can spread (metastasise) outside the CNS, but this is very rare. The problems caused by CNS tumours are almost always due to growth of the tumour itself. For the most common CNS tumours, called gliomas, the appearance of the tumour when looked at with a microscope is very important. This will show if the glioma is "high grade" (growing quickly) or "low grade" (growing slowly).'
Brain and Spine Foundation	IFP – 14	Changes to 'In most cases, images from scans (MRI or CT scans) are used to	

		diagnose that a person has a brain or other CNS tumour'. X-rays by themselves are very rarely used and we are not clear what the 'and so on' refers to.	
Brain and Spine Foundation	IFP – 17	Rephrase the last sentence. Para 12 in the full guidance makes the point that people should have access to the specialist healthcare professionals which is different to access to information and patient organisations (covered in 19 IFP). The last sentence should have access to specialist healthcare professionals for these problems (e.g., neuropsychologist, neuropsychiatrist).	
British and Irish Orthoptic Society		This organisation was approached but did not respond.	
British Association for Counselling and Psychotherapy		This organisation was approached but did not respond.	
British Association of Neuroscience Nurses		This organisation was approached but did not respond.	
British Association of Oral and Maxillofacial Surgeons		This organisation was approached but did not respond.	
British Dietetic Association		This organisation was approached but did not respond.	
British National Formulary (BNF)		This organisation was approached but did not respond.	
British Nuclear Medicine Society	P. 46, Box 3 and p. 51, Box 6	Under extended member category--- a "nuclear medicine" imaging specialist may be added	The wording of the membership in Box 3 has been adjusted to include possible inclusion of other individuals as necessary.
British Nuclear Medicine Society	Paras 165–171	Under "recommendations" the following can be added as a separate point-- MDTs should have access to local/regional PET or PET-CT scanning services to aid patient management prior to surgery and to assess treatment response	The Guideline Development Group (GDG) felt that PET or PET-CT remains an experimental tool and is not of proven benefit at present.
British Oncology Pharmacy Association		This organisation was approached but did not respond.	
British Psychological Society, The	416	There are particular psychological issues associated with CNS tumours. Fears of loss of control, dignity, and the ability to communicate are common and highly distressing. The burden patients anticipate placing on family members can feel intolerable. This, together with fears of personality disintegration, can lead to thoughts of suicide. Although the family may be willing to assume it, this encumbrance is very real and the family is rarely prepared for the months ahead.	Comments noted and these points are made in paragraph 416.

		Levels of distress, exhaustion and frustration among family members is thus high. This is especially true where there are communication difficulties which can result in isolation for both the patient and the family and frustrating communication.	
British Psychological Society, The	417–418	Much as it is desirable for all CNS cancer teams to have access to clinical neuropsychologists, the reality for most teams is that this very specialist resource is hard to come by. Where clinical neuropsychologists are unavailable the input of clinical psychologists should be sought. They will all have at least a rudimentary knowledge of neuropsychology but more importantly can co-ordinate the psychological care of patients and their carers.	The desirability of having neuropsychological input is acknowledged and resource implications are included in the guidance and in the economic analysis report. The GDG considered the level of neuropsychological input and was strongly supportive of consistent input for patients in this group.
British Psychological Society, The	General, neuropsychology	The guideline implies that neuropsychologists cannot contribute to the diagnosis of recurrence of a tumour. It should be noted that neuropsychologists have been asked to do this, since repeated imaging may not be always advisable.	The evidence to support this statement is included in the Evidence Review.
British Psychosocial Oncology Society		This organisation was approached but did not respond.	
British Society of Neuroradiologists		This organisation was approached but did not respond.	
British Society of Paediatric Radiology		This organisation was approached but did not respond.	
British Society of Rehabilitation Medicine	438/439	We are very pleased to note that the guidance includes mention of rehabilitation and the role of the neuro-rehabilitation team. However, this section currently fails to mention the important role of the specialist in Rehabilitation Medicine who not only plays a crucial role in any specialist rehabilitation team, but often fulfils the important function of managing the (often complex) medical needs of patients with CNS tumours in the context of their rehabilitation and providing information to guide the rehabilitation team with regard to prognosis etc.	We feel we have included the specialist in rehabilitation medicine in paragraph 443 when we mention the specialist neurorehabilitation team.
British Society of Rehabilitation Medicine	Chapter 8 (377–488)	The section on rehabilitation could usefully make reference to the National Clinical Guidelines for Rehabilitation following Acquired Brain Injury (*Rehabilitation following acquired brain injury: national clinical guidelines*. London: Royal College of Physicians, London. 2003). 'Acquired brain injury' in this context refers to ABI of any cause, including tumour and post-surgical damage. The guidelines were carefully developed in accordance with the	The suggestion of referencing the National Clinical Guidelines for Rehabilitation following Acquired Brain Injury is accepted and will be included at the beginning of the supportive care section (paragraph 377) and the rehabilitation section (paragraph

		AGREE criteria and provide evidence-based recommendations and useful practical advice.	435).
BUPA		This organisation was approached but did not respond.	
Cancer and Leukaemia in Childhood (UK)		This organisation was approached but did not respond.	
Cancer Research UK		This organisation was approached but did not respond.	
Cancer Services Collaborative 'Improvement Partnership' (CSCIP)		This organisation was approached but did not respond.	
Cancer Services Co-ordinating Group		This organisation was approached but did not respond.	
Cancer Voices		This organisation was approached but did not respond.	
CancerBACUP		This organisation was approached but did not respond.	
Chartered Society of Physiotherapy		The CSP has no further comments to make on this guideline.	Thank you for your comment.
Children's and Adolescent Cancer Partnership (CACP)		This organisation was approached but did not respond.	
Chronic Conditions Collaborating Centre		This organisation was approached but did not respond.	
Chugai Pharma UK Ltd		This organisation was approached but did not respond.	
Clatterbridge Centre for Oncology NHS Trust	General	The Guidance is best described as a curate's egg. Some of it is excellent (particularly the supportive care section and the sections on managing rare tumours via national protocol groups), but other sections are far too prescriptive, and appear in practice unworkable (and this applies to much of the material with respect to MDT meetings). The practical implications of implementing this for a cancer centre such as this would be very difficult, and potentially unfundable in the context of PbR, unless the tariff were made appropriate (which seems unlikely). In particular many patients would be discussed in more than one MDT. Furthermore, the proliferation of MDTs means that an increasing number of oncologists would be required to treat the same number of patients with an inevitable dilution of expertise.	The structure of multidisciplinary teams (MDTs) has been very carefully considered by the GDG. The critical importance of co-ordination of care during the components of the patient pathway subsequent to neurosurgical intervention stress the need for the cancer network MDT and the responsibilities of this MDT as laid out in Box 4. The required resources to support this are identified within the document, but it is not the responsibility of the GDG to address commissioning issues. However, the importance of optimum utilisation of staff

			is recognised: paragraph 90 has been strengthened to clarify that where the neurosciences MDT and cancer network MDT are discussing co-located patients, the same meeting can be used for fulfilling the respective responsibilities of the group.
Clatterbridge Centre for Oncology NHS Trust	P. 46, Box 3	What is the justification for specifying that neuro surgeons spend at least 50% of their programme activities in neuro-oncological surgery? Whilst access to a consultant neurologist with expertise in epilepsy is clearly essential, and an MDT should have an identifiable person to refer to, this is in practice an uncommon problem and does not justify the attendance of a neurologist at every meeting. It is difficult to justify the attendance of a neuro psychologist at every meeting and again the issue is one of access to such services.	It is the opinion of the GDG that a neurosurgeon that spends the majority of their time in neuro-oncology is the most appropriate surgeon to treat patients with CNS tumours. The core membership of the neurosciences MDT has been extensively discussed at the GDG and adjusted in consideration of comments from the 1st consultation. In response to this the core membership includes neurology, neuropathology, neuroradiology and palliative care. So many of the decisions are fundamentally pivotal on the input of these individuals that it is felt it would not be possible to proceed without them.
Clatterbridge Centre for Oncology NHS Trust	Section 89	The suggestion that there should be a Neurosciences Brain and other CNS tumours MDT and a separate Cancer Network Brain and other CNS tumours MDT seems inexplicable and produces duplication. At the majority of Networks there will be a single Neurosciences Centre and a single Oncology Centre dealing with these patients and the need for two separate MDTs with essentially overlapping membership seems entirely unnecessary and unjustifiable in terms of cost. There should at least be the option to combine these two MDTs where appropriate.	The importance of not duplicating work is included and has been emphasised by a change of wording in paragraph 90. This now clarifies the fact that the neurosciences MDT and cancer network MDT for patients who co-locate can cover the explicit and separate responsibilities as identified in Boxes 2 and 4. However, in many cases, as indicated in the background section, cancer centres do not co-locate with neurosciences centres and this is a common problem

			across the country. Indeed, for patients presenting to Clatterbridge it is understood that a proportion of patients are receiving a large component of their care and continuing support in North Wales and a cancer-centre-based MDT would be important for co-ordination of ongoing care of these patients.
Clatterbridge Centre for Oncology NHS Trust	Section 99	This suggests that the MDT makes a management plan in the absence of the relevant consultant – is this appropriate?	It is clear within the document that a clinical summary with imaging will be utilised to develop a management plan for the patient. Where possible the responsible clinician will be in attendance, but we recognise that this will not always be possible for some patients and is a model used widely and successfully in other malignancies.
Clatterbridge Centre for Oncology NHS Trust	Section 112, Box 6	This section suggests that this should be communicated to the GP. We do not believe that MDTs can or should make definitive decisions on patient management. They can appropriately review the possible options, but the decision on management has to be made by the responsible clinician in discussion with the patient. This means that the clinician takes responsibility for the plan and is medico-legally responsible through his Trust and individually responsible to the GMC. Submitting the suggestion of an MDT to the GP prior to the responsible consultant discussing treatment with the patient seems likely to only produce confusion.	The wording in Box 6 has been changed to stress that this is the proposed management plan, which will ultimately depend on the discussion between the referring clinician and the patient/carer. It would be standard practice where the final management plan differs from that defined within the MDT for the clinician to inform the GP of this alteration.
Clatterbridge Centre for Oncology NHS Trust	Chapter 6 (268–311)	It is not clear how often these MDTs are meant to meet. The resource implications (page 110) suggests a monthly meeting for the pituitary MDT. This is reasonable. The implication is that the same frequency will apply to the spinal cord and the skull base MDT. However, given that these two MDTs will deal with a significant number of malignant tumours, monthly meeting seems to pose difficulties. However, the small number of patients involved would inevitably mean that a weekly meeting of the MDT would be extremely inefficient. At many centres therefore it would make more sense if the spinal and skull base MDTs took place as part of a larger MDT. The spinal cord MDT would have to be part	The GDG feel that the local application of the guidance to ensure timely assessment and most appropriate use of resources should be left to local arrangements. Where staff can be utilised to cover more than one MDT, this would clearly be entirely appropriate.

		of the neuro-oncology MDT and the skull base MDT could be part of either the neuro-oncology MDT or the head and neck MDT with additional people attending the relevant part of the meeting.	
Clatterbridge Centre for Oncology NHS Trust	Paras 441–445	The issue of rehabilitation facilities for these patients is important. In general they have very little access to current neuro rehabilitation teams and very considerable funding would be required to achieve this. The suggestion of a Cancer Network Neuro-oncology Rehabilitation Team is interesting. However, in many Networks patients will come to the neurosurgical centre or the cancer centre from a long distance and whether centralising their rehabilitation the same way is feasible or desirable must be in some doubt.	The issue of resourcing rehabilitation facilities for these patients has been addressed in the document. Although there is centralisation of the neuro-oncology rehabilitation team, we have made it clear that a central role of the members of the team is to support and educate those in the community.
Clatterbridge Centre for Oncology NHS Trust	Section 461	The document underestimates the cost of providing appropriate neuro-rehabilitation services for these patients. Certainly in this area these patients currently have no access to neuro-rehabilitation facilities and it is unlikely that this network is unique.	We will ask the Health Economics team to review the costings for neurorehabilitation services.
College of Occupational Therapists	General	The guidance will be very useful to those working with this client group. We would like to thank the GDG for their hard work. In particular key recommendations 13 and 14, are welcome as they acknowledge the contribution that AHP`s can make to this group. Like many reports it is long but very comprehensive raising some key issues especially in relation to cognitive and behavioural problems as these can often be misunderstood.	Thank you for your comment.
College of Occupational Therapists	General	The document has obviously taken a considerable amount of time, thought and effort to produce. The College appreciates the value that has been placed on the role of AHP`s by the team. We understand that our last comments were not made available and so have included a more extensive comment on your report, which we hope will be useful and constructive. We hope that this does not cause any inconvenience.	Thank you for your comments on both the first and second drafts of the guidance. All your individual comments are included in this table; please see our responses.
College of Occupational Therapists	14	We do agree that rapid access for AHP assessment and rehabilitation is essential. Feedback from our practitioners does indicate that people with brain tumours may comprise only a small proportion of their workload for the neuro-rehabilitation teams. Frequently these patients have complex needs. Having specialists based at the cancer centre who can act as an educational resource has been valued by the Therapists working within the wider cancer network.	Noted with thanks.

		They also assist in the promotion and development of the best possible interventions for this group across their cancer networks (ref. Draft Rehabilitation report on services accessed for patients within the Yorkshire cancer network Aug.2003-June 2004 (DRR).	
College of Occupational Therapists	22	We welcome this comment. It is our experience that many people with 'benign` tumours may have significant and permanent changes in their ability to perform day-to-day tasks which have a major impact on their life. They are however excluded from many of the traditional cancer services. This does seem unfair.	Thank you for your comment.
College of Occupational Therapists	25 (old 22)	It is good to recognise and emphasise the complex nature of the patient problems. Quality of life being a key issue we should not lose sight of.	Thank you for your comment.
College of Occupational Therapists	26 (old 24) 70 (old 68)	Specialist neurosurgical units. From clinical experience often rehab at this point is related to discharge planning and referral then goes on to community rehab teams. There is often a wait for this because of limited resources The GDG suggests only neuro rehab teams – are any of the other local community teams considered suitable too, if given training and support from the lead AHP? 96% have access to specialist neuro-rehabilitation units but do we know what access means, do they take up places and refer patients? If they do refer would the patients be accepted? So Neuro-rehab unit may be co-located with Neurosurgery units but the criteria for rehab excludes patients with tumours of the brain and spinal cord. Point referred to in 366.	The rehabilitation and neurorehabilitation sections have been consolidated in light of your comments. Local community rehabilitation teams are indeed suitable to provide rehabilitation for neuro-oncology patients, with training and support from the cancer network lead AHP in neuro-oncology.
College of Occupational Therapists	32 (old 30) 81, 84 (old 79, 80)	Key workers and pathways are key and it is essential they include all member of the team often AHP are not available or not asked. Many community teams have a neuro bias but do not take referrals from this client group.	Thank you for your comment.
College of Occupational Therapists	37, 105–109 (old 35, 95)	This is an excellent idea and will hopefully help address the point above.	Thank you for your comment.
College of Occupational Therapists	64	We welcome the fact that AHP involvement is acknowledged but are unclear as to which AHP`s this relates to? Also although this information is useful it does not indicate the quality of care. Is the main emphasis on discharge planning or is their some time for very valuable rehabilitation?	Details of which Allied Health Professionals (AHPs) are included are provided in the needs assessment document. The quality of care provided was beyond the scope of the survey.
College of Occupational Therapists	70 and 79	Rehabilitation Units. Whilst we have found many of these units invaluable some people with chronic needs do not fit into their criteria. Where there are multiple complex needs rehabilitation can include an extended	This is the background section, which describes current service provision. It is not appropriate to include recommendations in

		team with, for example, specialist workers for visual difficulties and Disablement Resettlement Officers. Would the group consider recommending a key worker system here as well as further on in the guidance?	this part of the guidance.
College of Occupational Therapists	84	Initial feedback about specialist AHP posts such as the one in Leeds (pump primed by Macmillan) indicates that they are useful.	Noted with thanks.
College of Occupational Therapists	112 (old 98)	Communication. The setting of realistic goals used in rehab involves the exploration of the impact of the disease on day-to-day life. Which can be just as devastating as the bad news consultation. Rehab staff in all settings should have access to communication skills training in line with NICE Supportive and palliative care guidance (2004). Folkman and Greer (2001) and Brennan (2002) Psycho oncology- assumptions shattered by disease can be rebuilt through client centred rehab. Activity is another medium through which information can be given.	Cross-referencing to the NICE Supportive and Palliative guidance is explicit within the document and communications skills training is therefore assumed.
College of Occupational Therapists	201–210 (old 162–170)	Speedy access to rehab is essential. Could they suggest appropriate time scales to commence rehab after referral?	This does not fall under the remit of a national target and it is felt that this should be left to the local teams to define patient pathways and access times. The importance of rapid access is stressed in paragraph 443.
College of Occupational Therapists	241	Would quality of life also be considered an important factor as much as prolonged survival?	This paragraph is in the evidence section and these trials did not study quality of life as an endpoint.
College of Occupational Therapists	284 (old 240)	NICE supportive and Palliative Care Guidance (2004) suggests a four level model of rehab with the specialist AHP cascading information down to the other members for the team. Would this be appropriate for spinal cord tumours?	The four level model of rehabilitation is discussed in paragraph 440, which is a general section on rehabilitation and refers to all sections of the document. As such we would agree that this is appropriate for spinal cord tumours as is stated in paragraph 446.
College of Occupational Therapists	351 (old 299)	Functional readjustment to activity Anticipated Occupational Therapy should be available.	This comment does not appear to relate to paragraph 351.
College of Occupational Therapists	370 (old 312)	Is the NICE (2004) model of rehab appropriate here? Where there are functional problems this should be co-ordinated through the lead AHP.	This does not seem to relate to paragraph 370, but the NICE (2004) model of rehabilitation is thought to be appropriate

			and is referred to in section 440
College of Occupational Therapists	384 and 405 (old 323 and 340)	Communicating exactly what has been said should be relayed to rehab teams as this may come up in treatment sessions. Unclear communication can often lead to mixed messages that impact on participation in treatment.	An additional requirement for timely communication to rehabilitation services has been included in Box 6 and this point is re-iterated in paragraph 381. We would agree that this communication should include details about what patients and carers know.
College of Occupational Therapists	418 (old 348)	Occupational Therapy Specialist functional assessment, eg Assessment and Motor Processing Skills, can be used as it measures day to day performance and is less intrusive than formal testing.	Noted.
College of Occupational Therapists	435–450	Would the group feel it useful to cross-reference the Supportive and Palliative Care Guidance as regards key workers and co-ordinated multi-professional working of the wider rehabilitation team?	The comment is noted and is an integral part of the guidance with regard to the definition of key workers (paragraph 105).
College of Occupational Therapists	436	Some practitioners report that there may be restrictions on their services for prolonged periods because of other demands made on the service. This frequently results in physical needs being prioritised (ref. DRR).	Thank you for your comment.
College of Occupational Therapists	436 (old 361)	Rapid access essential.	Thank you for your comment.
College of Occupational Therapists	439 (old 364)	Should this list include visual impairment workers?	We have revised this paragraph to ensure that visual impairment workers are included although we haven't specified them.
College of Occupational Therapists	442 (old 367 following)	All points are key to successful delivery. Can provision meet demand? Education of professionals may increase referrals for rehabilitation.	We agree that all points are key to successful delivery. The resource implications have been spelt out in the document.
College of Occupational Therapists	463 (old 383)	Palliative care - Should memory and behavioural problems be included as symptoms along with pain, nausea, vomiting etc? This is currently not so well recognised.	We have included memory and behavioural problems in paragraph 468.
College of Occupational Therapists	Appendix 3, pp. 173–175	AHP`s. To implement the guidance it appears that AHP involvement is necessary however there appears to be no extra costing of this. With increasing demands being made on Therapists we feel that it is important for commissioners to be aware that this would involve extra staff hours.	Appendix 3 has been revised accordingly to include costing of AHPs.
Conwy and Denbighshire		This organisation was approached but did not respond.	

NHS Trust			
Department of Health	General	We have doubts about whether the guidance adequately addresses the question of how to achieve consolidation of services in reality. There is a lack of concrete requirements, which leave determinations to be made locally. The guidance may result in a form of MDT working to decide on treatment plans, but what else may be achieved seems debateable.	The GDG were unaware that the function of the guidance was to achieve consolidation of services. The perceived aim is to improve patient services and co-ordination of care and it is considered that the recommendations for service reorganisation will achieve this end.
Department of Health	Para 6	Clinical colleagues feel that the proposal of a trust lead for brain tumours will be unworkable and will be a role on paper only. They advise that nothing will be gained by setting up this role. You may wish to reconsider this recommendation in the light of these comments.	The comment is noted. This role was carefully considered within the GDG and indeed in further comments on the second draft of the document from the National Cancer Network Clinical Directors Group this particular role is highly commended. As such, we feel that the responsibilities of the role are clear within the document and it should remain as is.
Department of Health	Para 17	In your response to first round comments on this paragraph, it was indicated that you would clarify who should establish national tumour groups. This doesn't appear to have been done, please would you consider doing so in the final version of the guidance. .	The responsibility for establishing national tumour groups is now stated within the guidance.
Department of Health	Para 18	As the guideline on spinal cord compression has now been formally referred to NICE, please could you now consider referring to it in this guidance.	The NICE group will now be referenced.
Department of Health	Para 58	If brain tumours are more common than CNS, it is not clear why are they seen less frequently by GPs than CNS tumours? We would be grateful if you could check this statement is correct?	The text has been amended to clarify.
Department of Health	Box 2, p. 45 bullet 6, (111)	Please would you consider clarifying the 'standards of care' referred to here – is this a reference to the Manual of Cancer Services 2004?	The wording of the statement has been changed for clarification.
Department of Health	Para 270	Who is carrying out this national work – please consider clarifying/x referring as appropriate.	The Society of British Neurological Surgeons (SBNS) is currently considering manpower planning for specialist services for the next 10 years.
Department of Health	Box 9 (284)	In response to first consultation comments, you agreed that you would clarify the	The definition of spinal surgeon in Box 9

		specialist organisation referred to here. You don't appear to have done so. Please could you consider doing so in the final version?	has been amended and now reads, 'Specialised spinal surgeon (neurosurgical/orthopaedic) but spends at least 50% of clinical programmed activities in neuro-oncological spinal surgery/spinal surgery are appropriately trained and participate in a specialist clinic.'
Department of Health	Para 315	DH asked that you clarify who should co-ordinate this – you do not appear to have done so, even though you indicated in your response that you would. This comment also applies to paragraphs 316,323,332,349,348 Please could you consider clarifying in the final version.	The responsibility for establishing national tumour groups is now stated within the guidance.
Department of Health	Para 327	Please consider amending this para as it is not entirely accurate; suggest '…meet the national guidance on the safe administration of intrathecal chemotherapy and the corresponding measures in the Manual for Cancer Services 2004.	We have made this amendment to the text.
Department of Health	Para 465	Please consider amending the last sentence of this para to read: 'when *and how* to seek advice.'	The text has been amended.
Department of Health	Para 488	Please consider replacing the following line "*ideally undertaken with or by a social care professional"* with "*someone with the necessary competencies."*	Thank you for your comment, which we have given consideration but we will leave social care professional as it stands.
Department of Health	Para 517	Please consider clarifying who should produce the report referred to in this para.	Thank you for your comment. We will revise this sentence.
Department of Health	Para 527	Does this assume that the MDT co-ordinator provides clerical support for data collection? Is that that a reasonable assumption or should there be 2 different roles? Please consider whether this paragraph should be amended.	The role of the MDT co-ordinator relates to all tumour types, not just brain and CNS. Data collection is included in the role of the MDT co-ordinator, described in the Cancer Measures.
Department of Health	Para 538	Please consider stating who cancer networks will need to demonstrate this to.	We have given this comment consideration, but feel that adding to whom the cancer networks will need to demonstrate this to will not be helpful. Ultimately cancer networks are accountable to strategic health authorities and the Department of Health.
Department of Health	439	Please consider including orthotists in paragraph 438 rather than 439.	We have amended paragraph 439.

		There is a mix of healthcare professionals and healthcare interventions in para 439. It refers to other healthcare professionals including 'neuropsychology' and 'neuropsychiatry'. Please consider amending to read 'neuropsychologists' and 'neuropsychiatrists'.	
Department of Health	439	Please also consider removing psychological therapy from this paragraph as it is also an intervention and may be provided by a range of healthcare professionals. Paragraphs 419 and 422 reflect this. For consistency, please consider amending chaplaincy service to read chaplains Wheelchair services may be provided by a range of healthcare professionals including AHPs and Healthcare Scientists. Also they are only one aspect of assistive technology/equipment which patients and carers may benefit from as part of rehabilitation. Please consider replacing this with 'Healthcare Scientists/Clinical Technologists.' Inclusion of the range of interventions which might be required within a rehabiltation programme is a valuable point. If this is retained, please consider including an additional paragraph which specifically draws attention to this point.	We have amended paragraph 439.
Eisai Limited		This organisation was approached but did not respond.	
Eli Lilly and Company Ltd	General	We are pleased with the overall content of this guideline document and believe it clearly defines the appropriate treatment and care of patients with brain and other CNS tumours.	Thank you for your comment
Eli Lilly and Company Ltd	531	This paragraph relates to clinical/therapeutic issues that need consideration in research development programmes. In particular it states that patient entry criteria for clinical trials in brain tumours in the past have been selective and that future trials should aim to include the patients from the spectrum of the disease. Whilst we agree this would be ideal, it should be recognised that these patients may have a prognosis of a few months only, can deteriorate rapidly and may not	Comment noted with thanks

		be able to consent to treatment in advanced relapsed disease. This may mean that in order to show a response over a reasonable time frame patients need to be recruited while they still have reasonable performance status e.g. above KPS 70.	
Faculty of Public Health		This organisation was approached but did not respond.	
GE Health Care		This organisation was approached but did not respond.	
Gloucestershire Hospitals NHS Trust		This organisation was approached but did not respond.	
Gorlin Syndrome Group	Section 364, p. 120	Genetic predispositions and in particular all references to Gorlin's Syndrome need amending to read Gorlin Syndrome.	Apologies for this error. The text has been amended
Gorlin Syndrome Group	Section 364, p. 120	Gorlin Syndrome is a condition which affects many organs and as such the need for MDT care is essential. It is vital that a child presenting with Medulloblastoma where Gorlin Syndrome is suspected is referred along with family members to Genetic Cancer Services for genetic screening and diagnosis. This will enable appropriate review and monitoring of the condition.	This is covered in paragraph 370.
Hammersmith Hospitals NHS Trust		This organisation was approached but did not respond.	
Hampshire & Isle of Wight Strategic Health Authority		This organisation was approached but did not respond.	
Headway – The Brain Injury Association		This organisation was approached but did not respond.	
Healthcare Commission		This organisation was approached but did not respond.	
Help Adolescents with Cancer		This organisation was approached but did not respond.	
Help the Hospices		This organisation was approached but did not respond.	
Hertfordshire Partnership NHS Trust		This organisation was approached but did not respond.	
Hinckley & Bosworth Primary Care Trust		This organisation was approached but did not respond.	
International Brain Tumour Alliance	General	Thank you for forwarding to us your comments about our submission on the first draft of this Guidance (specifically the "Information for the Public" or "IFP"). We have re-read the Committee's comments and also the second draft of the IFP and feel that a number of the points we initially raised in our first submission should be reconsidered based on the importance we feel is attached to them,	Thank you for your comment.

		from the brain tumour patient and carer perspective. We feel these points are of sufficient merit to be reviewed again.	
International Brain Tumour Alliance	Sections 35 to 37 under Aetiology and risk factors	As a follow on from the discussion of the aetiology and risk factors involved in brain tumours, it would be helpful to include in this section a statement to the effect that: **"The causes of brain tumours are generally unknown, apart from cases of ionising radiation and certain inherited syndromes. Unlike a number of other cancers, there is no current evidence that brain tumours can be prevented by lifestyle changes."** We raised this point because it underscores the fact that brain tumours are very different from some other types of cancer in that there is nothing that can be done (that we know of at this stage) to avoid getting them. One of the many searching questions that brain tumour patients and their carers ask is "What caused me to have a brain tumour?" Including a comment like the one above may go some way to help patients understand that there was probably nothing in their lifestyle that they could have changed to avoid getting a brain tumour.	The following text has been inserted at the end of paragraph 35: 'Unlike a number of other cancers, there is no current evidence that brain tumours can be prevented by lifestyle changes.'
International Brain Tumour Alliance	39	Add after "…there is a long delay from first symptoms to reaching a diagnosis causing considerable stress and anxiety" the words **"and in some cases, there is financial hardship as the symptoms of a brain tumour might affect one's ability to drive, hold down a job or remain independent."** We appreciate that this may relate to social service provision, but as this is an information document for the public, we feel that this very important aspect of brain tumours should be stated here. The physical and mental deficits which result from a brain tumour impact in ways that other cancers do not.	As observed the details of social services provision are outside the remit of this document. However, the general comment about support of this nature is covered in paragraph 488.
International Brain Tumour Alliance	71	With reference to our previous suggestion of listing the eight stereotactic radiosurgery centres in England and Wales, we don't understand the committee response comment: "The questionnaire sent to provider units in England and Wales was confidential, so none will be named in the document." Why, then, does this section state: "Much of the stereotactic radiosurgery is undertaken at the national centre in Sheffield."? This section goes on to state: "However, there are eight centres in total in England and Wales to whom patients are referred by neuroscience centres for stereotactic radiosurgery." We don't understand why an indication cannot be given of where	It was not deemed to breach the trust of the questionnaire suppliers to indicate that many units refer to Sheffield, which is a recognised national referral centre for this procedure.

		these other seven centres are and why their location is 'confidential'?	
International Brain Tumour Alliance	118 (under Measurement)	Under "Structure", fifth bullet point. Add the word "secure" so it reads: "Establishment of **secure** internet based database for central data collection.	The importance of information security is stressed in paragraphs 511 and 524.
International Brain Tumour Alliance	170	Add: **"... but should not yet be used as a basis for rationed access to emerging therapies until the efficacy of these diagnostic tests has been fully determined".**	The GDG feel that paragraph 170 is clear and explicit and additional wording would not contribute to this.
International Brain Tumour Alliance	208	Correction from "temozolamide" to "**temozolomide**"	We agree and have made the amendment.
International Brain Tumour Alliance	209	See para 170 above. Add: **"... but should not yet be used as a basis for rationed access to emerging therapies until the efficacy of these diagnostic tests has been fully dtermined".**	The GDG feel that paragraph 170 is clear and explicit, and additional wording would not contribute to this.
International Brain Tumour Alliance	229	Last sentence should read: "Patients and carers should be given clear information as to how and whom to contact if they are concerned about their condition, **including out-of-hours emergency contacts**." We feel this is a very important point and should be included.	This paragraph relates to the contact between healthcare professionals and specialist teams. The emergency cover out of hours for patients is most appropriately provided through standard emergency care; it would be inappropriate to build in emergency cover by specialist teams for these patients by direct patient contact.
International Brain Tumour Alliance	234	Sentence should be amended to read: "Novel treatments currently under evaluation should not generally be used outside the context of a clinical trial/research setting, **but nevertheless should be discussed with the patient and carer so that they are aware of any relevant clinical trials and research on a particular treatment**." It is vitally important that patients and carers are made aware of relevant clinical trials and emerging, new therapies. Patients are very resourceful these days and use various means (such as the Internet, talking to other patients, etc) to discover information about new treatments and clinical trials. But it is important that this information is also conveyed to brain tumour patients by their doctors in a timely fashion. We appreciate that there is mention of this in Section Number	The text of paragraph 234 is appropriate considering the context of the document as guidance. However, the importance of supporting trials is stressed including the key recommendation in paragraph 16.

		401, but feel it is important to mention it also in Section 234.	
International Brain Tumour Alliance	416	Amend paragraph to read: "Patients with CNS tumours may experience psychological difficulties adjusting to a serious, life-threatening condition in the same way as other cancer patients." Add**: "However, it is recognised that patients with CNS tumours may have burdens imposed upon them additional to those of other cancer patients such as the withdrawal of their driving licences**." Patients and carers would say that this is a vital difference between brain tumour patients and other cancer sufferers and that this sentence should be included, as the withdrawal of a driving licence due to a brain tumour may indeed have psychological impact as well as economic impact.	The emphasis put on appropriate MDT input for these patients and assessment thereof will allow problems such as withdrawal of driving licence to be highlighted and supported appropriately.
International Brain Tumour Alliance (IBTA)		This organisation was approached but did not respond.	
Joint Committee on Palliative Medicine		This organisation was approached but did not respond.	
Link Pharmaceuticals		This organisation was approached but did not respond.	
Macmillan Cancer Relief		Thank you for your invitation to respond to the second draft of the guidance for brain and other CNS tumours. We were pleased to see that many of the recommendations we made in response to the first draft were accepted and have been included in the latest draft. We were, however, disappointed that our request that supportive and palliative care was given much greater emphasis in the guidance was not accepted. Whilst we acknowledge that reference is made to the NICE Supportive and Palliative Care Guidance in the current draft, we do think that there is merit in giving much greater emphasis to the detail of supportive and palliative care in the 'Improving Outcomes' guidance. The elements of such care are so important to patients and their families that they should be included in all NICE guidance, so that healthcare professionals can be explicit about this aspect of a person's care. We believe that it would simply be much easier for postholders to deliver this important component of care if the detail of supportive and palliative care were included in all guidance rather than being referred to a separate volume. Patients and their families will have many practical, social, financial and	Thank you for your comment. The degree to which general supportive and palliative care guidance is cross-referenced or actually included in the document was carefully considered by the GDG. To avoid duplication and unnecessary weighty guidance it is felt that the approach taken is the most appropriate one.

		emotional needs which must be supported, and it is our view that the draft guidance is still weak in this respect.	
Marie Curie Cancer Care		This organisation was approached but did not respond.	
Medeus Pharma Ltd		This organisation was approached but did not respond.	
Medical Research Council Clinical Trials Unit		This organisation was approached but did not respond.	
Medicines and Healthcare Products Regulatory Agency (MHRA)		This organisation was approached but did not respond.	
National Alliance of Childhood Cancer Parent Organisations		This organisation was approached but did not respond.	
National Cancer Alliance		This organisation was approached but did not respond.	
National Cancer Network Clinical Directors Group	General	All diagnostic, treatment and supportive care services should be made available for the whole spectrum of grades and tumour type as necessary. There is a possibility that Trusts will concentrate on the high grade tumours at the expense of the lower grade tumours especially if historically NONS were provided by pump-priming finance from cancer charities. Whilst the urgency (in some cases) of service provision is of a different order for low grade tumours, they should still be put in place and adequately resourced.	The document is clear and explicit in its covering of all grades of cancer. There is a section, for example paragraphs 197 and 378, concentrating on low-grade tumours and stressing the needs of these patients.
National Cancer Network Clinical Directors Group	General	National Service Framework for Long Term Conditions. There needs to be some direct cross-referencing to the NSF for Long Term Conditions. Very many components of the NSF apply to people affected by brain and CNS tumours.	Cross-referencing to the NSF for Long Term Conditions and has been noted and is now included in paragraphs 377 and 435.
National Cancer Network Clinical Directors Group	General	Diagnosis and communication. When people are diagnosed with a brain or CNS tumour most are “shocked” by the diagnosis. A lot depends on the jargon used eg Space Occupying Lesion on referral to Neuroscience centre will mean little to the vast majority of people, whereas use of the phrase “suspected brain tumour” will. There is a need for training on “breaking bad news” and also to identify when support needs to start, information given etc. This includes the various stages	The importance of communication skills training is clear within the document in paragraphs 383 and 384.

	Para 85	of:- • initial presentation at an Acute Trust • review of imaging at the neuroscience centre • histopathological review • when therapy is instigated Where possible people with brain tumours and other CNS tumours and the dedicated voluntary sector EG brain tumour charities should be involved in the design and delivery of training to staff, including senior staff, around this subject.	
National Cancer Network Clinical Directors Group	General	Role of relatives and carers It is welcomed that the role of relatives and carers is recognised as crucial and that they have their own needs for information and support. This is not only when the patient has cognitive impairment but in many areas of decision making around treatment and care. The need to identify occasions when "face to face" communications are required at key points in the patient (and carer) pathway needs to be strengthened in local protocols. There needs to be a consistent reference to the role of the relative/carer in the Guidance. *For example*, Add 'support for relatives/carers'	Noted with thanks.
	Para 61	Add "relatives and carers" under outcomes.	This is in the background section and describes current service provision.
	Para 397	Add "local" before 'national'.	Consistency will be established throughout the document.
	Para 400	Suggest that a local directory of supportive care is made available in each locality	Local will be added.
	Para 402	Add "relatives and Carers"	This is an issue for the NICE guidance on Supportive and Palliative Care.

	Para 404		
National Cancer Network Clinical Directors Group	General Para 482	Patient and carer satisfaction It is welcomed that there is a commitment to obtain patient and carer satisfaction with the range of services provided. To ensure that this takes place, there needs to be a consistent reference under 'Measurement' in all sections of the Guidance to this effect, eg *para 360* and add a *new paragraph after para 375*. Surveys of palliative care experiences are also welcomed.	Comment noted. Patient/carer satisfaction will be added to the outcome section as suggested.
National Cancer Network Clinical Directors Group	General	Supportive Care The emphasis on supportive care is welcomed and should be provided across the tumour types. Also, joint clinics could be useful in ensuring that all services are properly co-ordinated . These could be "nurse led" in certain situations. There is a strong and genuine desire amongst the general brain and spine charities and condition-specific brain tumour and other charities and support groups to provide an input to the 'supportive care' needs of people affected by these conditions. This should be harnessed.	We acknowledge your comments and direct you to paragraph 380 where the possible role of joint clinics is identified. The details of local provision of service are outside the scope of this guidance.
National Cancer Network Clinical Directors Group	General, 95	Role of the MDT Co-ordinator A key role of co-ordinator should be to allocate people newly diagnosed (confirmed) into the relevant category high grade, low grade, rare etc. Local protocols should be in place to enable those with a suspected brain tumour, which subsequently turns out to be something else eg cyst, to be picked up and supported appropriately. It is important that they don't get the impression	The GDG feel that the appropriate categorisation of patients is a responsibility of the neurosciences MDT. It is considered to be outside the scope of the document to advise on the management

		that " you don't have a brain tumour, we are no co-ordinated services for you". If no other monitoring system is in place, the Cancer MDT co-ordinator should track individuals along the patient pathway for their respective tumours. From the MDT meeting, as well as a "key worker", it needs to be clarified and explained to the patient and their relative/carer, what the various roles are of the members of the health team that they come in contact with and which doctor is in overall charge of their care.	of patients who subsequently turn out not to have cancer. It is the responsibility of the neurosciences and cancer network MDTs to record data on these patients. The co-ordinating role of the key worker is clear and by working through the MDT structure, appropriate referrals of patients to other members of the team will be made. It is clearly a professional responsibility of those individuals to clarify with relatives, patients and carers the details of their roles and responsibilities. The GDG will consider the addition of an explicit responsibility of the MDT to nominate a doctor responsible for care at any point in the patient's pathway.
National Cancer Network Clinical Directors Group	Appendix 6 – Glossary	Can you please insert a definition of 'anaplastic'?	A definition of anaplastic will be added to the glossary.
National Cancer Network Clinical Directors Group	Miscellaneous Title of medical condition	The members of the Gorlin Syndrome support group request that the name of the condition should appear without the apostrophe and letter 's'.	Thank you for your comment. The Gorlin Syndrome support group have contacted us separately and we have made this amendment.
National Cancer Network Clinical Directors Group	Make up of MDTs	Welcome • designation of a lead in every acute Trust • Neuroscience and Cancer Brain and Other CNS tumour MDTs	Thank you for your comment.

	Key Recomendations, Para 6 Paras 419–423 Additional comments	• Key workers for patients and carers Inclusion of a Neuropsychiatrist or Neuropsychologist in MDT is particularly welcomed but it is vital that sufficient resources are made available to enable Psychologists to be fully involved. 1. Despite the emphasis on this guidance being for health professionals there should be reference to the desirability of including representatives from the voluntary sector where they are organised and present in the geographical areas covered by the respective Trust. This applies generally and in specific circumstances eg Pituitary Tumours, Tuberous Sclerosis, Neurofibromatosis. 2. Equally, there should be reference to the desirability of including social workers as members of the MDTs (preferably hospital based and knowledgeable about neurosciences and cancer treatments)	The suggestion of including representatives of the voluntary sector is outside the scope of this document. Inclusion of social workers within the MDT is outside the remit as these are non-NHS employees.
National Cancer Network Clinical Directors Group	Referral Key Recomendations, Para 7	Welcome emphasis on referral without delay	Thank you for your comment.
National Cancer Network Clinical Directors Group	Neuropathology and Neuroradiology Key Recommendations, Para 8	Welcome establishment of adequate services for neuropathology and neuroradiology services to provide appropriate diagnostic interventions	Thank you for your comments.

	General	Imaging after any neurosurgery, and where Oncology radiological imaging has been undertaken, should be co-ordinated to reduce duplication, avoid confusion and unnecessary inconvenience to patient/carer and health professionals involved. There is also a potential saving and knock-on improvement for other people requiring imaging.	
National Cancer Network Clinical Directors Group	Neurosurgical services Key Recommendations, Para 9	Welcome emphasis on ready access to biopsy and or resection services	Thank you for your comment.
National Cancer Network Clinical Directors Group	Communications along the patient pathway Key Recommendations, para 10	Welcome and reiterate the importance of face-to-face communications at critical points in the care pathway for all people affected by brain and other CNS tumours and the need for written information for patients, relatives and professionals	Thank you for your comment.
	Para 395	The point is well made that people with tumours may well have cognitive impairments which makes it even more important that information is available in a variety of formats eg leaflets, tapes videos and in different languages.	Paragraph 401 has been altered to indicate that responsibility for information giving is that of all healthcare professionals.
	Para 397	Having a dedicated Information Lead is a good idea but there is a possibility of leaving everything to that person and not seeing information as everyone's responsibility. The costings seem very modest for quality information in various formats.	

	Para 413 General	It should be included as a recommendation that all Trusts producing basic leaflets about their service, should reference the voluntary sector in the provision of information and investigate collaborative working to avoid duplication. People affected by brain and other CNS tumours should be involved in the design and delivery of training of staff, including senior staff, in communications around this subject. Financial resources should be made available to enable this input, eg payment of volunteer expenses.	The costings have been checked and revised upwards. The GDG is not in a position to quality assure information sources, including voluntary sector, and as such is not in a position to reference documents from these sources. Other details of training and communication skills are outside the remit of this guidance.
National Cancer Network Clinical Directors Group	Clinical Nurse Specialists and Key workers Key Recommendations Para 11 Para 225, Box 7, p. 95 and elsewhere	Strongly endorse the need for more Clinical Nurse Specialists and their likely role of 'key workers', especially during the early stages of clinical care. There is reference to key workers throughout the guidance to help deliver the supportive services, access rehabilitation etc that people require. It is probably ideal for these to be provided by a Clinical Nurse Specialist. However, it is welcomed that their role is highlighted for the low grade tumours,, rare tumours, pituitary, spinal cord, and skull base tumours, etc. Ideally, the NONS would cover both the Neuroscience and cancer treatment centres. This would enable continuity of care to be provided by one person "Key Worker" from pre-diagnosis in the Neuroscience Centre to post-therapy treatment as an outpatient in the cancer centre. It is important that sufficient resources are identified to enable a reasonable workload/case mix for each NONS so that a quality service can be delivered.	Thank you for your comment.

	Para 82	It is also important that the Guidance makes allowances for the time NONS spend on Education and Training of other health and social care professionals.	
National Cancer Network Clinical Directors Group	Palliative Care Key Recommrn dations, para 13 Para 491 Para 464 General	 The advice available to both MDTs of palliative care specialists as core members is welcomed. Ideally each Neuroscience and Cancer centre should have on site a palliative care service and they should be represented on the two MDTs. The emphasis on early involvement of Palliative care is welcomed as palliative care effectively starts at diagnosis. The Guidance should recommend also that local protocols are drawn up to give some criteria for referral to Palliative Care Specialists. For example:- • Late diagnosis/enhanced condition • Metastases • Rapid progression • Lack of domestic support/carers issues • General health and frailty • No surgery or therapy given or none response to treatment	 Thank you for your comment. We feel this is covered at sufficient level in paragraph 494 and that more detail would constitute clinical guidelines rather than service guidance.
National Cancer Network Clinical Directors Group	Rehabilitati on Key Recommen	 Welcome emphasis on rapid access to Allied health Professionals and rehabilitation services and specialist equipment where necessary.	 Thank you for your comment.

	dations, Para 14 General Para 322 Para 396 General	Although there is a need for flexibility at local level, there perhaps needs to be greater clarity about what "rehabilitation" is for brain and CNS Tumours. For example, is it possible to identify different types or levels of rehabilitation, such as • post surgical • post symptomatic • post therapy • supportive care during remission • Complementary therapies to be promoted Some aspect of rehabilitation eg neuropsychological support would be present throughout the patient pathway. There should be a reference in every Brain tumour and CNS sub division to rehabilitation in the recommendations. Vocational Rehabilitation. There is no reference in the Guidance to the importance of Vocational Rehabilitation. For a significant proportion of people affected by brain and CNS tumours, vocational rehabilitation will remain a significant aspect of their lives.	We feel this falls within the remit of clinical guidelines rather than service guidance. We feel this would be unwieldy and the importance of rehabilitation (which we would assume incorporates vocational rehabilitation) is covered within paragraph 443.
National Cancer Network Clinical Directors Group	Research Para 16 Para 528	Welcome intention to develop portfolio of research trials and potential for increased patient access to them. It is noted with regret that there is a marked lack of evidence and research into surgical, medical and psycho-social aspects of care for people affected by brain and other CNS tumours and there is a lack of evidence of the incidence of some rare tumours, which is in line with the lack of epidemiological data for all neurological conditions. This needs to be urgently addressed if adequate planning and allocation of resources is to be possible.	Thank you for your comment. A consequence of implementation of this guidance will be the rapid accumulation of epidemiological and other evidence to support the development of services.

	Para 535 Para 539 General	It is acknowledged that individual practitioners and MDTs will have developed great expertise in their respective fields but where possible trusts should try to collaborate (regionally, nationally and internationally) and try to identify partners ,including the voluntary sector to attract funds for research. Welcome the intention to collect and store adult tumour samples to aid future research subject to normal consent. As well as through individual Trusts or research leads, information, eg web-based and/or newsletter, should be published to dis-seminate developments in research in this field for people affected by brain and CNS tumours, perhaps involving the voluntary sector.	Comment noted. Comment noted. Comment noted.
National Cancer Network Clinical Directors Group	Para 256 Specialisation at hospitals and within neurosurgical teams	It is noted that where certain “high volume” hospitals concentrate on surgery that outcomes are better. It is also noted that where individual neurosurgeons sub-specialise that outcomes are better for the patient (and relatives). Whilst it is acknowledged that all neurosurgeons need to maintain their skills and techniques, greater co-operation is desirable amongst neuroscience centres - on a regional or national basis if necessary - to develop expertise in sub-specialities to further improve outcomes for people affected by the rarer tumours. It is acknowledged that there are implications for patients and relatives of a non-medical nature eg transport costs, time off work, lack of visitors etc and some undermining of access to key worker by this approach.	Noted.
National Cancer Network Clinical Directors Group	204	This should be the "decision" to treat date, not "definition"	The text has been amended.
National Cancer Network Clinical Directors Group	395	Cross referencing to trusts need to copy patients in to correspondence would be helpful	As this is a national initiative, cross-referencing within this guidance would not be beneficial.
National Patient Safety Agency		This organisation was approached but did not respond.	
National Public Health		This organisation was approached but did not respond.	

Service – Wales			
Neurological Alliance		This organisation was approached but did not respond.	
NHS Direct		This organisation was approached but did not respond.	
NHS Health and Social Care Information Centre		This organisation was approached but did not respond.	
NHS Modernisation Agency, The		This organisation was approached but did not respond.	
NHS Quality Improvement Scotland		This organisation was approached but did not respond.	
Novartis Pharmaceuticals UK Ltd		This organisation was approached but did not respond.	
Nursing & Supportive Care Collaborating Centre		This organisation was approached but did not respond.	
Pfizer Limited		This organisation was approached but did not respond.	
Plymouth Hospitals NHS Trust		This organisation was approached but did not respond.	
Primary Care Collaborating Centre		This organisation was approached but did not respond.	
Princess Alexandra Hospital NHS Trust		This organisation was approached but did not respond.	
Richmond and Twickenham PCT		This organisation was approached but did not respond.	
Royal College of Anaesthetists		This organisation was approached but did not respond.	
Royal College of General Practitioners	General	The importance of comorbidity isn't sufficiently emphasised. As pointed out in 27 and 31, the incidence of brain tumours is increasing because more are being found in the elderly (who are likely to have significant comorbidity) and in the increased investigation of alzheimers and strokes. Therefore for many patients their brain tumour may not be their most important problem, and so the concept of every patient having to go through the same process should be modified. In cases of significant comorbidity, the G.P. should have a central role is deciding management.	It is explicit in the document (paragraph 103) that poor performance status patients should have management plans developed through, but not necessarily be seen by, members of the neurosciences MDT.
Royal College of General Practitioners	General, 483	IOGs have in the past been used, amongst other things, to persuade commissioners to increase the funding for a specialist hospital service. There	The scope of the economic review is to examine the main cost implications of the

		should be a move to seeing the service as something which isn't just delivered in hospital but throughout the health service. In the competitive nature of demands for funding, it is possible for an IOG such as this one to draw resources from community initiatives, even when these are vital for the brain tumour service as a whole :see 483. It would be better to cost for the whole service rather than encourage damaging competition as is happening with this document. There should be an attempt to include primary care costs in the economic evaluation.	guidance. Although there may be some cost implications for primary care, the GDG did not anticipate that it would be high in relation to the guidance as a whole. The analysis therefore concentrates on other aspects of the guidance.
Royal College of General Practitioners	Key recommendations	The importance of communication between the mdt and the primary health care team/G.P. should be added As should be the importance of providing rapid and appropriate access for G.P.s to imaging services in order to cut the delay in diagnosis (see140, 143)	This is a general comment on communication rather than specific to brain and CNS tumours and therefore is not a key recommendation relevant to this patient group. Access to imaging is outside the scope of this document.
Royal College of General Practitioners	42	This is unclear: by present do you mean to the G.P.? I suspect not because the "differential diagnosis" suggests professional intervention. If the delay is at the G.P. end then improved access to brain scans is a step forward	Clarification of paragraph 42 has been achieved by changing the sentence and the delays in diagnosis are covered in paragraph 39.
Royal College of General Practitioners	47	I think the G.P. should be mentioned as the foremost worker in this field, since the G.P.s role is to provide practical, emotional and psychological help for patients and carers over the long term and not just for a particular problem.	The wording of this paragraph has been carefully considered by the GDG and they have concluded that healthcare professionals acknowledge in an equitable way the contribution to care of a range of individuals who have an input into these patients' care.
Royal College of General Practitioners	82	It should be added that when due to progression/state of disease, the focus changes to community care, the primary health care team, specialist palliative nurses and the Gold Standards Framework, assume the major role in coordination, key workering and care	It is felt that disease progression per se would not necessarily be an indication for transferring care to the community team, but that paragraphs 81, 82 and 106 emphasise the appropriateness of the key worker at various stages in the disease. It may be appropriate that on disease progression, patients are considered for further

			intervention and treatment through the MDT structure.
Royal College of General Practitioners	89	No mention of G.P. : the G.P.s role is vital and when faced with comorbidities may be the most important one	Your comment is noted but the paragraph referred to relates to co-ordination of care and specifies the key worker in this role. Paragraph 108 makes the point that the key worker is the individual most appropriate for care of any individual patient and includes the GP amongst a range of healthcare professionals.
Royal College of General Practitioners	105, 108	108 quite rightly points out that key workers change when morbidity changes. It should be possible for the G.P./community team to assume key worker status when obviously needed without the mdt having to sanction it.	The importance of the GP being included in the list of possible key workers is emphasised in paragraph 108. It does, however, remain important that the link with the MDT is clear, so that all members are aware who the key worker is. It would of course be assumed that clinical priorities would allow the most appropriate person to act in the patient's best interest at any given time.
Royal College of General Practitioners	165	Add "and G.P. referred" to outpatient investigations	It is felt that this is outside the remit of this guidance and is covered within the referral criteria for 2-week wait.
Royal College of General Practitioners	196	Comorbidity should be added to the deciding factors for management (as in 201)	It is felt that the importance of comorbidity is covered in paragraph 103 and does not need reiteration in each section.
Royal College of General Practitioners	204	The waiting time targets are specifically cancer ones	The text has been amended.
Royal College of General Practitioners	279	G.P.s should be added to the list: for example I suspected/diagnosed the last 2 pituitary tumours	GPs were not included in this list as the GDG took the view that the GP would have continued involvement in the patients' management (particularly when patients are receiving medical treatment).
Royal College of General	280	Some endocrinologists may wish to emphasise the importance of the G.P. in the	This comment emphasises our point in

Practitioners		team management of patients with pituitary tumours. I have been approached when consultants wanted to "share care" which involved my prescribing Human Growth Hormone	response to your comment 17.
Royal College of General Practitioners	381	Surely a place to mention patient held records?	It is not within the remit of this guidance to make recommendations on patient held records. This is not a particular issue with respect to brain and CNS tumours.
Royal College of General Practitioners	428	This has to be balanced against the desire for patients to die at home (479), so perhaps this line of management should be used primarily for those with good prognosis?	This paragraph relates to information within the evidence section of the document and does not constitute a recommendation.
Royal College of General Practitioners	434	Include an element for cost of primary crae psychological support	The document is looking at specialist services and does not comment on general support
Royal College of General Practitioners	479	An additional reason is poor G.P. out of hours services. As is poor coordination by the primary health care team, though Gold Standards Framework can address this.	Thank you for your comment.
Royal College of General Practitioners	481	Improvement in G.P. out of hours services should be added here. It should also be costed/ as should Gold Standards Framework. It is feasible to provide a bespoke service for terminally ill cancer patients.	Thank you for your comment.
Royal College of General Practitioners	503	Death in preferred place of care is as important and should be added.	We feel that death in preferred place of care is not an appropriate measure for these patients, as explained in paragraph 468.
Royal College of General Practitioners	511	Hopefully this is exactly what CfH is providing	Indeed, this is what CfH is providing.
Royal College of General Practitioners	537	An additional powerful recruiter to trials would be to make information about all trials available to the public/self-help groups and via a website.	We think this is included in paragraph 401.
Royal College of General Practitioners	Appendix 3/General	There is no mention of primary care costs which would be needed to provide a service for brain tumours	The scope of the economic review is to examine the main cost implications of the guidance. Although there may be some cost-implications for primary care, the GDG did not anticipate that it would be high in relation to the guidance as a whole. The analysis therefore concentrates on other aspects of the guidance.

Royal College of General Practitioners	Appendix3/ General	I'm not sure what to think about having a formula for deciding which people are necessary for an mdt, then assuming half won't ever be there. There seems an inconsistency here.	The 50% attendance at MDTs is the standard from the cancer measures
Royal College of General Practitioners	Appendix3/ General	In calculating opportunity costs for mdts, the fact that members may have had to see the patient individually otherwise and don't have to as result of discussion is ignored. These could be significant opportunity savings which should be offset eg "there's no point referring the patient to me for radiotherapy because…."	Thank you for your comment. The scope of the economic analysis is to give broad estimates of the main cost implications of the guidance. We are not able to examine the fine detail.
Royal College of General Practitioners	Appendix4/ p. 176/first sentence	I would presume that in addition it is intended to guide the 10000+ practices who will be engaged in practice-based commissioning?	Thank you for your comment.
Royal College of General Practitioners Wales		This organisation was approached but did not respond.	
Royal College of Nursing (RCN)	General	The Royal College of Nursing welcomes this document.	Thank you for your comment.
Royal College of Nursing (RCN)	Full Guidance – General	If the guidance is implemented it will have a big impact on the standard of care patients and carers receive.	Thank you for your comment.
Royal College of Paediatrics and Child Health	General	We are submitting feedback to this second draft on behalf of the UKKCSG Brain Tumour Committee. The UKCCSG Brain Tumour Committee consists of a network of neuro-oncology specialists from paediatric oncology, clinical oncology, neuro-surgery, neuropathology, and neuroradiology. This Committee has, over the last 25 years or so, promoted clinical trials in CNS tumours of childhood and adolescence. The current Committee has an expanded membership of about 50 people with sub-groups concerned with: • astrocytic tumours - high grade*/low grade*, brain stem* • embryonal tumours – standard risk and high risk medulloblastoma*, supratentorial PNET*, metastatic PNET*, and infant PNET • ependymal tumours – with trials open in infant ependymoma* and phase II trials of chemotherapy in ependymoma* in infants and older children • intracranial germ cell tumours* with an international trial in development	Structure noted with thanks.

		• functional imaging with an established network of collaborating imaging centres and two open studies* • rare tumours – protocols in development to study craniopharyngioma and atypical teratoid rhabdoid tumours (ATRT) • quality of survival – this is a new group which has been formed in response to the need for incorporation of quality of survival outcome measures in tumours of infancy, childhood and adolescence. There are a number of trials where such measures are being considered primary outcome measures for future trials. (*trials open in these categories) Currently the NCRN website registers 10 open trials in childhood brain tumours. It is from this perspective that we read the current guidelines that are circulated in draft form.	
Royal College of Paediatrics and Child Health	19	The Adult guidelines for Brain and other CNS tumours mention the guidelines for children and young people with cancer and also refer to the UKCCSG's expertise in some of the rare tumours that are more common in childhood. However, we are concerned that there is still little importance given to age stratification in this document. Clearly as paediatricians, we are dealing with rapidly developing and maturing individuals. However we perceive the need for greater emphasis being given to the age stratified judgements about CNS tumour management within adult practice as well. Specifically, we make the following recommendations: 1. The NICE guidance for children and young people with cancer identified that the age group covered by children and young people could extend up to 25 years of age and certainly the childhood National Services Framework extends to 19 years of age. We would not consider it appropriate, therefore, that this adult document refers to the 15-19 year old age group and consider that any data in the 20-25 year old age group was clearly marked as relating to the hinterland between young people's practice versus adult practice. There needs to be more flexibility in the approach to patients in this age spectrum.	The issue with regard to age stratification is noted. However, there are very little data and almost no research stratifying patients within the adult age group into these subgroups. The importance of considering prognostic factors is considered within the document (e.g. paragraphs 201 and 103), with regard to treatment protocols. It was felt by the GDG that further stratification would be unhelpful. There is clear cross-reference (paragraphs 19, 135, etc.) within this guidance to the NICE Children and Young People with Cancer guidance regarding the interface between children, adolescent and adult services. The Rare Tumours Chapter 7 also highlights that the neuroscience MDT may benefit from paediatric oncology input.

		2. The document makes little recognition for the different approaches that are necessary in young adults compared to the elderly. This is particularly important given the health economic judgements being made by NICE with respect to drug funding. The health economic impact of disability and loss of life years is far greater in those who are young. Lumping all ages together as in this document results in an insensitive structure to the clinical situations that present in young adults versus the elderly when diagnosed with a brain tumour. It also ignores the difference in outcome for these different age groups. Our practice of treating children and young people with a positive intent at all times is just as relevant to the people up to the age of 40 and 50. There is increasing evidence that some of the newer, more successful, tumour therapy strategies are more successful in the young than they are in the old. There is established evidence that young people with high-grade tumours live longer than elderly people with high-grade tumours. It would seem, therefore, that in this document some effort should be made to reflect upon this difference in outcome. We would also suggest that recognition be given to a difference in attitude with respect to curative intent, but also the duration of rehabilitative support that would be necessary within the broader health community. 3. This document, with its lack of age stratification, makes little mention of the needs of the adolescent and young adult with respect to the management of the primary tumour types that predominate in that age group, and, most importantly, with respect to the management of relapses or complications of tumour management where the original treatment was delivered <19 years. Overall, children's brain tumours have a 60-70% 5-10 year survival with current practice. An increasing number of patients, therefore, will be entering the adult age range with the consequences of prior therapy. The adult neuro-oncology MDTs, as they develop, will be the place for these cases to be discussed. This guidance fails to identify this as an area of future practice and is therefore an important omission. It should be noted that 1 in 950 adults are now survivors of childhood cancer, indeed it is estimated that there are 26000 adult survivors of childhood cancer in the UK-	In addition, the issue of patients treated in childhood requiring subsequent follow-up and late effects is within the remit of the NICE guidance on Children and Young People with Cancer and is not within the scope of this guidance.

		up to a quarter of whom will have survived treatment for a CNS tumour. This group of patients need ongoing specialist multi-disciplinary care. This group of patients with other cancers are at the focus of developing network of adolescent oncology teams. The hinterland between childhood (<16) and adulthood (>25) is an area where children's specialists and adult specialists meet and may well share their expertise. Specific mention of the needs of this group of patients in this document is important as it would provide clear direction to the adult teams offering specialist support, as well as the paediatric teams seeking reliable transition arrangements for their mature patients.	
Royal College of Paediatrics and Child Health	Box 3 (after 111)	There is no mention of the importance of attracting medical oncologists into this speciality and their involvement in the MDT. If part of this NICE strategy is to promote a more vigorous clinical trials programme, which it must be, then academic leadership and the involvement of medical oncologists as well as clinical oncologists will be very important.	The role of the medical oncologists in adult neuro-oncology is more limited than in paediatrics. Clinical oncologists in the UK have extensive knowledge and input into chemotherapy management and at present it was felt by the GDG that medical oncology input would not be a good use of resources.
Royal College of Paediatrics and Child Health	*20*	You state that these guidelines do not offer level of detail required to inform about decision making about specific diagnoses for individual patients. However, there is a partial attempt to describe management of some CNS tumour entities in their current form. It is our view that this aspect of the proposal is insufficiently developed to be truly useful and either needs considerable more work to make the guidance accurate, reliable and comprehensive or the guidance for specific tumour types should be excluded altogether. As written they do not meet current standards of practice (ie Germ cell tumours, optic pathway glioma, ependymoma, craniopharyngioma, medulloblastoma).	The comments put within the treatment section are intended to be general and guidance in terms of areas of practice where resource implications may follow. There is no intention that this guidance forms recommendations in detail for treatment as would be covered in a clinical guideline. The document is explicit that the treatment protocols for these patients will be managed nationally through the specialist groups.
Royal College of Paediatrics and Child Health	160	The involvement of a medical/clinical oncologist in pre-operative discussion of cases should be strongly encouraged as this allows an opportunity to decide and refine the treatment strategy at the outset. This has been particularly important	As neurosurgical intervention is pivotal in the establishment of diagnosis in many of these patients, the GDG felt that pre-

		in paediatric cases.	operative medical and clinical oncology input into these patients would be introducing an unnecessary delay and not beneficial
Royal College of Paediatrics and Child Health	165	Where a brain tumour is suspected at a DGH/secondary centre we would recommend that limited MR scan is sufficient as the initial diagnostic imaging. Clearly there is often reluctance to repeat complex MR series which often means that newer imaging modalities, such as MRS diffusion/perfusion studies, may not be carried out. The role of functional imaging in determining the biological nature of tumours is the subject of intense research at the moment. The new neuro-oncology MDTs will need to have access to both these methods of biological assessment within the foreseeable future and integrate the results of the current translational research into practice within the next five years. Though raised, this point has not been emphasised within this document.	The responsibilities of the neurosciences and cancer network MDTs to optimise patient pathways and introduce new investigations and treatment as they become available inevitably means that access to imaging will change over time. As indicated this is the subject of research at present and clear recommendations to commissioners are not possible at present.
Royal College of Paediatrics and Child Health	190	We fully back the need for more neuropathologists who are key to improvements in patient care through a better understanding of the disease process. Their role in biological studies in reliably identifying clinicopathological entities cannot be overstated. As biological and other novel therapies become available their role and importance will increase.	Noted with thanks.
Royal College of Paediatrics and Child Health	335–343	Intracranial germ cell tumours are listed under the heading of pineal region tumours which is conventional in adult texts but not children's texts. These tumours also arise in other regions. Population registries and literature clearly show that these tumour age incidence falls across the childhood, young people and adult age ranges. They are the most chemotherapy/radiotherapy sensitive of all intracranial malignant tumours, germinomas having greater than 95% survival, non-germinomatous GCTs 70% survival. Because these tumours span the childhood/adult age groups, it is, therefore, important that they are mentioned specifically. We have learned much about these relatively rare tumours through an international trial (SIOP Germ Cell Tumour 1996). There is an increasingly active international dialogue about their management, linking Europe, the US and Asia. Important lessons regarding staging and surgery have been learnt. It is from this standpoint that we are extremely concerned as the guidelines, as written, are **incorrect** and are, in fact, dangerous. The guidelines should	The comments with regard to intracranial germ cell tumours are noted. It should be noted that this is service guidance, rather than a clinical guideline on management. However the wording of paragraphs 335–339 has been changed to include the importance of hormonal marker measurement, the possibility that this will remove the need for tumour biopsy and the measurement of CSF cytology. The importance of managing these patients through nationally agreed protocols is of course made within the document.

		include measurement of hormonal markers at diagnosis as the decision-making trigger to different strategies. For those that are hormonal marker positive, there is **no** need to biopsy and primary chemo-therapy is recommended followed by a consideration of surgery for residual disease and radiotherapy. It should be mentioned that in the marker positive patient that very high levels of hormonal markers are indicative of poor prognosis. There should also be clear guidance about CSF analysis for tumour cells. It has been shown that prognosis is better in those patients that are correctly staged and managed. For those that are hormonal marker negative and typical tumours on scan of a germ cell tumour, then biopsy is mandatory. These patients require full MDT discussion before management is initiated after initial stabilisation of raised intracranial pressure.	
Royal College of Paediatrics and Child Health	344–353	The guidance specifies for optic pathway glioma that the majority of these patients present in childhood are predominantly pilocytic and that they need lifelong follow-up. We concur with this view and would recommend that efforts are put to establishing a national register of optic pathway gliomas for this reason as, in childhood, they are associated with 90% survival and the biological behaviour of those tumours arising in childhood is unclear in the adult age groups and requires further study. We would propose that this national registry be based upon the existing children's low-grade astrocytoma database at the UKCCSG that has emerged from recent international pilot study of chemotherapy in low-grade glioma. The heading of this sections disregards that low-grade glioma in childhood can occur in any part of the brain and the current evidence is that where the tumours are pilocytic their biological behaviour and sensitivity to adjuvant treatment is similar justifying a histological structure to disease classification rather than an anatomical structure. Anatomical locations will determine symptomatology and suitability for surgical management.	The suggestion of having a national register for optic pathway gliomas is acknowledged. An additional recommendation in the introductory section of chapter 7 has been included to require a managed national register as a responsibility for all the national rare tumour groups. Low-grade gliomas are covered extensively elsewhere in the text and the use of the anatomical model fits with the construction of the MDTs to support the patients.
Royal College of Paediatrics and Child Health	335	Pineoblastomas, whilst rare in adults, are essentially high-grade malignancies and respond well to chemotherapy and radiotherapy according to the PNET III protocol.	These will become part of the guidelines produced by the specialist groups.

Royal College of Paediatrics and Child Health	197–200	There is no mention of the very different biological behaviour of low-grade astrocytomas in childhood, that is pilocytic tumours, compared to low-grade gliomas in adulthood, which are predominantly grade II astrocytomas and are considered pre-malignant lesions. There is very little evidence that the pilocytic astrocytomas represent a pre-malignant condition.	This is why it was not mentioned.
Royal College of Paediatrics and Child Health	330	PNET/medulloblastoma is mentioned and the expertise in paediatric practice acknowledged. There is now an international acceptance of the benefit of chemotherapy in addition to surgery and craniospinal radiotherapy. Recent evidence shows that adults treated on paediatric-style protocols have a better outcome (Spreafico et al, "*Survival of adults treated for medulloblastoma using paediatric protocols*". European Journal of Cancer 2005; 41: 1304-1310 and Herrlinger et al *Adult medulloblastoma : prognostic factors and response to therapy at diagnosis and relapse.* J Neurology 252 :291-299). Adults with relapsed disease seem to have a more favourable outcome than children and consideration of further therapy in this cohort should be considered (Herrlinger et al *Adult medulloblastoma : prognostic factors and response to therapy at diagnosis and relapse.* J Neurology 252 :291-299).	Noted with thanks.
Royal College of Paediatrics and Child Health	General	The paediatric trials' network have considerable expertise in medulloblastoma, ependymoma, low grade glioma, intracranial germ cell tumours and growing expertise in craniopharyngioma as welll as a variety of very rare tumours such as atypical tetraploid rhabdoid tumours, DNET, etc.. A major factor determining the lack of collaboration resides within the research networks within the NCRI where, by and large, the paediatricians have not been integrated with the adult networks and the eligibility criteria for trials are set at a legal limit of 18 rather than at levels determined by biology of disease. Specific mention of this latter point may well assist with enhanced collaboration in the future so that a more comprehensive range of trials can be developed for CNS tumours across the ages, reducing the inevitable disadvantage that having a rare CNS tumour carries where progress is slow due to a lack of scientific endeavour.	Noted with thanks.
Royal College of Paediatrics and Child Health	Chapter 11 (528–548)	**Research** This recommendation links into the acknowledged lack of research activity in the area of neuro-oncology which, in turn, is linked to the absence of sub-specialisation within medical and clinical oncology within neuro-oncology in adult	We feel this is adequately covered in the key recommendation (paragraph 16).

		practice. This situation can only be resolved by the focus of government and charitable medical research funding for which this document will act as a very important and influential factor. While it might be beyond the scope of the NICE guidance, it would be important for the document to make firm recommendations in this regard allocating the responsibility for developing research led and evidence based practice of neuro-oncology, it is otherwise, unlikely to happen.	
Royal College of Paediatrics and Child Health	Chapter 11 (528–548)	**Trials groupings** The recommendation of forming new groups, as stated in this guidance, could be augmented by seeking collaborations with existing paediatric neuro-oncology groups that are already very active through the activities of the UK Children's Cancer Study Group (UKCCSG). It could be proposed, therefore, that in the recommendation number 535, it might be appropriate to include in this paragraph that the UKCCSG Brain Tumour Committee should be part of this collaborative effort. We realise that the attitudes and matters outlined in this response may be challenging to existing practice in adult neuro-oncology. However, as it is already acknowledged that adult neuro-oncology is under-developed, this document is setting a blue print for future developments, and our experience of rapid trial development in the past decade in this area, justifies giving our suggestions due weight. They are offered in the spirit of collaboration with our adult neuro-oncology colleagues with whom we are working increasingly closely in centres, but not, as yet, in national groupings such as NCRI.	Since the draft document was published, we have received overwhelming support for the recommendations in the research chapter.
Royal College of Paediatrics and Child Health	435–462	**Rehabilitation** The recommendation that rehabilitation services are an important part of brain tumour management is welcome. We feel that there is a case for the recommendations with respect to rehabilitation to be strengthened and feel that where appropriate, as decided by the MDT, it is a patient's right to have full access to a range of neuro-rehabilitation services including clinical psychology, specific neuro-psychological expertise, spinal rehabilitation, etc. We have found this to be particularly important for children. Rehab services in paediatric services still fail to acknowledge the need for special support for children with	The comments are noted with thanks. The GDG feel that the appropriate importance and strength has been obtained within the recommendations in this chapter.

		brain tumour. This document recommending such support for adult patients with CNS tumour will be valuable additional focus to highlight the plight of CNS tumour in rehab service planning in the younger age group. There is no doubt that the provision of effective rehab services is fundamental to recovery for anyone being treated for CNS tumour treatment related acquired CNS injury threatens their ability to fulfil their potential.	
Royal College of Paediatrics and Child Health	General – Our summary and conclusions	We welcome such a detailed document outlining current practice in adult neuro-oncology. These guidelines identify the scope of the problem and go a long way to describe the complexity of CNS tumour management. We believe that these guidelines are a constructive starting point and should, if pursued with vision, take the sub-specialty forward. Overall the key recommendations are clear and appropriate. We are impressed with the breadth of the proposal and endorse the multi-disciplinary working described in this document, particularly with respect to the importance of psychological, social and rehabilitative support for people acquiring brain injury as a result of tumour. We strongly support the linking of the neuroscience diagnostic expertise to the multi-disciplinary team discussions that are now taking place in the majority of centres around the country. The document describes the linkage of the neuroscience MDT, the network cancer MDT and the skull-based/pituitary MDT. We have been working in multi-disciplinary teams in childhood oncology for over 20 years. In our centres the childhood neuro-oncology MDT is a separate entity from our other oncology practice because of the need to incorporate neuro-pathologists, neuro-imagers and neurosurgeons in clinical discussion. It is important that the published guidelines are used to make it more attractive for others to join this sub-specialty area of clinical practice and put greater energy into examining new ways of treating CNS tumours across the ages, particularly if the funding for these developments is made available. We believe that with the increasing interest in drug therapies in adult neuro-oncology, a new focus for practice will lead to the emergence of medical neuro-oncology sub-specialists where neuro-rehabilitation and oncology expertise are combined through extended multi-disciplinary teams that have been identified in the document.	Thank you for your comments.

Royal College of Pathologists		The Royal College of Pathologists have no further comments to make at this stage of the consultation.	Thank you for your comment.
Royal College of Physicians of London and Association of British Neurologists – joint response	General	We note that the neurologist has now been included in the Neuroscience MDT and Cancer Network MDT. We feel that this will improve the breadth of expertise within the MDTs. However, where this is referred to in the relevant text, we would suggest that the statement is modified so that in some MDT's the neurologist may be a core MDT member, but in others the neurologist will for now be an extended member, particularly with availability to give expertise in epilepsy management. Widespread full core membership has to be aspirational due to the current paucity of oncology-trained neurologists, a deficiency which is being addressed in neurology training.	This has been debated, and the importance of core membership is agreed by the GDG. The issue of deficiency in trained individuals is outside the scope of this document.
Royal College of Physicians of London and Association of British Neurologists – joint response	Needs assessment	The needs assessment is comprehensive and we note that only between 30-40% of Neuroscience and Cancer Network MDTs currently have a named lead neurologist. Hopefully the *future* requirement of a neurologist in all MDTs will facilitate and stimulate more widespread neurological involvement. The ABN will be looking at the role of the neurologist in the neuro-oncology team in SpR training.	Thank you for your comment.
Royal College of Physicians of London and Association of British Neurologists – joint response	Full – para 4	Dr Fergus Macbeth? We are unsure what this means.	For clarification, this is the author of the section that precedes paragraph 4.
Royal College of Physicians of London and Association of British Neurologists – joint response	Para 15	There need to be an agreed national Minimum Dataset and agreed data definitions.	The national minimum dataset project is outside the remit of this document and a minimum dataset already exists for CNS tumours.
Royal College of Physicians of London and Association of British Neurologists – joint response	Para 96	The responsibility of the Lead Clinician is to ensure processes are in place to get information, but these processes must be adequately resourced or they will be unsuccessful. This should be made more transparent.	The resource implications of the document are identified and in paragraph 126 the additional administrative staff is indicated and covered under section 5 of the economic analysis report. In addition, resources are identified for provision of the support of information management in paragraph 527.
Royal College of Physicians	Box 3 and	See General comment above. The neurologist role is now included as a core	We agree.

of London and Association of British Neurologists – joint response	Box 5	activity of both MDTs, recognising the significant resource implications. This will therefore be a pre-requisite for MDTs when sufficient numbers of trained neurologists are available and will extend the role of the neurologist more formally in neuro-oncology care. This should be considered for inclusion in the training of future neurologists.	
Royal College of Physicians of London and Association of British Neurologists – joint response	Para 112 Box 6	This significantly raises the bar regarding information available at MDT meetings and communication is general. It will require appropriate resources in many centres to achieve this. The timescales are still regarded as aspirational and may not be realistic even with additional resources.	Thank you for your comment.
Royal College of Physicians of London and Association of British Neurologists – joint response	Full Economic Review	This seems comprehensive and would be ideal if setting up a unit from scratch. It is acknowledged that this is a difficult task where there is heterogeneity of existing services.	Thank you for your comment.
Royal College of Radiologists		This organisation was approached but did not respond.	
Royal College of Speech and Language Therapists	General	As there is such emphasis on the importance of communication in the document, we would suggest that Aphasia is specified. This is a cognitive process and skills are required to help the person with aphasia make sense of their diagnosis – this is a key role of a speech and language therapist.	Specific components of deficit and management are the remit of clinical guidelines and not service guidance and therefore have not been included.
Royal College of Speech and Language Therapists	Chapter 2, section 112, Box 6	*Referral to supportive care services and palliative care team* – we feel that AHPs should be added here.	The wording has been adjusted in Box 6 to accommodate this.
Royal College of Speech and Language Therapists	Chapter 8, section 418	We welcome the acknowledgement of psychology within supportive care but are disappointed that language impairment is overlooked. Language impairments, such as aphasia, can compromise a person's ability to benefit from psychological input.	It was felt by the GDG that the input of speech and language therapists was not best covered within the psychology component of the document. The importance of neuropsychology input is acknowledged within the rehabilitation section and in their identification as core members of the MDT (see Box 3)
Royal College of Surgeons of England		This organisation was approached but did not respond.	
Royal College Patient Liasion Groups		This organisation was approached but did not respond.	
Royal Liverpool Children's		This organisation was approached but did not respond.	

NHS Trust			
Royal Pharmaceutical Society of Great Britain		Please note that the Royal Pharmaceutical Society of Great Britain will not be commenting on the above.	Thank you for your comment.
Samantha Dickson Research Trust, The		This organisation was approached but did not respond.	
Sanofi-Aventis		This organisation was approached but did not respond.	
Schering-Plough Ltd	P. 77, section 208	• Temozolomide spelt incorrectly • Date of new NICE guidance is wrong, should be 2006-01-17	Thank you for your comments
Schering-Plough Ltd	P. 84, section 243	No notice has been taken of our last comments on adding in actual 2 year survival figures and 2 year progression free survival data.	This level of detail is not appropriate in the evidence section of the guidance manual. However, this data are included in the evidence review that accompanies the guidance.
Schering-Plough Ltd	P. 85, section 245	All wrong, mentions an appraisal in 2001 for newly diagnosed tumours which is all incorrect, there was an appraisal on relapsed tumours but that didn't include Carmustine implants at that time.	The wording has been changed and the errors corrected.
Schering-Plough Ltd	Appendix 3, p. 171	Includes MGMT testing costs but MGMT not mentioned throughout the document?	The MGMT assay is included as an example to indicate to commissioners that molecular diagnosis is likely to be an additional cost and is an expanding field. This is made clear in paragraphs 170 and 171 and the costings are for illustration only.
Scottish Intercollegiate Guidelines Network (SIGN)		This organisation was approached but did not respond.	
Sheffield Children's Hospital NHS Trust		This organisation was approached but did not respond.	
Sheffield South West Primary Care Trust		This organisation was approached but did not respond.	
Sheffield Teaching Hospitals NHS Trust	291, p. 105	Similarly to the previous comment, "stereotactic radiosurgery" should be the phrase used rather than "stereotactic radiotherapy" which is not the standard modality used. Currently more patients with acoustic neuromas are treated in Sheffield using radiosurgery (as stated in paragraph 71), than using any other technique including surgery or radiotherapy by any other department. This	The text has been amended.

		makes the distinction important to make: commissioning radiosurgery based upon this NICE Guidance would be difficult as only radiotherapy is mentioned in the paragraph.	
Society and College of Radiographers		This organisation was approached but did not respond.	
Society for Endocrinology	General	The Guidance on the management of pituitary tumours is welcomed by the Society for Endocrinology and the proposed infrastructure for the management of patients is sound	Thank you for your comment.
Society for Endocrinology	Para 281	There is an apprehension that the second sentence of paragraph 281 will result in patients not being referred to a specialist endocrinologist. The risk is that non-specialist endocrinologists will present patients to the MDT and that management plans are proposed resulting in patients continuing to be managed in an inappropriate environment rather than referred to specialist endocrinologists. The first sentence of paragraph 281 is sufficient and the second sentence should be deleted.	The definition of the specialist endocrinologist has been strengthened within the core membership of the MDT (Box 8). The requirements are explicit that all patients with pituitary tumours are discussed at the specialist MDT and will therefore have the input of the specialist endocrinologist. Applying this standard will avoid the possibility that patients will not receive the input of a specialist endocrinologist.
Society for Endocrinology		There is no definition of a specialist pituitary endocrinologist. While it is accepted that it is difficult to define a specialist pituitary endocrinologist, the majority of endocrinologists are involved in the care of patients with diabetes and devote a minority of their time to endocrinology which is often dominated by thyroid disease. We propose that specialist pituitary endocrinologists run a weekly pituitary endocrine clinic and work with an endocrine nurse specialist and have access to a specialist programmed investigation unit.	The definition in Box 8 has been extended to include the specialist clinic.
Society for Endocrinology	General and chapter 6	The desire to define a specialist pituitary surgeon is supported by the Society for Endocrinology however the proposed definition of 'specialist pituitary surgical responsibility for at least 50% of their programmed clinical activity' is arbitrary and is likely to be met by few, if any, surgeons in the UK. An alternative and more realistic definition would be based on a minimum number of pituitary operations undertaken per year, say 50. This is an arbitrary number and therefore open to negotiation but could be easily assessed and is high enough to preclude those surgeons undertaking only occasional pituitary surgery	The definition of a pituitary surgeon in Box 8 has been altered and now reads: 'A neurosurgeon or ENT surgeon with appropriate training who works in close association with the specialist endocrinologist, including specialist pituitary clinics, and has specialist pituitary surgical responsibility.'

Society for Endocrinology	General and chapter 6	The notion of involvement of allied health professionals is supported but it would be exceptional for any of the AHPs listed to be involved in the care of patients with pituitary tumours. We believe the ability to be able to call upon these AHPs is important but it is not necessary for them to be represented on the MDT.	AHPs have now been moved from core to extended MDT members of the pituitary MDT in Box 8.
Society for Endocrinology	Para 280	We believe that with increased disease awareness pituitary pathology is being diagnosed more frequently and that although improvements in medical therapy mean surgeons will operate on a smaller proportion of patients there will not be a reduction in surgical workload (paragraph 280).	Comment noted.
Society for Endocrinology	Box 8 (282)	On P99 it is stated '*A nurse with expertise and experience in neurology/neurosurgery and/or endocrinology working in close association with the specialist endocrinologist as defined by the Manual of Cancer Standards22*'. It is not clear where the definition comes from in the cancer standards. As this is a document of 463 pages it would be helpful if this was better defined.	The reference to the *Manual of Cancer Standards* has been clarified.
Society for Endocrinology	Box 8, Sent in an email to NICE	We are preparing our submission to this guidance, which we need to return to you by Friday. We need a little bit of clarification on one thing. On page 99 of the guidance you state that the clinical nurse specialist should be: 'A nurse with expertise and experience in neurology/neurosurgery and/or endocrinology working in close association with the specialist endocrinologist as defined by the Manual of Cancer Standards22'. We've had a look at the Manual of Cancer Standards, and it's not obvious where this definition lies (the manual is 463 pages long, see: http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4090081&chk=hq28gu). Could you give us some clarification on where this is defined.	Please see our response to comment 7.
Society of British Neurological Surgeons		This organisation was approached but did not respond.	
South West Peninsula Strategic Health Authority		This organisation was approached but did not respond.	
Southampton University	Section	gliadel wafers appraisal will be available in 2006. I am not sure what the other	Current publication of guidelines will be

Hospitals NHS Trust	208	gliadel/temo appraisal is but website says november 2007	taken into consideration in the final document.
Southampton University Hospitals NHS Trust	242	it does not state what chemotherapy it is referring to and is not referenced? is it supposed to be gliadel wafers?	Paragraph 242 is referenced within the Evidence Review. The chemotherapy used within these studies contained a variety of agents.
Southampton University Hospitals NHS Trust	243	incorrect comments are made about the temozolomide study. the study actually demonstrated a survival advantage giving temozolomide concurrently with radiotherapy versus standard treatment (which was most commonly radiotherapy first and temozolomide on recurrence). Incorrect to say 'radiotherapy alone'	The evidence as quoted and the randomisation within the trial is correctly identified. The standard arm within the study was to radiotherapy alone. The subsequent use of chemotherapy was not defined or prescriptive within the study.
Southampton University Hospitals NHS Trust	245	same comment as above on timing of gliadel/temo NICE appraisal – I am confused, I am sure others will be. Is it August 2006 or not?	The wording has been changed and the errors corrected.
Southampton University Hospitals NHS Trust	390	Exactly what or who is 'a key professional with advanced communication skills'? How is this training done and by whom? Presumably the aforementioned professional!	Thank you for your comment.
Teenage Cancer Trust, The		This organisation was approached but did not respond.	
Thames Valley Strategic Health Authority	6 and later	The Guidance recommends a neurosciences MDT should exist in every network with a neurosciences centre, which we fully endorse. However, the requirement for every Network to have a cancer network MDT as well as a neurosciences MDT (if they have one) seems excessive. Where a neurosciences centre covers at least the geographic area of the cancer network - it seems unnecessary to have a cancer network MDT as well – all the personnel attending the neurosciences MDT (which meets weekly) are included in the cancer network MDT(which is to meet monthly) other than a therapy radiographer who is in the cancer network MDT only. In the first draft of the guidance – para 103 + structure a statement about the cancer network MDT "where circumstances make the existence of the MDT necessary" has been removed for the second draft – para 118. It is not clear what the cancer network MDT will achieve when there is a functional neurosciences MDT. IN addition, for networks without a neurosciences centre, networks are given the option of not having a cancer network MDT but amalgamating with an adjacent cancer network MDT in para 124 under the cost of the exercise – this is mentioned no where else, and does suggest that the	The opportunity for co-location of the neurosciences MDT and the cancer network MDT, depending on geographical constraints, is acknowledged. Paragraph 90 in the new document will strengthen this statement. In addition, paragraph 124 has been revised for clarification.

		cancer network MDT should be an option rather than a must do.	
Thames Valley Strategic Health Authority	11 and later	Fully support all the additions to the guidance regarding the importance of the role of the clinical nurse specialist.	Thank you for your comment.
Thames Valley Strategic Health Authority	98	The guidance should be more explicit about the oncological workload of specialist neurosurgeons. In para 98 – indicates that ALL neurosurgeons treating patients with CNS tumours should be a core member(s) of the neurosciences brain and other MDTS. in box 3 it indicates that Neurosurgeon in the MDT will be specialist neurosurgeon(s) who spend at least 50% of their time in neuro-oncological surgery and specialitiy clinic. It should be made explicit in the text of para 98, what the requirement is of the neurosurgeon in terms of % time spent on neuro-oncology. The cost implications of this should also be considered (see comment below against para 125) – which could be significant for those centres who don't have one or 2 site specialised neuro-oncological surgeons yet.	It is felt that as paragraph 98 clarifies that neurosurgeons treating patients with CNS tumours should be core members of the neurosciences MDT, and by providing a definition with Box 3 for this, the document is explicit with regards to the definition of a neurosurgeon in this context. Box 3 has now been cross-reference from paragraph 98. The resource implications are explicit within the resource section and it was felt by the GDG that a significant component of the provision of specialist neurosurgical input relates to organisation of caseload within neurosurgical units.
Thames Valley Strategic Health Authority	207	Incorrect. Temodal + RT as first line treatment improves 2 year survival from 10% to 26%. This is not a "small but significant improvement" –it is currently being reviewed by NICE – due out 2006	This comment relates to the use of standard adjuvant treatment and the GDG feel that the text stands as is. The role of concurrent chemotherapy (rather than adjuvant) as indicated is currently under review.
Thames Valley Strategic Health Authority	208	NICE review of temodal +RT / gliadel due out 2006 not 2007.	The text has been amended.
Thames Valley Strategic Health Authority	246	Incorrect. There are a number of randomised studies looking at the use of palliative chemotherapy for relapsed high grade glioma – not just case reports. (eg Temodal vs procarbazine, PCV papers…) – Temodal is of course already approved by NICE for second line chemotherapy of relapsed HGG. This statement must be more thorough and confirm that a nitrosurea single agent or combination regimen is used routinely as first line therapy for relapsed high grade glioma with second line Temozolamide being a NICE approved indication. – due for re-review in 2007.	The wording has been changed to clarify.
Thames Valley Strategic Health Authority	275	Is it possible to state that the pituitary, spinal or skull base MDT can be held as part of the Neurosciences MDT if all relevant staff attend that MDT? – also	The GDG feel that the local application of the guidance to ensure timely assessment

		frequency of meetings of the pituitary, spinal and skull base MDT is not mentioned at all.	and most appropriate use of resources should be left to local arrangements. Where staff can be utilised to cover more than one MDT, this would clearly be entirely appropriate.
Thames Valley Strategic Health Authority	530	As per my comments on the first draft to para 437. This has not been changed and should be. Please acknowledge the success of the NCRI CNS Tumours group under XXX chaimanship (from the earlier MRC trials group). A number of very successful studies have been held over the past 10 years (BR2, BR5, BR12 as examples). The UKCRC is already funding research into CNS tumours through the NCRI / NCRN (has done so since 2001). Unlikely that the UKCRC will allocate further funding to CNS tumours.	We have revised paragraph 530 to take account of this.
The Medway NHS Trust		This organisation was approached but did not respond.	
The Royal Society of Medicine		This organisation was approached but did not respond.	
The Royal West Sussex Trust		This organisation was approached but did not respond.	
UK Children's Cancer Study Group	General	We are submitting feedback to this second draft on behalf of the UKKCSG Brain Tumour Committee. The UKCCSG Brain Tumour Committee consists of a network of neuro-oncology specialists from paediatric oncology, clinical oncology, neuro-surgery, neuropathology, and neuroradiology. This Committee has, over the last 25 years or so, promoted clinical trials in CNS tumours of childhood and adolescence. The current Committee has an expanded membership of about 50 people with sub-groups concerned with: • astrocytic tumours - high grade*/low grade*, brain stem* • embryonal tumours – standard risk and high risk medulloblastoma*, supratentorial PNET*, metastatic PNET*, and infant PNET • ependymal tumours – with trials open in infant ependymoma* and phase II trials of chemotherapy in ependymoma* in infants and older children • intracranial germ cell tumours* with an international trial in development • functional imaging with an established network of collaborating imaging centres and two open studies* • rare tumours – protocols in development to study craniopharyngioma and	Structure noted with thanks.

		atypical teratoid rhabdoid tumours (ATRT) • quality of survival – this is a new group which has been formed in response to the need for incorporation of quality of survival outcome measures in tumours of infancy, childhood and adolescence. There are a number of trials where such measures are being considered primary outcome measures for future trials. (*trials open in these categories) Currently the NCRN website registers 10 open trials in childhood brain tumours. It is from this perspective that we read the current guidelines that are circulated in draft form.	
UK Children's Cancer Study Group	19	The Adult guidelines for Brain and other CNS tumours mention the guidelines for children and young people with cancer and also refer to the UKCCSG's expertise in some of the rare tumours that are more common in childhood. However, we are concerned that there is still little importance given to age stratification in this document. Clearly as paediatricians, we are dealing with rapidly developing and maturing individuals. However we perceive the need for greater emphasis being given to the age stratified judgements about CNS tumour management within adult practice as well. Specifically, we make the following recommendations: 4. The NICE guidance for children and young people with cancer identified that the age group covered by children and young people could extend up to 25 years of age and certainly the childhood National Services Framework extends to 19 years of age. We would not consider it appropriate, therefore, that this adult document refers to the 15-19 year old age group and consider that any data in the 20-25 year old age group was clearly marked as relating to the hinterland between young people's practice versus adult practice. There needs to be more flexibility in the approach to patients in this age spectrum. 5. The document makes little recognition for the different approaches that are necessary in young adults compared to the elderly. This is particularly	The issue with regard to age stratification is noted. However, there are very little data and almost no research stratifying patients within the adult age group into these subgroups. The importance of considering prognostic factors is considered within the document (e.g. paragraphs 201 and 103), with regards to treatment protocols. It was felt by the GDG that further stratification would be unhelpful. There is clear cross-reference (paragraphs 19, 135, etc.) within this guidance to the NICE Children and Young People with Cancer guidance regarding the interface between children, adolescent and adult services. The Rare Tumours chapter 7 also highlights that the neuroscience MDT may benefit from paediatric oncology input. In addition, the issue of patients treated in childhood requiring subsequent follow-up

		important given the health economic judgements being made by NICE with respect to drug funding. The health economic impact of disability and loss of life years is far greater in those who are young. Lumping all ages together as in this document results in an insensitive structure to the clinical situations that present in young adults versus the elderly when diagnosed with a brain tumour. It also ignores the difference in outcome for these different age groups. Our practice of treating children and young people with a positive intent at all times is just as relevant to the people up to the age of 40 and 50. There is increasing evidence that some of the newer, more successful, tumour therapy strategies are more successful in the young than they are in the old. There is established evidence that young people with high grade tumours live longer than elderly people with high grade tumours. It would seem, therefore, that in this document some effort should be made to reflect upon this difference in outcome. We would also suggest that recognition be given to a difference in attitude with respect to curative intent, but also the duration of rehabilitative support that would be necessary within the broader health community. *6.* This document, with its lack of age stratification, makes little mention of the needs of the adolescent and young adult with respect to the management of the primary tumour types that predominate in that age group, and, most importantly, with respect to the management of relapses or complications of tumour management where the original treatment was delivered <19 years. Overall, children's brain tumours have a 60-70% 5-10 year survival with current practice. An increasing number patients, therefore, will are entering the adult age range with the consequences of prior therapy. The adult neuro-oncology MDTs, as they develop, will be the place for these cases to be discussed. This guidance fails to identify this as an area of future practice and is therefore an important omission. It should be noted that 1 in 950 adults are now survivors of childhood cancer, indeed it is estimated that there are 26000 adult survivors of childhood cancer in the UK- up to a quarter of whom will have survived treatment for a CNS tumour. This group of patients need ongoing specialist multi-disciplinary care. This group of patients with other cancers are at the focus of developing network of	and late effects is within the remit of the NICE guidance on Children and Young People with Cancer and is not within the scope of this guidance.

		adolescent oncology teams. The hinterland between childhood (<16) and adulthood (>25) is an area where children's specialists and adult specialists meet and may well share their expertise. Specific mention of the needs of this group of patients in this document is important as it would provide clear direction to the adult teams offering specialist support, as well as the paediatric teams seeking reliable transition arrangements for their mature patients.	
UK Children's Cancer Study Group	Box 3	There is no mention of the importance of attracting medical oncologists into this speciality and their involvement in the MDT. If part of this NICE strategy is to promote a more vigorous clinical trials programme, which it must be, then academic leadership and the involvement of medical oncologists as well as clinical oncologists will be very important.	The role of the medical oncologists in adult neuro-oncology is more limited than in paediatrics. Clinical oncologists in the UK have extensive knowledge and input into chemotherapy management and at present it was felt by the GDG that medical oncology input would not be a good use of resources.
UK Children's Cancer Study Group	20	You state that these guidelines do not offer level of detail required to inform about decision making about specific diagnoses for individual patients. However, there is a partial attempt to describe management of some CNS tumour entities in their current form. It is our view that this aspect of the proposal is insufficiently developed to be truly useful and either needs considerable more work to make the guidance accurate, reliable and comprehensive or the guidance for specific tumour types should be excluded altogether. As written they do not meet current standards of practice (ie Germ cell tumours, optic pathway glioma, ependymoma, craniopharyngioma, medulloblastoma).	The comments put within the treatment section are intended to be general and guidance in terms of areas of practice where resource implications may follow. There is no intention that this guidance forms recommendations in detail for treatment as would be covered in a clinical guideline. The document is explicit that the treatment protocols for these patients will be managed nationally through the specialist groups.
UK Children's Cancer Study Group	160	The involvement of a medical/clinical oncologist in pre-operative discussion of cases should be strongly encouraged as this allows an opportunity to decide and refine the treatment strategy at the outset. This has been particularly important in paediatric cases.	As neurosurgical intervention is pivotal in the establishment of diagnosis in many of these patients, the GDG felt that pre-operative medical and clinical oncology input into these patients would be introducing an unecessary delay and not beneficial.
UK Children's Cancer Study	165	Where a brain tumour is suspected at a DGH/secondary centre we would	The responsibilities of the neurosciences

Group		recommend that limited MR scan is sufficient as the initial diagnostic imaging. Clearly there is often reluctance to repeat complex MR series which often means that newer imaging modalities, such as MRS diffusion/perfusion studies, may not be carried out. The role of functional imaging in determining the biological nature of tumours is the subject of intense research at the moment. The new neuro-oncology MDTs will need to have access to both these methods of biological assessment within the foreseeable future and integrate the results of the current translational research into practice within the next five years. Though raised, this point has not been emphasised within this document.	and cancer network MDTs to optimise patient pathways and introduce new investigations and treatment as they become available inevitably means that access to imaging will change over time. As indicated this is the subject of research at present and clear recommendations to commissioners are not possible at present.
UK Children's Cancer Study Group	188	Molecular diagnosis focuses on one parameter (MGMT). The number of markers will increase over time and this needs to be understood and accounted for. The identification of the t(1;19) in oligodendroglioma would be one other important current marker that determines the likelihood of response to chemotherapy in this tumour type, though mentioned is not costed.	The MGMT assay is included as an example to indicate to commissioners that molecular diagnosis is likely to be an additional cost and is an expanding field. This is made clear in paragraphs 170 and 171 and the costings are for illustration only.
UK Children's Cancer Study Group	190	We fully back the need for more neuropathologists who are key to improvements in patient care through a better understanding of the disease process. Their role in biological studies in reliably identifying clinicopathological entities cannot be overstated. As biological and other novel therapies become available their role and importance will increase.	Noted with thanks.
UK Children's Cancer Study Group	Chapters 5–7 (191–376)	**Tumour types** The document describes in great detail the commonest group of tumours, high grade and low grade glioma and goes on to refer to a range of other tumours under the rare tumour category giving them, therefore, a lower status and less detail. These, by and large, are the tumours for which we have greatest expertise in the childhood group and this is acknowledged in the document. However, we think there are a number of comments we would make: There is no mention of ependymoma. We recognise this is a sub-type of glioma but it clearly has different biological origins and anatomical distribution. There are specific recommendations for its management in childhood and in evidence of efficacy of chemotherapy and specific strategies emerging with respect to surgery that bear mention as this should have bearing on adult practice.	The comment on ependymomas is noted and additional text will be added.

		There is also no mention of craniopharyngioma. Craniopharyngiomas occur throughout childhood, adolescence and adulthood up until old age. They are a complex disorder presenting with severe neurological signs affecting vision and hypothalamic function. They require treatment with surgery and radiotherapy and on occasions can be treated with local chemotherapy. They often fall into the remit of the multidisciplinary team. They can cause severe disability due to hypothalamic damage, hormonal difficulties, visual difficulties and associated behavioural disturbance. They would benefit from the multidisciplinary environment created by this document. They should be mentioned in a document attempting to address this issue.	Craniopharyngioma are covered in paragraph 278.
UK Children's Cancer Study Group	335–343	Intracranial germ cell tumours are listed under the heading of pineal region tumours which is conventional in adult texts but not children's texts. These tumours also arise in other regions. Population registries and literature clearly show that these tumour age incidence falls across the childhood, young people and adult age ranges. They are the most chemotherapy/radiotherapy sensitive of all intracranial malignant tumours, germinomas having greater than 95% survival, non-germinomatous GCTs 70% survival. Because these tumours span the childhood/adult age groups, it is, therefore, important that they are mentioned specifically. We have learned much about these relatively rare tumours through an international trial (SIOP Germ Cell Tumour 1996). There is an increasingly active international dialogue about their management, linking Europe, the US and Asia. Important lessons regarding staging and surgery have been learnt. It is from this standpoint that we are extremely concerned as the guidelines, as written, are **incorrect** and are, in fact, dangerous. The guidelines should include measurement of hormonal markers at diagnosis as the decision-making trigger to different strategies. For those that are hormonal marker positive, there is **no** need to biopsy and primary chemo-therapy is recommended followed by a consideration of surgery for residual disease and radiotherapy. It should be mentioned that in the marker positive patient that very high levels of hormonal markers are indicative of poor prognosis. There should also be clear guidance about CSF analysis for tumour cells. It has been shown that prognosis is better in those patients that are correctly staged and managed. For those that are	The comments on intracranial germ cell tumours are noted. It should be noted that this is service guidance, rather than a clinical guideline on management. However, the wording of paragraphs 335–339 has been changed to include the importance of hormonal marker measurement, the possibility that this will remove the need for tumour biopsy and the measurement of CSF cytology. The importance of managing these patients through nationally agreed protocols is of course made within the document.

		hormonal marker negative and typical tumours on scan of a germ cell tumour, then biopsy is mandatory. These patients require full MDT discussion before management is initiated after initial stabilisation of raised intracranial pressure.	
UK Children's Cancer Study Group	344–353	The guidance specifies for optic pathway glioma that the majority of these patients present in childhood are predominantly pilocytic and that they need lifelong follow-up. We concur with this view and would recommend that efforts are put to establishing a national register of optic pathway gliomas for this reason as, in childhood, they are associated with 90% survival and the biological behaviour of those tumours arising in childhood is unclear in the adult age groups and requires further study. We would propose that this national registry be based upon the existing children's low grade astrocytoma database at the UKCCSG which has emerged from recent international pilot study of chemotherapy in low grade glioma. The heading of this sections disregards that low grade glioma in childhood can occur in any part of the brain and the current evidence is that where the tumours are pilocytic their biological behaviour and sensitivity to adjuvant treatment is similar justifying a histological structure to disease classification rather than an anatomical structure. Anatomical locations will determine symptomatology and suitability for surgical management.	The suggestion of having a national register for optic pathway gliomas is acknowledged. An additional recommendation in the introductory section of chapter 7 has been included to require a managed national register as a responsibility for all the national rare tumour groups. Low-grade gliomas are covered extensively elsewhere in the text and the use of the anatomical model fits with the construction of the MDTs to support the patients.
UK Children's Cancer Study Group	335	Pineoblastomas, whilst rare in adults, are essentially high grade malignancies and respond well to chemotherapy and radiotherapy according to the PNET III protocol.	These will become part of the guidelines produced by the specialist groups.
UK Children's Cancer Study Group	197–200	There is no mention of the very different biological behaviour of low grade astrocytomas in childhood, that is pilocytic tumours, compared to low grade gliomas in adulthood, which are predominantly grade II astrocytomas and are considered pre-malignant lesions. There is very little evidence that the pilocytic astrocytomas represent a pre-malignant condition.	This is why it was not mentioned.
UK Children's Cancer Study Group	330	PNET/medulloblastoma is mentioned and the expertise in paediatric practice acknowledged. There is now an international acceptance of the benefit of chemotherapy in addition to surgery and craniospinal radiotherapy. Recent	Noted with thanks.

		evidence shows that adults treated on paediatric-style protocols have a better outcome (Spreafico et al, "*Survival of adults treated for medulloblastoma using paediatric protocols*". European Journal of Cancer 2005; 41: 1304-1310 and Herrlinger et al *Adult medulloblastoma : prognostic factors and response to therapy at diagnosis and relapse.* J Neurology 252 :291-299). Adults with relapsed disease seem to have a more favourable outcome than children and consideration of further therapy in this cohort should be considered (Herrlinger et al *Adult medulloblastoma : prognostic factors and response to therapy at diagnosis and relapse.* J Neurology 252 :291-299).	
UK Children's Cancer Study Group	General, rare tumours/clinical trials	The paediatric trials' network have considerable expertise in medulloblastoma, ependymoma, low grade glioma, intracranial germ cell tumours and growing expertise in craniopharyngioma as welll as a variety of very rare tumours such as atypical tetraploid rhabdoid tumours, DNET, etc.. A major factor determining the lack of collaboration resides within the research networks within the NCRI where, by and large, the paediatricians have not been integrated with the adult networks and the eligibility criteria for trials are set at a legal limit of 18 rather than at levels determined by biology of disease. Specific mention of this latter point may well assist with enhanced collaboration in the future so that a more comprehensive range of trials can be developed for CNS tumours across the ages, reducing the inevitable disadvantage that having a rare CNS tumour carries where progress is slow due to a lack of scientific endeavour.	Noted with thanks.
UK Children's Cancer Study Group	Chapter 11 (528–548)	**Research** This recommendation links into the acknowledged lack of research activity in the area of neuro-oncology which, in turn, is linked to the absence of sub-specialisation within medical and clinical oncology within neuro-oncology in adult practice. This situation can only be resolved by the focus of government and charitable medical research funding for which this document will act as a very important and influential factor. While it might be beyond the scope of the NICE guidance, it would be important for the document to make firm recommendations in this regard allocating the responsibility for developing research led and evidence based practice of neuro-oncology, it is otherwise, unlikely to happen .	We feel this is adequately covered in key recommendation (paragraph 16).
UK Children's Cancer Study	Chapter 11	**Trials groupings**	Since the draft document was published, we

Group	(528–548)	The recommendation of forming new groups, as stated in this guidance, could be augmented by seeking collaborations with existing paediatric neuro-oncology groups that are already very active through the activities of the UK Children's Cancer Study Group (UKCCSG). It could be proposed, therefore, that in the recommendation number 535, it might be appropriate to include in this paragraph that the UKCCSG Brain Tumour Committee should be part of this collaborative effort. We realise that the attitudes and matters outlined in this response may be challenging to existing practice in adult neuro-oncology. However, as it is already acknowledged that adult neuro-oncology is under-developed, this document is setting a blue print for future developments, and our experience of rapid trial development in the past decade in this area, justifies giving our suggestions due weight. They are offered in the spirit of collaboration with our adult neuro-oncology colleagues with whom we are working increasingly closely in centres, but not, as yet, in national groupings such as NCRI.	have received overwhelming support for the recommendations in the research chapter.
UK Children's Cancer Study Group	435–462	**Rehabilitation** The recommendation that rehabilitation services are an important part of brain tumour management is welcome. We feel that there is a case for the recommendations with respect to rehabilitation to be strengthened and feel that where appropriate, as decided by the MDT, it is a patient's right to have full access to a range of neuro-rehabilitation services including clinical psychology, specific neuro-psychological expertise, spinal rehabilitation, etc. . We have found this to be particularly important for children. Rehab services in paediatric services still fail to acknowledge the need for special support for children with brain tumour. This document recommending such support for adult patients with CNS tumour will be valuable additional focus to highlight the plight of CNS tumour in rehab service planning in the younger age group. There is no doubt that the provision of effective rehab services is fundamental to recovery for anyone being treated for CNS tumour treatment related acquired CNS injury threatens their ability to fulfil their potential.	The comments are noted with thanks. The GDG feel that the appropriate importance and strength has been obtained within the recommendations in this chapter.

UK Children's Cancer Study Group	General – Our summary and conclusions	We welcome such a detailed document outlining current practice in adult neuro-oncology. These guidelines identify the scope of the problem and go a long way to describe the complexity of CNS tumour management. We believe that these guidelines are a constructive starting point and should, if pursued with vision, take the sub-specialty forward. Overall the key recommendations are clear and appropriate. We are impressed with the breadth of the proposal and endorse the multi-disciplinary working described in this document, particularly with respect to the importance of psychological, social and rehabilitative support for people acquiring brain injury as a result of tumour. We strongly support the linking of the neuroscience diagnostic expertise to the multi-disciplinary team discussions that are now taking place in the majority of centres around the country. The document describes the linkage of the neuroscience MDT, the network cancer MDT and the skull-based/pituitary MDT. We have been working in multi-disciplinary teams in childhood oncology for over 20 years. In our centres the childhood neuro-oncology MDT is a separate entity from our other oncology practice because of the need to incorporate neuro-pathologists, neuro-imagers and neurosurgeons in clinical discussion. It is important that the published guidelines are used to make it more attractive for others to join this sub-specialty area of clinical practice and put greater energy into examining new ways of treating CNS tumours across the ages, particularly if the funding for these developments is made available. We believe that with the increasing interest in drug therapies in adult neuro-oncology, a new focus for practice will lead to the emergence of medical neuro-oncology sub-specialists where neuro-rehabilitation and oncology expertise are combined through extended multi-disciplinary teams that have been identified in the document.	Thank you for your comments.
University College London Hospitals NHS Trust		This organisation was approached but did not respond.	
University Hospital Birmingham NHS Trust		This organisation was approached but did not respond.	
Vale of Aylesbury Primary Care Trust		This organisation was approached but did not respond.	
Velindre NHS Trust		This organisation was approached but did not respond.	

Walton Centre for Neurology and Neurosurgery NHS Trust	General	There is much in the guidance that is commendable but we are concerned that some aspects are practically unworkable and not in the patients best interests.	Specific comments will be dealt with later.
Walton Centre for Neurology and Neurosurgery NHS Trust	Page 46 – Box 3	Whilst expertise from some of the areas desirable, it is hard to justify the time of a rehab or epilepsy neurologist at a weekly MDT, though clearly this expertise should be available. A similar argument will apply to palliative care. It is easier to consider a minimum quorum – this will be neurosurgeon, neuro-oncologist and co-ordinator. The consultant responsible for the patient must be present. I would consider adding to this the neuropathologist and neuroradiologist. There remains confusion over the roles of the cancer MDT and the neuroscience MDT. It may be the intention to regard the cancer MDT as a local body in the referring DGH, and the neuroscience MDT as the preserve of the tertiary centre. If so this should be made explicit. If not then there is much duplication. Box 4 contains no functions that will not be accomplished better by the neuroscience MDT. The membership is inappropriate as it does not contain a neurosurgeon – unless it refers to an MDT outwith the neuroscience centre. It is questionable then whether a visiting neurologist could be expected to be a regular participant in such a meeting. The comment that the lead neurosurgeon at an MDT must do >50% neuro-oncology ignores neurosurgical subspecialization. How is 50% defined? A neurosurgeon with a specialist interest in neurooncology might not be an appropriate lead in skull based, pituitary or spinal tumours and might in fact have little experience of them.	The core membership of the neurosciences MDT has been extensively discussed at the GDG and adjusted in consideration of comments from the 1st consultation. In response to this the core membership includes neurology, neuropathology, neuroradiology and palliative care and so many of the decisions are fundamentally pivotal on the input of these individuals that it is felt it would not be possible to proceed without them. The GDG has considered the function of the cancer network MDT and the responsibilities are seen as separate and explicit. It has previously been clarified that where there are co-located patients, many of the same individuals will provide the functions of both MDTs. It is the opinion of the GDG that a neurosurgeon that spends the majority of their time in neuro-oncology is the most appropriate surgeon to treat patients with CNS tumours.

			The surgeons for pituitary skull base and spinal surgery are defined within the appropriate boxes, e.g. Box 8 for pituitary.
Walton Centre for Neurology and Neurosurgery NHS Trust	Paragraph 62	Measurements should include some assessment of clinical outcome.	This comment does not appear to relate to the measurement section and is within the background section.
Walton Centre for Neurology and Neurosurgery NHS Trust	Paragraph 71	Should note the two methods of delivery of stereotactic radiotherapy – the gamma knife, LINAC, whilst other techniques – interstitial brachytherapy, heavy particles such as protons and baryons should be mentioned in passing. Sheffield is known for its use of the gamma knife only. The guidance misses the opportunity to scope this area and indicate to the NHS the capacity that should be made available, and the evidence base or lack of it for some of the rarer techniques.	We would like to point out that this paragraph lies within the background section of the document and is not a description of global services.
Walton Centre for Neurology and Neurosurgery NHS Trust	Paragraph 94	All brain tumours should be reviewed by a neurosurgeon, who participates in the MDT, as only the neurosurgeon is competent to make decisions as to the operability of the lesion. It is reasonable that all low grade tumours are reviewed by a neurosciences MDT.	The GDG would agree with the comment and refer to paragraph 98 where it is explicit that specialist neurosurgeons should be core members of the MDT and that all patients should be reviewed by the neurosciences MDT.
Walton Centre for Neurology and Neurosurgery NHS Trust	Paragraph 97	The production of local guidelines should allow patient treatment to proceed even before discussion at an MDT. That is the point of producing guidelines. Forcing all patients to be discussed before treatment will lengthen length of stays and delay treatment. This would be true even if MDT was held weekly. All patients should however be discussed at some point in the early stage of their treatment.	It is clear within the guidance that where clinically imperative, patient management can be instituted prior to MDT discussion (paragraph 100). However, outside these clinical exceptions it is accepted as a standard of care for all malignancies that discussion at MDT is an appropriate standard of care.
Walton Centre for Neurology and Neurosurgery NHS Trust	Paragraph 99	While we support the principle of MDT assessments any MDT creates a fundamental problem in respect of medical responsibility. Currently the responsibility for the patients care resides with a named consultant under whose care the patient is admitted. This consultant is answerable not only to the trust for which he/she works but also to the GMC. Accordingly it is not appropriate for a management decision to be made by an MDT without the consultant (or their representative) responsible for the patient present. The MDT may provide help	The principals of applying service-wide agreed protocols to patients based on MDT decisions is universally accepted across all cancer sites. It is clear, however, within the guidance (paragraph 100) that the recommendations of the neurosciences MDT are advisory. As for other

		and advice but the guidance should consider who has the casting vote!!! An MDT cannot function democratically by reason of sub-specialisation – eg the nurse specialist cannot be asked to vote on the resectability of a tumour. An MDT can provide an opinion, but the final decision must be reached through discussion and agreement of the patient and the responsible medical team. What is NICE suggesting should be the procedure if there is disagreement concerning management at an MDT? We would suggest that the final decision rests with the patient and the responsible medical team.	malignancies, the responsibility will remain with the referring clinician to the MDT and in consultation with the patient and their carers.
Walton Centre for Neurology and Neurosurgery NHS Trust	Paragraph 102	There appears to be unnecessary duplication with neuroscience and cancer network MDT. Both functions could be performed by an appropriately run neuroscience MDT. Without class I evidence of improvement in outcomes then the cost of such duplication tabled in the appendix cannot be justified. The neuroscience MDT should include oncological and radiotherapy input so that it is perfectly reasonable for the non-surgical treatment to be decided by the neuroscience MDT. Referral back to the cancer network MDT will delay treatment.	Please refer back to our previous comment, which clarified this. The GDG emphasise the importance of the breadth of the MDT input at the cancer network MDT and this stresses the importance of the whole patient pathway. It would be inappropriate to focus this exclusively on oncology and radiotherapy.
Walton Centre for Neurology and Neurosurgery NHS Trust	Paragraph 108	A useful and important function for the nurse specialist is to co-ordinate care: thus this individual can be the key worker, and this defines that persons role – one important part of this role is to make sure the patient is aware at anytime who is the responsible clinician. Treatment and management decisions are the preserve of the responsible consultant – a neurosurgeon in the neuroscience centre, and oncologist in the oncology centre. In the community this will be the GP, elsewhere (DGH, hospice) the admitting consultant.	Comment noted.
Walton Centre for Neurology and Neurosurgery NHS Trust	Paragraph 113, 114	Very little evidence exists to support the benefit of an MDT in improving outcomes for cancer, and none specifically for CNS tumours; thus whilst a dedicated neurosciences MDT is a supportable idea (based on case volume studies) there is a very limited case for two MDTs.	As previously clarified.
Welsh Assembly Government		Thank you for giving the Welsh Assembly Government the opportunity to	Thank you for your comment.

(formerly National Assembly for Wales)		comment on the guideline. We are content with the technical detail of the evidence supporting the provisional recommendations and have no further comments to make at this stage.	
West Midlands Specialised Services Agency		This organisation was approached but did not respond.	