Brain and other CNS tumours – 1st consultation – Stakeholder comments

31 March 2005 – 25 July 2005

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 Palliative 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)	General	The Association of Neuro-Oncology Nurses (ANON) applauds the guidance as an important and positive document which should enhance patient and family care as well as encourage inter-professional/multi-disciplinary working. However, there are a couple of issues that warrant closer attention, that is:	Thank you for your comments.
Association of Neuro-oncology Nurses	Key recommen	The guidance is vague and needs to be clearer on the key worker. ANON acknowledges that although not always, in	We agree that neuro-oncology Clinical Nurse Specialists (CNSs) are very important to the Multidisciplinary Team (MDT). However,

(ANON)	dations.	the VAST majority of cases the key worker for the speciality is the Clinical Nurse Specialist (CNS)/Neuro-Oncology. The CNS/Neuro-Oncology is generally responsible for the co-ordination of patient care throughout all stages of illness i.e. from diagnosis to palliative care. It is therefore imperative that the guidance in its key recommendations acknowledges this critical role. This acknowledgement would help to encourage Hospital NHS trusts/foundation to appoint and develop nurse specialist posts to benefit patient care. It is ANON view that 'all patients with central nervous system tumours should have access to a specialist nurse in neuro-oncology' and that this should be reflected as an important key recommendation in the guidance document.	the neuro-oncology CNS is not the key worker throughout the course of the patient pathway. Neuro-oncology CNSs are hospital-based, and much of a patient's care may be community-based. The Guideline Development Group (GDG) have taken this into account in deciding that the key worker may change according to patient needs, and the GDG decision also concurs with national cancer peer review standards and NICE Supportive and Palliative Care for Adults with Cancer guidance.
Association of Neuro-oncology Nurses (ANON)	Key recommen dations	ANON acknowledges the critical role of the palliative care specialist, but question them being in the key recommendations in particular when the guidance is for all central nervous system tumours many of whom would never require referral to palliative care. It would therefore be more appropriate for the palliative care specialist to have been included in Box 3 'Membership of the neuroscience brain and other CNS tumours MDT'.	The GDG agreed that brain tumours are the majority of CNS tumours and that in general CNS tumours have a poor prognosis. The GDG also agreed that it is important to encourage closer collaboration with, earlier referral to, and utilisation of, specialist palliative care skills. The Key Recommendation supports and promotes these aims. The Palliative Care Specialist is already a member of the neuroscience brain and other CNS tumours MDT. The Palliative Care Specialist is not a core member in those rarer CNS tumour MDTs where the majority of patients have benign tumours and/or a long prognosis. Within the GDG there was a clear process for deciding the key recommendations to be included in the final document and it is felt that this priority should remain.
Association of Neuro-oncology Nurses (ANON)	General/Key recommen dations.	ANON wishes to highlight that in general it is the CNS/Neuro-Oncology who co-ordinate services for this group of patients and provides specialist advice, support and symptom management together with the medical and other multi-disciplinary and community team members. ANON wishes to emphasise that although not always, in	We agree that neuro-oncology CNSs are very important to the MDT. However, the neuro-oncology CNS is not the key worker throughout the course of the patient pathway. Neuro-oncology CNSs are hospital-based, and much of a patient's care may be community-based. The GDG have taken this into account in deciding that the key worker may change according to patient

		most instances it is the CNS/Neuro-Oncology the one that initiates referrals to other multi-disciplinary/community health care professionals to include palliative care referral at the appropriate and most suitable time (this may well be from diagnosis) for the patient and family.	needs, and the GDG decision also concurs with National Cancer Peer Review standards and NICE Supportive and Palliative Care for Adults with Cancer guidance.
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)	General	The ABPI welcomes the NICE Guideline on Improving Outcomes for People with Brain and Other Central Nervous System Tumours. We have no specific comments to make.	Thank you for your comments.
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	General	Overall, if implemented, this guidance would improve the	Thank you for your comments.

Foundation		quality of services offered to people diagnosed with a brain tumour and we very much welcome the inclusion of 'benign' tumours in the recommendations.	
Brain and Spine Foundation	20	Perhaps include the statistics demonstrating that brain tumours have the highest number of life years lost	We are unaware of these statistics and would be grateful if these are made available to us.
Brain and Spine Foundation	79/95	In a recent survey conducted by a collaboration of brain tumour charities the co-ordination of a patient's care across different clinical departments was highlighted as problematic by a majority of respondents. We endorse the suggestion that the Key worker may not necessarily be a clinical nurse specialist, especially given the scarcity of this 'resource' (especially for patients with benign or non-cancerous tumours).	Noted with thanks.
Brain and Spine Foundation	107	Delays in diagnosis are frequently mentioned in calls to the helpline and in patient surveys. We would support research in to the most effective methods of improving the identification of signs and symptoms in general practice and by non-specialist healthcare professionals suggestive of a brain tumour/ rare conditions.	Thank you for your comment.
Brain and Spine Foundation	131	We highlight the need to ensure that the patient and their family understand why it can take sometime before the type and grade of the tumour is known and to avoid conflicting or contradictory information being given to patients by different healthcare professionals during the 'waiting period'	We acknowledge this comment and feel that this is reinforced in paragraph 336.
Brain and Spine Foundation	319	In our experience, a significant number of patients and carers are not aware of the full range of healthcare professionals who could help with symptom control etc. This seems to particularly apply to patients and carers with cognitive, behavioural and emotional problems.	Comment acknowledged. We have included this in the section on information for patients.
Brain and Spine Foundation	323	Patients with meningioma's often find it difficult to access services and we strongly support the need for long term ongoing face-to-face communication with this patient group	Thank you for your comment.
Brain and Spine Foundation	334/335/336	Many callers to our helpline were not given any patient information or details of where they can go for further information and support. The issue of how to 'kitemark'	Thank you for your comment.

		information resources used within the NHS is still under review and is especially pertinent given the demise of The Centre for Health Information Quality.	
British and Irish Orthoptic Society		This organisation was approached but did not respond.	
British Association for Counselling and Psychotherapy	General	This is a comprehensive and well considered guideline. We particularly like the way in which it refers constantly to the NICE guideline 'Improving supportive and palliative care to adults with cancer' as opposed to inserting one simple statement at the beginning of the manual.	Thank you for your comments
British Association for Counselling and Psychotherapy	19	The statement saying that this guidance is not a clinical guideline is confusing. NICE do place its cancer service guidelines under the umbrella of clinical guidelines, so it would be better if the paragraph was simplified to read, for example: 'This cancer service guidance manual is intended to inform the commissioning and provision of services for people with brain and other CNS tumours. It will not offer the level of detail required to inform decision-making about specific treatments for individual patients. This background section is intended to inform non-specialist readers about this group of diseases and their management.'	We acknowledge there is some element of confusion and the guidance has been amended appropriately.
British Association for Counselling and Psychotherapy	97 and Box 5	It is important that the Cancer Network MDT provide an access point for patients who may request or benefit from psychological therapies, whether individual or group based - at diagnosis, during treatment or follow-up - as referred to in the last sentence of paragraph 45 (p.19) and paragraphs 353 and 354 (p113). Psychological therapies may not relate specifically to psychologists, palliative care professionals or allied health professionals. We therefore recommend that the 'Others as required (extended MDT members)' include the term 'psychological therapist' in preference to simply 'psychologist', as a more inclusive term.	Thank you for your comment. We feel that psychology adequately covers these professionals.
British Association for Counselling and	103	This paragraph does not make sense – especially in light of the fact that most, if not all, of the various NICE cancer	The paragraph still stands as there is no grade 1 evidence to support MDTs.

Psychotherapy		service guidelines recommend the use of MDTs and extended MDTs. We suggest the paragraph may be mis-worded, as it seems likely that the point being made is that there is little evidence to support an optimal configuration of MDTs, standardised for all types of cancer.	
British Association for Counselling and Psychotherapy	224	This paragraph should state clearly that a Cancer Network MDT should also be developed for these specific types of brain and CNS cancers and that membership should follow that detailed in Boxes 4 and 5 (p.41-44)	We think that this is clarified in Box 7.
British Association for Counselling and Psychotherapy	299	We believe that psychological support should be made available to all cancer patients and that this should be via the Cancer Network MDT. The basis for this argument is that cancer, irrespective of type or bodily location, often strikes fear and anxiety in people both before and following diagnosis.	Thank you for your comment. We have revised the paragraph accordingly.
British Association for Counselling and Psychotherapy	364	The second bullet point should read: 'Neuropsychology, neuropsychiatry and psychological therapy' for the reasons stated above and in line with the NICE guideline 'Improving supportive and palliative care for adults with cancer.'	Thank you for your comment. We have revised the paragraph accordingly.
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 Oncology Pharmacy Association	General	A useful and comprehensive document that addresses most aspects of service provision for this group of patients	Thank you for your comments.
British Oncology Pharmacy Association	97	It would be useful to include a specialist oncology pharmacist within the membership of the cancer network brain and other CNS tumours MDT, in view of the fact that treatment regimens, especially those containing oral	We do not consider that a specialist oncology pharmacist should be a core member of either MDT. However, their input would be sought through other network mechanisms, e.g. the network drug and therapeutics group.

		chemotherapy, are complex and rely heavily upon the co-operation and understanding of the patients and carers. There is also the need to monitor the effects of, and potential for interaction with, supportive care medication.	
British Oncology Pharmacy Association	275	Intrathecal chemotherapy should be prescribed and administered in accordance with national standards by accredited staff	We have revised this comment accordingly.
British Psychological Society, The		This organisation was approached but did not respond.	
British Psychosocial Oncology Society		This organisation was approached but did not respond.	
British Society of Neuroradiologists	Para 9	“Neuropathology and neuroradiology services should be provided to a level that ensures practitioners in these specialties can provide appropriate diagnostic investigations in a timely and efficient manner, (and) can be involved in pre- and post-operative management decisions” This is a commendable recommendation but there is clear concern that in many areas, neuroradiological services lack sufficient staff and access to facilities for investigation. Worthwhile participation in MDT meetings and appropriate specialised investigation of patients suspected of having brain tumours as proposed could occur only at the expense of existing commitments. Guidelines already issued by NICE and intercollegiate bodies (for the management of patients with head injuries and stroke) have contributed to increased demands made on imaging departments which often cannot be met within recommended timescales given existing resource constraints.. In September 2003, Officers of the Royal College of Radiologists issued advice to Fellows:	The guidance directs itself to appropriate care and if the current provision falls short of that then it is an incentive to upgrade staff and facilities to meet this. To dilute the recommendations because other imaging areas have already made demands seems inappropriate. We agree that this work should be ‘enshrined’ in job plans. Again. it is not our job to say how it should be done only that it should!

		"…the bulk of the work involved in the preparation for, and presentations at, MDT meetings has fallen on Consultants in Clinical Radiology and Pathology who have been asked to add these fixed meetings to their work schedules. Attendance at, and participation in them has been assumed and rarely enshrined in consultant work plans. *….the majority of radiologists and oncologists are now expected to participate in MDTs by squeezing the extra commitment into their working week without any proper readjustment of pre-existing job plans."* In many regional neuroradiology departments where patients suspected of having brain tumour will be referred for more specialised imaging, significant constraints on timely access to investigation already exist, and waiting times, particularly for MRI, are at unacceptable levels. Independent providers of outsourced MRI services are willing to accept only the most basic of investigations. Due consideration of all resource implications of the guidelines, and appropriate resource allocation will be required if they are to be followed as intended, and without detriment to existing services, and it is understood that this will be addressed in a second guideline draft. Attention will be need to be given to any concurrent initiatives , such as "*payment by results*" that reward service providers for procedural work but make no allowance for time consuming specialised investigations or activities such as MDT participation.	
British Society of Paediatric Radiology		This organisation was approached but did not respond.	
British Society of		This organisation was approached but did not respond.	

Rehabilitation Medicine			
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	General	Appears to be a good comprehensive overview of this patient group & well assembled, easy to read document. Good links with NICE: Palliative & Supportive Care Guidance 2004. Good consistent identification & incorporation of rehabilitation services essential for these patients- it will be interesting to see what is identified within the resource implications for all sections to be seen in 2nd draft- & how feasible this will actually be across Cancer Networks / Rehab teams/units etc – of note is the recent news of a local Specialist Neurological rehabilitation Unit closure (Harrowlands Rehab Unit, Dorking, Surrey) Clear patient pathway diagrams used through document.	Thank you for your comments.
Chartered Society of Physiotherapy	General	Scope: is clearly set out. Practical value of the document: It clearly states in the scope that it is not a clinical guideline but intended to inform commissioning & provision of services – as discussed later - ? not sure at this stage the feasibility or practicality to match the guidance related to service provision, prioritisation of care within local teams/ hospice /cancer centres due to	We note the comment but feel that the prioritisation of services is the responsibility of the commissioners not the GDG.

		national staffing levels/shortages and the subsequent necessary service prioritisation.	
Chartered Society of Physiotherapy	68	Of note as above re closure by PCT's of Specialist Neuro-rehab unit	This comment is not appropriate for the background section.
Chartered Society of Physiotherapy	76	Need mention of Clinical Nurse Specialist specifically in management of the patient	We feel that this paragraph does not need to be amended to specifically mention the CNS at this point.
Chartered Society of Physiotherapy	81	Good that the need for clinical assessment by AHP/ Supportive Care specialist is identified but this may not be required unless symptoms show it to be appropriate, rather than identifying its need at 3 specific stages.	The assessment of needs is an ongoing process but these are the three key stages.
Chartered Society of Physiotherapy	Box 5	Specialist AHP's are not always available throughout all Cancer Networks, rather they tend to be focussed at Specialist Cancer Centres.	Patients should have access to these specialists in order for their rehabilitation to be directed/facilitated by non-specialists.
Chartered Society of Physiotherapy	326	Noted potential useful article re disclosure of diagnosis to cancer patients although not specifically CNS tumours : Salander, P (2002) Bad news from the patient's perspective: an analysis of the written narratives of newly diagnosed cancer patients *Social Science and Medicine* 55 pg 721-732	Thank you for this reference. We will assess it and add it to the evidence section as appropriate.
Chartered Society of Physiotherapy	P. 120–124	Resource implications – need for improved resources for rehab services within Palliative/Hospice Care to provide services required locally due to service prioritisation in local PCT teams does not incorporate Palliative management.	The resource implications will be considered in the second draft of this guidance.
Chartered Society of Physiotherapy	366	Good to identify potential gaps in service provision / availability	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		This organisation was approached but did not respond.	

College of Occupational Therapists		This organisation was approached but did not respond.	
Conwy and Denbighshire NHS Trust		This organisation was approached but did not respond.	
Department of Health	General	This is a document about adults, would you consider stating this at the outset? Children and transitional care are dealt with in the children and young people's Improving Outcomes Guidance.	The document clearly indicates that this relates to adults exclusively in paragraph 17 of the background.
Department of Health	General	The terms 'palliative care' and "specialist palliative care" are used. Would you consider clarifying the differences between the two?	The Brain and Other CNS Tumours guidance cross-refers to the Improving Supportive and Palliative Care document. We will ensure that the definitions from the Improving supportive and palliative care document are used consistently in the Brain document.
Department of Health	General	In respect of references to cancer networks would you consider clarifying whether you mean the normal 34 cancer networks or the "supra" cancer networks needed for the rarer cancers? Would you also consider specifying what the planning population for a CNS cancer centre is, for example, one million, two million?	With regard to the first half of this comment, the document is clear in discussing cancer networks as indicated in the 34 cancer networks. Where this is not the implication of the use of the term cancer network, supra cancer networks are used as a phrase and we feel this is clear and does not need further clarification. With regard to the use of specific populations for defining service provision, this was discussed extensively by the GDG. The decision of the GDG was that the requirements for providing the service would define which centres could provide this service rather than using an arbitrary population base.
Department of Health	General MDTs	We have a number of comments in respect of Multi Disciplinary Teams and therefore felt these would be best placed in the General comments section.	Thank you for your comments.
Department of Health		Whilst not explicitly stated the phrase '*the cancer network brain and other CNS tumours, MDT*" suggests there should be one only per network. If not, you may wish to consider the following: (a) should there be as many as the network decides there can be? , or	It is felt that the network should decide the number of cancer network brain and other CNS tumours MDTs required for their network. It is explicit in the document in Box 4 the responsibilities of this group and the network will be in the best position to decide how those responsibilities are discharged and how the service needs to be structured to achieve this.

		(b) should there be any other constraints to the number of MDTs per network?	
Department of Health		"*The neuroscience brain and other CNS tumours MDT*" suggests that this deals with all CNS tumours, however, a number of other MDTs are described such as spinal tumours and skull base tumours. You may wish to consider whether it would be helpful for the guidance to set out how these MDTs might fit together? For example: • paragraph 226 "in some cases there will be overlap between the membership of the pituitary and neurosciences MDTs". You may wish to consider whether the teams meet separately, or are the same MDT? You may also wish to consider what happens if the neuroscience and the spinal MDTs both think they are dealing with the patient? • paragraph 227 "*for spinal and skull base tumours the specialist teams <u>are likely</u> to relate to more than one neuroscience centre …there will need to be clear pathways of referral to these very specialist teams*" We believe that every neuroscience centre will want to treat every type of CNS malignancy. Every centre will tend to declare itself as having these "*very specialist teams*", with the result that they will be no more specialist than any other CNS MDT. You may wish to	Paragraph 226 – the guidance is explicit in paragraph 226 that the pituitary MDT is a separate meeting and has particular expertise contained within it. It is the responsibility of local service organisations to define the most efficient method of running these MDTs. The signposting within the definition of responsibilities for the designated lead and the neuroscience MDT has been clarified to avoid such eventualities. Para 227 – the GDG feel that the clear definitions of the core team members for the spinal and skull base MDTs will inevitably restrict these very specialist teams to a small number of centres.

		consider whether you want the treatment expertise for these rare cancers to be consolidated into fewer than all the neuroscience centres. If so, we feel that it would be helpful for there to be concrete discriminating factors between those MDTs which are “very specialist” for objective reasons and those MDTs which just want to call themselves “very specialist” . We would suggest that the discriminating factors should be measurable and objective.	
		There is some existing ‘objective discriminating factors’ for these MDTs set out in the guidance so far. You may wish to consider redrafting the relevant sections of the guidance in the light of these comments:	Box 8 Pituitary – thank you for your comment. We have made the appropriate amendment.
		Box 8 – Pituitary *“A neurosurgeon ………………. and has specialist surgical responsibility for at least 50% of their programmed activities”.* Would you consider making it clear that the specialist surgical responsibility is explicitly for pituitary surgery?	Thank you for your comment. We feel that this does consolidate the expertise.
		We are concerned that relying on a parameter to do with the amount of time spent on a rare cancer, rather than consolidating the expertise, may result in a lot of time being spent on very few patients.	Box 9 Spinal – thank you for your comment. We have made the appropriate amendment.
		Box 9 – Spinal. • *“Specialised spinal surgeon …………….. but spends at least 50% of clinical programmed activities in neuro-oncology/spinal surgery……….”* We believe that the addition of neuro-oncology to	

		programmed activities (taken literally neuro-oncology is not specific to spinal tumours) affects the percentage of time the surgeon would actually be spending on spinal surgery. • *“Member of a national specialist organisation” Would you clarify* a. whether there is a national specialist organisation for spinal tumour surgery, and if so, b. can any neuro or orthopaedic surgeon join, or do they need some other objective proof of spinal surgical expertise? Box 10 – Skull Base. There is no real discriminating factor. The concept of the skull base MDT is being covered independently by the head and neck IOG which is already published. Currently out for national consultation are the head and neck Measures for the Peer Review and the Manual for Cancer Services. We are concerned that the two IOGs and any resulting Measures will have some incompatibilities. You may wish to consider this.	Thank you for your comment. We will clarify this with appropriate GDG members. Box 10 – Discriminatory factors – thank you for your comment. We will clarify this with appropriate GDG members. Box 10 – Skull base. Although the concept of skull base MDT has been covered in head and neck (IOG), the MDT has not been defined, so we think incompatibilities are unlikely.
Department of Health		You may wish to consider whether there should be any constraints as to catchment or case numbers for the neuroscience MDT, and whether the absence of such constraints is likely to give rise to an increase in the number of surgical treatment teams.	With regard to the use of specific populations for defining service provision, this was discussed extensively in the GDG. The decision of the GDG was that the requirements for providing the service would define which centres could provide this service rather than using an arbitrary population base.
Department of Health		There appears to be no direct link between attending the MDT (ie being a core member) and being able to operate on brain tumours. For example, (para 78) “taking part in the MDT” must mean something different than actually being	Thank you for your comments. The wording of paragraph 78 has been changed to be more explicit. Paragraph 189 in the treatment section reinforces this and the mechanism of registering positive radiology within the neuroscience MDT should avoid missed

		subject to the attendance requirements, since all neurosurgeons have to "take part" but only 2 need to be core members and therefore have to attend. You may wish to consider whether this needs amending as the following scenario is likely – 1 or 2 neurosurgeons in a centre attend the MDT and the rest are named as members of the "extended MDT" which commits them to little or nothing and isn't designed for people who deliver any of the definite treatments. They are supposed to be core members. (see Manual of Cancer Services, Measure 2E-108 and ditto for all other MDTs). The non-attending surgeons are then supposed to be told who they should or shouldn't operate on, by the other surgeons who attend the MDT, where the treatment decisions should be made. In the light of these comments you may wish also to consider the need for a mechanism to allow MDT treatment decisions to be made by the people who are supposed to carry them out.	cases. It is the intention of the GDG that there will be two core neurosurgical members of the neuroscience MDT. Their role is to define protocols and advise on management of the majority of patients. However, there will be occasions when, for instance, patients managed in an emergency will have been operated on by neurosurgeons other than core members. In this instance it would be expected that the neurosurgeon would present the case to the MDT. With regard to the value of the MDT, where none of the major contributors have ever seen the patient it is acknowledged that by registering all patients through the MDT and advising on their management plan (in the presence of adequate clinical information) an audit trail will exist and protocol-driven management will be the norm.
Department of Health		It appears that the guidance seems to find the evidence for consolidation of treatment expertise into specialist units, inconclusive, as there are few firm recommendations regarding it. This implies that the status quo is acceptable. We believe the danger here is that the increased profile given to the national infrastructure by the IOG, the Measures and the Peer Review, will tend of itself to change that infrastructure. In the absence of any recommendations about catchment or workload, for a neuroscience centre, that change will tend to be uncontrolled. It seems that, in the context of estimated case numbers in neurosurgical units varying widely from 63-700 a year and in radiotherapy units from 17-350 a year, this is an inherently unstable situation. You may wish to consider that some pragmatic	We have had considerable support for the model we propose. We feel that the ground rules have been made explicit through the membership and responsibilities of the MDTs. We recognise that this will require consolidation of services across overlapping networks and this will be determined locally.

		ground rules should be agreed. This has been the case for some other IOGs, since for rare cancers, it may be inherently impossible to obtain clear research evidence for the value of consolidating services or at least, curbing their further dissemination. Would you consider whether additional recommendations should be made in the guidance in light of these comments?	
Department of Health		The rationale for the Neuroscience and then the Network MDT seems unclear. We are concerned that this doesn't seem to be providing better care and may lead to further delays in the patient pathway. The Neuroscience MDT suggests that it mainly deals with decisions around surgery, and that the Network MDT then plans for any other treatments. MDT working suggests that all parties should be part of the decision making process at the outset. Would you consider the need for a catchment population for this MDT/service or any case numbers?	With regard to the use of specific populations for defining service provision, this was discussed extensively in the GDG. The decision of the GDG was that the requirements for providing the service would define which centres could provide this service rather than using an arbitrary population base.
Department of Health	Para 70	The guidance argues that the Neuroscience departments are not coterminous with Cancer Networks which appears to say that this service should be planned across Networks and should be part of the specialised commissioning processes. You may wish to consider extending para 70 to reinforce the need for the service to be planned by Specialist Commissioning groups. (This is in effect what has been done with pancreas, penile and testicular services where the precedent has already been made with multiple Networks referring to one Specialist MDT and SCG's have been asked to co-ordinate these plans. Again the comment about catchment/population size applies.)	Given the impending reconfiguration of the NHS we feel it would be unhelpful to make specific reference to specialist commissioning groups. However, if the Department of Health has further advice on this, it would be gratefully received.
Department of Health	General	You may wish to consider whether more could be made of linkages with the IOG to avoid potential areas of overlap or conflict?	We feel as a GDG that wherever cross-reference to IOGs is necessary we have made this point. If the Department of Health has specific examples of where we have failed to this we would be

			happy to clarify within the document.
Department of Health	Para 1	Please would you consider amending the wording "this is a group of patients whose care is currently often fragmented." to read "this is a group of patients whose care can be fragmented..."	Thank you for your comment. The guidance has been amended appropriately.
Department of Health	Para 6	MDTs are not usually network based. Please would you consider clarifying what is meant here -if the intention is to recommend one MDT for a network population, it is important to note that network population varies from 600,000 to 3 million?	First, we feel that it is not unusual particularly in rarer malignancies for MDTs to be network-based, this is true for urological cancers, upper GI, head and neck cancers, and others. The responsibilities of the Cancer Network Brain and Other CNS Tumours multidisciplinary team (MDT) are clearly defined in Box 4 of the document. It will therefore be the responsibility of networks to decide the service structure within their network that adequately fulfils the responsibilities as defined.
Department of Health	Para 11	Please would you clarify who would establish national tumour groups?	Thank you for your comment. National tumour groups have already been established and we will address this point during the second consultation period.
Department of Health	Para 17	You may wish to add that the guidance is explicitly dealing with low-grade brain tumours. Would you also consider adding a reference here to the planned clinical guideline on spinal cord compression?	This is explicitly addressed in paragraph 20 indicating the range of pathologies included. It is not possible to comment on the planned clinical guideline on spinal cord compression as this is not yet finalised.
Department of Health	Para 19	Whilst reference is made that the guidance is intended to inform commissioning, there appears to be no advice anywhere on commissioning arrangements. Would you consider addressing this?	It is outside the remit of this guidance to suggest commissioning arrangements.
Department of Health	Para 40	Would you consider clarifying that these symptoms are a common presentation for benign not malignant tumours?	No.
Department of Health	Para 44	This paragraph states 'in a few cases biopsy is not feasible or clinically inappropriate' - if you include older patients this is likely to be 20%+ . Would you consider amending this paragraph?	The issue was discussed at considerable length within the GDG and it was the view of the group that biopsy in clinically safe situations should be a standard of care regardless of age.
Department of Health	Para 45	Would you consider replacing the word 'invasive' with "infiltrating" ?	The wording will be changed accordingly.
Department of Health	Para 45	We feel the term "May be a benefit" underplays the importance of these treatments, there may be a benefit for	We feel that 'may be of benefit' stands scrutiny and should remain unchanged.

		surgery also. Would you consider redrafting this paragraph to reflect this?	
Department of Health	Para 46	Rarer Tumours – Would you consider listing some examples here?	Rarer tumours are defined within the appropriate sections and inclusion here would unnecessarily extend the document.
Department of Health	Para 51	Many patients are managed medically as primary treatment, would you therefore consider expanding this paragraph to reflect this?	The wording has been adjusted in paragraph 51 to accommodate medical management.
Department of Health	Para 53	The last sentence in this paragraph refers to the controversial nature of treatment, would you consider clarifying what the controversy is?	The wording has been changed to clarify.
Department of Health	Para 54	Would you please consider replacing the word "specialist" with "specialised"?	Thank you for your comment. The appropriate changes have been made.
Department of Health	Paras 55 to 58	Would you consider whether it is possible to give the England and Wales figures separately?	Why?
Department of Health	Para 63	Would you please consider whether the figure of between 17 and 350 used is acceptable?	The numbers are statements of fact within the context of the background chapter.
Department of Health	Para 64	Would you please clarify whether these comments are in respect of first definitive treatment or at any point in the treatment pathway?	Clarification on these comments is not possible as these were not part of the questionnaire.
Department of Health	Para 70	There seems to be confusion over level 1 and level 2 commissioning in this paragraph. Would you consider redrafting to make this clearer?	Due to reconfiguration in the NHS we think it would be unhelpful to further define levels of commissioning.
Department of Health	Para 70	Would you consider re-siting this paragraph as it appears to be a recommendation rather than background information?	Thank you for your comment. This was discussed by the GDG and this paragraph has been transferred to the recommendations section of the MDT chapter.
Department of Health	Para 71	Would you consider expanding this to make the link with the NSF for long term conditions more explicit?	Thank you for your comment. We think it is important to make a link with the NSF and this will be addressed during the second consultation period
Department of Health	Para 74	Would you consider redrafting this paragraph to clarify that it is attendance by MDT members that is meant here, rather than patients?	Thank you for your comment. The wording will be clarified as appropriate.
Department of Health	Para 77	Would you please clarify what is meant by “.. become more rigorous? Would you also consider revising the UK figures quoted	The wording concerning the rigorousness of the role of core members has been changed as appropriate. There is no difference between the figures. Furthermore, the

		here, as the scope of this guidance is for England and Wales only?	Department of Health should note that the guidance is for England only although we do not think that the figures for the UK are different of England, Scotland and Wales separately. However, we will review the 30% figure during the second consultation period.
Department of Health	Para 81	Would you also consider those patients who need to be discussed at relapse, as mentioned in para 91? It would be helpful to include the page number for box 2 here.	Para 81 refers to clinical assessment and clinical review here covers patients who have relapsed. Noted.
Department of Health	Para 85	Would you please consider whether a designated lead in each trust is viable?	We consider a designated lead in each trust as essential.
Department of Health	Para 87	Would you please consider whether this is likely to speed the patient through the system?	We think this is the most effective way of ensuring that all patients are considered by the specialist MDT.
Department of Health	Para 89	Would you consider redrafting? – the lead clinician would ask someone else to get the information for them	Thank you for this comment. We will amend as appropriate.
Department of Health	Para 96	Would you please consider whether monthly meetings are feasible as they may be too infrequent for networks?	Monthly meetings were considered the minimum.
Department of Health	Box 3, p. 39	Would you consider making clear in all MDT membership tables who the core members are and who are the extended members? It may not be appropriate for all members to be core members?	Thank you for your comment, the membership of the teams has been revised accordingly.
Department of Health	Box 4, p. 41	Would you please consider the possibility of having key workers, ie one from neuroscience and one from the network?	We consider it important that a patient only has one key worker at any one time.
Department of Health	Box 4, page 42 – 4th bullet	Would you consider cross referring to the "national standards of care" mentioned here?	We will revise this bullet point as appropriate.
Department of Health	Box 4	Would you consider stating the membership of the Network site specific group here?	Thank you for your comment. We do not feel it is appropriate for us to state the membership of the site-specific group. This should be determined locally by the cancer network
Department of Health	Box 5	Would you please reconsider the need for a therapy radiographer as they are short in number?	We feel it is very important that a therapy radiographer is included.
Department of Health	Para 103	Would you consider adding ‘lower operative deaths and better patient care’ here?	We do not think it appropriate to add ‘lower operative deaths and better patient care’ here as is said in the paragraph there is limited evidence.

		Would you also consider adding to the Structure section (below this paragraph) which national teams should be accessed?	We do not think it is appropriate to list all national teams in this section
Department of Health	Para 106	Would you consider stating the evidence of limited services and delay affecting outcomes?	Where available the evidence is in the evidence section. Further detailed evidence is available in the evidence review published with the second draft.
Department of Health	Para 107	Would you consider whether the reference to the referral guidelines here is accurate - are the guidelines now for primary care teams and not just general practitioners?	We have revised the paragraph accordingly.
Department of Health	Para 112	Would you please clarify where patients will be referred and who will arrange referral?	We feel that clarification is not necessary, as we have established that this is for local arrangement.
Department of Health	Page 114	As there may be a GP referral if sent to independent sector – would you please consider whether GPs should refer direct to the neuroscience MDT?	GPs will not refer directly to the neuroscience MDT, as this will be the responsibility of the consultant in the independent sector.
Department of Health	P. 121	Would you consider including cancer waiting times?	The audit measures in the process section will be extractable from the cancer waiting times data.
Department of Health	P. 124	Would you consider stating whether there is any evidence to support this?	Evidence will be included in the subsequent evidence review.
Department of Health	P. 125	Please consider clarifying this paragraph – is the suggestion that patients have a second MRI? Would you also consider clarifying where the MRI should be undertaken – would this be at the neuroscience unit?	Yes, it may be necessary for some patients to have a second MRI scan. In the majority of cases this will be done at the neurosciences unit. However, we do not feel it is necessary to revise the guidance as this decision will be made at a local level.
Department of Health	Para 129	Would you consider clarifying whether these are in addition to MDT meetings?	Ideally these discussions should occur at a structured GDG meeting. However, in practice some patients will require urgent surgery prior to the MDT.
Department of Health	Para 138	Would you consider making this paragraph more specific i.e. what is meant by "a timely and efficient manner..."?	Thank you for your comment. The guidance has been revised to: ‘In a timely and efficient manner, complying with national cancer waiting times targets’.
Department of Health	Paras 129 and 130	We believe that intra-operative histopathological assessment can be valuable, and to allow best use of resources should be planned as with any other investigation where possible between surgeon, radiologist and pathologist. The facility needs to be available in a centre and so resources need to be adequate, however for spinal	Thank you for your comments. This will be discussed by the GDG and addressed in the second consultation period.

		tumours it is stated to be essential. We believe that this should not be stated in any of the contexts, cerebral or spinal, presented here. Imaging techniques continue to improve, and some of the studies on its value in obtaining an adequate specimen are old. In the case of small biopsies, if a key area of tissue is smeared and not available for definitive paraffin sections, final diagnosis may be impaired. Finally, given small biopsies, the advent of molecular techniques (and the desire to store tissue for much needed research) may mean that there are competing demands on tissue. In light of the above comments would you consider whether it would be better to state that this is an investigation which can be of great value in certain circumstances and which therefore should be available in a centre. Its use should be at the discretion of the neurosurgeon and neuropathologist so that the most appropriate use of tissue as well as the best procedure should be planned. We believe that the use of the term "essential" is not justified by evidence and may cause difficulties, would you consider redrafting?	
Department of Health	Para 159	Would you consider providing EORTC criteria as an annex?	Thank you for your comment. The EORTC criteria will be included in the appendices. This will be addressed during the second consultation period.
Department of Health	Para 167	Would you consider mentioning short and long course radiotherapy?	We feel that further qualification with regard to short and long course radiotherapy is unnecessary and does not add anything.
Department of Health	Para 169	Would you please clarify whether this paragraph refers to gliadel wafers?	We do not feel it is appropriate to be specific about concomitant treatments and intraoperative implants.
Department of Health	Para 170	Would you consider specifying the frequency of follow up and who does it?	We are not sure why you request details on frequency of follow-up in relation to this paragraph. Follow-up is dealt with in the appropriate section for each type of tumour although not in detail as that is not appropriate for service guidance.
Department of Health	Para 172	As for 169 above. Would you also consider clarifying whether you are referring to temozolomide in the last	We do not think it is appropriate to name specific treatments in this section.

		sentence?	
Department of Health	Para 172	Would you consider redrafting this paragraph, juxtaposition of last sentence with the previous one suggests that we should look to treating older patients with newer chemotherapy regimes?	Thank you for this comment. We have revised this paragraph accordingly.
Department of Health	Para 191	Please consider clarifying this paragraph as it is not clear whether you are recommending a one member of staff appointment at an outpatients clinic not necessarily doctor led?	We have given this due consideration and feel that further clarification is not necessary.
Department of Health	Para 214	We are advised that there is no evidence of RT neurotoxicity if given at 2GY/# or less, would you consider amending this paragraph in the light if these comments?	Thank you for your comment. We have revised the paragraph as appropriate.
Department of Health	Box 9	Would you clarify the specialist organisation meant here?	Thank you for your comment. We will contact the appropriate GDG members and clarify this statement during the second consultation period.
Department of Health	Para 226	The second sentence states that "Work is currently underway at a national level to help define this", would you clarify who is undertaking the work, the DH or colleges?	Thank you for your comment. We will contact the appropriate GDG members and clarify this statement during the second consultation period
Department of Health	Para 263	Would you consider clarifying who would coordinate this, DH or professional associations?	Thank you for your comment. We will discuss this issue with the GDG and address it during the second consultation period
Department of Health	Para 272	Would you consider cross referring to the haematology IOG here?	We would cross-refer to the haematology IOG but there is no mention of these tumours in that guidance.
Department of Health	Paras 274 and 290	We understand that insisting on having neuropathology services on-site for intra-operative histopathological evaluation, given the national shortage of neuropathologists, may not be deliverable. Would you consider other ways of accessing such scarce expertise in a timely way?	We do not feel that there is still a national shortage of neuropathologists and consider that on site intra-operative histopathological evaluation is essential.
Department of Health	Para 275	Would you consider clarifying what is meant by accredited as it is important that the NHS meets the national guidance and associated manual measures?	We have revised this paragraph to remove the word 'accredited'.
Department of Health	Para 313	Would you please clarify whether the combined specialised neurogenetic clinics referred to are already established?	Please note that this is a recommendation.
Department of Health	Para 321	In respect of the sentence "In such cases, carers may need to be more involved in decision-making than the patient", you may wish to consider whether there should be	Thank you for your comment, but after giving this due consideration we have decided not to include this statement.

		reference/consideration here to any relevant rules regarding power of attorney?	
Department of Health	Para 437	You may wish to consider whether language such as "haphazard and uncoordinated", "dwindling from lack of support", "until funding for research is at least equivalent" is appropriate for a national guidance document?	Thank you for your comment. However, we have given it due consideration and feel the paragraph should stand.
Eisai Limited		This organisation was approached but did not respond.	
Eli Lilly and Company Ltd	General	No comment	Thank you for your response.
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		This organisation was approached but did not respond.	
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	408	Specialist Palliative Care – Whilst Help the Hospices agrees in principle with the majority of the section on specialist palliative care, we are concerned over the viability of requiring a palliative care specialist to be included in neuroscience brain and other CNS tumours MDTs. Neuroscience MDTs tend to cover wide areas. It would therefore often be difficult for the palliative care specialists to travel to neuroscience MDT meetings. Whilst we appreciate	We recognise that this presents resource issues. However, a clinical nurse specialist could be the representative or the cross-cover for the consultant.

		that these meetings may sometimes take place in the form of a video conference, the palliative care specialist still has to travel to a centre with the necessary facilities. Many hospices do not have access to video conferencing facilities and so the specialist may well be required to travel some distance. Given the shortage of palliative care specialists, we are concerned that this requirement may be a further demand on their time. If there is good communication between the MDT and the palliative care specialist we would question the value of the palliative care specialist attending the meetings.	
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 (IBTA)	General	Brain tumours throughout the Draft Guidance are referred to as either “benign”, “malignant” or “uncertain”. Should all brain tumours be described as “benign, low grade, malignant or uncertain” throughout the Guidance?	Thank you for your comment. This was discussed by the GDG and we have made the appropriate amendments. Tumours are now referred to as high or low grade
International Brain Tumour Alliance (IBTA)	8	The first sentence reads: “Cancer networks should set up robust local mechanisms to ensure that every patient with radiology that suggests a diagnosis of CNS tumour is discussed by the neuroscience brain and other CNS tumours MDT without delay.” Add after first sentence "... and has urgent access to an MRI to confirm the suspected diagnosis".	It is felt that MRI is not needed to confirm a diagnosis and not appropriate for this document. It is also clear in the key recommendations that the confirmation of the radiological diagnosis is confirmed by the MDT.
International Brain Tumour Alliance (IBTA)	22	The last sentence reads: “In view of the poor survival of many patients, even with optimal treatment, an important aspect of improving outcome is through maximising quality of life.” Add: "... particularly through support for both patient and their carer in what is often a short and intensely traumatic experience".	We do not intend to alter paragraph 22.
International Brain Tumour Alliance	26	The last sentence reads: “At a national level a substantial number of CNS tumours do not have specific morphology	It is not felt that adding this sentence contributes further to the paragraph.

(IBTA)		recorded, and so reliable data is not available for tumour subtypes defined by their morphology (for example, oligodendroglioma.” Add: "... and consequently the identification of any trends in the occurrence of sub-types is not possible".	
International Brain Tumour Alliance (IBTA)	32	Add "brain" after "rarer", otherwise there may be confusion with "rarer tumours/cancers" in general.	Thank you for your comment. The appropriate changes have been made to the guidance.
International Brain Tumour Alliance (IBTA)	33	The reference to AIDS in connection with PCNSL tumours here and elsewhere may be embarrassing to those whose tumour has nothing to do with AIDS. Add at end of paragraph: "... but in other cases it has no relevance".	The wording will be changed to alter the emphasis.
International Brain Tumour Alliance (IBTA)	35	As a follow on from the discussion of the aetiology and risk factors involved in brain tumours, it might 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 do not feel that further qualification is necessary in paragraph 33.
International Brain Tumour Alliance (IBTA)	37	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.”	This is a valid point, although it cannot be contained within the guidance as it is not an issue for the national health service, but relates to social service provision.
International Brain Tumour Alliance (IBTA)	39	Replace "epilepsy" with "seizures". Patients are not generally told they have developed "epilepsy" but that they have had a "seizure" or "convulsion". See Para 41 in the Draft Guidance.	The use of the term ‘epilepsy’ is explicit and important as there may be legal connotations that would not follow with the use of the word ‘seizure’. As such, the current language needs to remain unchanged.
International Brain Tumour Alliance (IBTA)	45	Line 8 substitute " associated with treatment by resection, radiotherapy, chemotherapy, or a combination of both". This allows for neurosurgery also involving the insertion of Gliadel wafers, and concomitant radiotherapy and temozolomide, for example.	The sentence will be changed to include resection or combination treatments.

International Brain Tumour Alliance (IBTA)	46	See 32 above.	Thank you for your comment. We have made the appropriate changes.
International Brain Tumour Alliance (IBTA)	52	See 32 and 46. See also comments at para 33 re PCNSL tumours.	Adjustments have been made to rarer CNS tumours as indicated. The comments regarding increasing incidence in CNS lymphomas are correct and will be left unchanged.
International Brain Tumour Alliance (IBTA)	56	The sentence reads: “Patients may present to general practitioners, accident and emergency departments or other acute medical services before being referred on to specialist services.” Add: "... and consequently such staff, through unfamiliarity with brain tumours and their symptoms, may be responsible for mis-diagnosis and/or may inadvertently be responsible for critical delays in patients having access to urgent and appropriate treatment".	The additional comment does not add anything to the guidance and implementation of the guidance as it stands would streamline care in conjunction with the referral guidelines for suspected cancer.
International Brain Tumour Alliance (IBTA)	60	Would it be possible and practicable for brain tumour patients and carers to attend their own MDT meetings?	It is felt by the GDG that the practicalities of patients and their carers attending MDTs would be insurmountable and should not be considered.
International Brain Tumour Alliance (IBTA)	64	Add: "A delay of the magnitude of 8-12 weeks may involve a doubling of the size of a highly malignant brain tumour as a result of the rapid proliferation of cells."	This comment is not appropriate in the background section.
International Brain Tumour Alliance (IBTA)	69	Would it be possible to list the eight centres in England and Wales which have neurosurgical units for stereotactic radiotherapy?	The questionnaire sent to provider units in England and Wales was confidential so none will be named in the document.
International Brain Tumour Alliance (IBTA)	71	The most essential difference, which should be the lead dot point, is that brain tumours attack the physical and mental capacity of the patient. The brain is the core of one's existence and is responsible for our intellectual capacity.	We feel that the mental capacity of the patient is covered in this background section. The bullet points have equal weighting. There is no intention of inferring priority.
International Brain Tumour Alliance (IBTA)	76	See comments in regard to para 45. This should be reworded to cover combination therapies.	Thank you for your comment. This paragraph will be amended as appropriate.
International Brain Tumour Alliance (IBTA)	95	What provision is made for access to alternate "key workers" for advice on non life-threatening issues at irregular hours?	We consider that provision of advice on non life-threatening issues should be within regular hours.
International Brain Tumour Alliance	103	Under “Structure”, fifth bullet point. Add the word “secure” so it reads: “Establishment of secure internet based	Point acknowledged and noted. We have revised the guidance to take account of data protection issues.

(IBTA)		database for central data collection." The word "secure" should be inserted and apply to all references to an internet database.	
International Brain Tumour Alliance (IBTA)	106	The third line is missing an "a" before the words "brain tumour".	Thank you for your comment. The sentence has been amended accordingly.
International Brain Tumour Alliance (IBTA)	109	See comments at para 56	The additional comment does not add anything to the guidance. Implementation of the guidance as it stands would streamline care in conjunction with the referral guidelines for suspected cancer.
International Brain Tumour Alliance (IBTA)	139	Add: "... but should not be used as a basis for rationed access to emerging therapies in particular, for which long-term data of their efficacy has not yet been assembled".	Thank you for your comment, but we will not be revising that paragraph.
International Brain Tumour Alliance (IBTA)	148	This appears to imply that resection lacks any value but it needs to be stated that the established line of attack in dealing with a highly malignant brain tumour is to offer resection (where possible) with a view to reducing the tumour mass for radiation therapy and possible chemotherapy.	This paragraph summarises the current available evidence.
International Brain Tumour Alliance (IBTA)	151	The last word in the last line is mis-spelled: "temozolimide" should be corrected to "temozolomide".	Thank you for your comment. We will make the appropriate amendment.
International Brain Tumour Alliance (IBTA)	165	Agree that current waiting time targets of two months from GP referral to first definitive treatment and one month from diagnosis to first definitive treatment should be very flexible for those with CNS tumours who need to be seen on an urgent basis. However, these patients may include those with rapidly growing tumours OR significant symptoms. Therefore, change sentence to read "…although there may be some patients with rapidly growing tumours or significant or worsening symptoms of a physical or psychological nature who will need treatment much more quickly." Use of the words "pressing symptoms" might be confused with only one of the many symptoms of a brain tumour: pressure on the brain.	Thank you for your comment. We have made the appropriate amendment.
International Brain	170	See para 139 above.	We have revised this paragraph.

Tumour Alliance (IBTA)			
International Brain Tumour Alliance (IBTA)	172	The limitation of TMZ to recurrence has now been superseded by the results of the EORTC/NCI Phase III trial. Unlike other cancers the evaluation mechanisms for proposed new therapies do not seem to match the special challenges posed by HGG tumours, including the failure over the past 30 years of what has been regarded as standard therapy. Emerging new therapies often take more time to become legally approved and available. This inevitably results in brain tumour patients not being able to have quick access to these emerging new therapies because these patients don't have the luxury of time or periods of remission such as are experienced by patients with other types of cancer."	Thank you for this comment.
International Brain Tumour Alliance (IBTA)	190	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 will not add details about who to contact in out of hours emergency situations, as this implies that there should be specific services for these patients out of hours. We do not think this would be appropriate.
International Brain Tumour Alliance (IBTA)	195	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."	Thank you for this comment. We feel that this area fits more comfortably in the section on information for patients, para 336.
International Brain Tumour Alliance (IBTA)	204	See 172 above.	Thank you for this comment.
International Brain Tumour Alliance (IBTA)	267	Prognosis is usually very poor - relatively to other brain tumours, or absolutely?	We feel that the paragraph is appropriate as it stands.
International Brain Tumour Alliance (IBTA)	268	PCNSL tumours are usually quite responsive to steroids.	We have said that PCNSL tumours respond to steroids.
International Brain	323	Sentence should read: "Healthcare professionals should	Thank you for your comment. We have added 'carers' to this

Tumour Alliance (IBTA)		have face-to-face communication with patients and carers at critical or significant points in the care pathway to discuss diagnosis, prognosis, treatment options (including no treatment), recurrence and end-of-life care and any other matters.	paragraph but have not added ‘any other matters’.
International Brain Tumour Alliance (IBTA)	325	Add the word “carers” after both mentions of “patients”. Sentence should read: “Good communication will improve the experience for patients and carers and healthcare professionals throughout the patient pathway and ensure that, whenever possible, patients and carers can participate in the decision-making process.”	Thank you for your comment. We have amended the paragraph as appropriate.
International Brain Tumour Alliance (IBTA)	326	Suggest that communication skills training should encompass elements of how to relay distressing news to patients and carers in an appropriate manner.	This paragraph summarises the current available evidence.
International Brain Tumour Alliance (IBTA)	335	A website based in the USA www.virtualtrials.com is universally regarded by patients as containing some of the most up to date and comprehensive information for brain tumour patients and carers. The Yahoo e-mail discussion group for UK patients and carers, BTUK, provides a forum for support and information. See: http://groups.yahoo.com/group/btuk/	It is not appropriate for the guidance to recommend specific websites as we have no control over their content.
International Brain Tumour Alliance (IBTA)	336	Amend first sentence to read as follows: “Information material containing clear, accurate and relevant information about each CNS tumour type should be made available to patients and carers in a timely fashion.	We feel that ‘relevant’ is sufficient.
International Brain Tumour Alliance (IBTA)	346	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.”	Thank you for your comment. However, we do not feel the suggested sentence adds anything to the paragraph.
International Brain Tumour Alliance (IBTA)	348	Amend sentence to read: “Regular assessment of patients’ psychological needs and monitoring of cognitive and personality changes are an important part of their continuing	Thank you for your comment. We have amended the paragraph as appropriate.

		care, regardless of whether their brain tumours are benign, low grade or malignant.	
International Brain Tumour Alliance (IBTA)	352	Add the following sentence: "In addition, support should be made available to carers who may also require psychological support in order to sustain their role throughout the patient's pathway."	Thank you for your comment. We have amended the paragraph as appropriate.
International Brain Tumour Alliance (IBTA)	422	Amend the last sentence in this paragraph to read: "Consideration should be given to a secure web-based information system that will allow easy but safe data sharing across the service."	Point acknowledged and noted. We have revised the guidance to take account of data protection issues.
International Brain Tumour Alliance (IBTA)	430	Amend first sentence to read: "A secure web-based database and data collection system will enable members of the MDT…"	Point acknowledged and noted. We have revised the guidance to take account of data protection issues.
International Brain Tumour Alliance (IBTA)	434/D	Bullet point under "Structure". Amend sentence to read: "Compatible secure local, regional and, eventually national electronic information systems."	Thank you for this comment. We have amended this sentence as appropriate.
International Brain Tumour Alliance (IBTA)	438	Third dot point – see para 148 above.	Please see response to para 148 above.
International Brain Tumour Alliance (IBTA)	438	Fourth dot point – delete these words (in red): "There are (a) several (of) new radiotherapy techniques, new chemotherapy agents and methods of drug delivery…"	Thank you for your comment. We will revise accordingly.
International Brain Tumour Alliance (IBTA)	346	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."	Thank you for your comment. However, we do not feel the suggested sentence adds anything to the paragraph.
International Brain Tumour Alliance (IBTA)	348	Amend sentence to read: "Regular assessment of patients' psychological needs and monitoring of cognitive and personality changes are an important part of their continuing care, regardless of whether their brain tumours are benign, low grade or malignant.	Thank you for your comment. We have amended the paragraph as appropriate.
International Brain	352	Add the following sentence: "In addition, support should be	Thank you for your comment. We have amended the paragraph as

Tumour Alliance (IBTA)		made available to carers who may also require psychological support in order to sustain their role throughout the patient's pathway."	appropriate.
Joint Committee on Palliative Medicine		This organisation was approached but did not respond.	
Link Pharmaceuticals	*general*	It is unclear from the guidance whether the neuroscience MDT meets before or after surgical intervention to plan the management for individual patients. An MDT meeting post surgery misses the opportunity to consider intraoperative chemotherapy options.	We agree and we have made the appropriate amendments.
Link Pharmaceuticals	129	For the reasons given above, we suggest the following wording for this paragraph: There should be pre-operative discussion between the neurosurgeon, neuropathologist and neuroradiologist regarding the optimum approach to surgery, including the use of intraoperative chemotherapy if appropriate, and the processing of tissue specimens, including intraoperative histopathological evaluation.	Thank you for your comment. However, we will not be changing this paragraph.
Link Pharmaceuticals	169	We feel that the information contained within this paragraph is slightly out of date and should reflect the current situation. Suggested wording: The use of concomitant chemoradiotherapy and intraoperative chemotherapy implants has recently been assessed in clinical trials. A NICE technology appraisal is underway and guidance is anticipated in August 2006, the results of which should be incorporated into clinical protocols.	We feel that the wording concerning the NICE technology appraisal is appropriate for service guidance.
Link Pharmaceuticals	205	This paragraph should be amended to provide the same level of detail and comment as paragraph 204, which relates to temozolomide. In the UK, the accepted term for the dosage form is implant as opposed to wafer. Please see the pdf files attached to the e-mail for a reference supporting the additional information. Suggested wording: The use of slow release, local chemotherapy using biodegradable polymer implants (Gliadel) in the treatment of	Thank you for your comment. We will review the level of detail on research trials in the evidence sections during the second consultation period.

		newly-diagnosed high grade malignant glioma has been studied in two (well conducted) randomised, placebo-controlled, double-blind, phase III clinical trials. In the larger study (n=240) a median survival benefit of 2.3 months (hazard ratio 0.71, p=0.03) and a five-fold increase in 3-year survival (9.2% vs 1.7%) were demonstrated for those patients in the Gliadel treatment group. Gliadel has also been shown to be effective in the treatment of recurrent glioblastoma multiforme at the time of second surgery.	
Macmillan Cancer Relief	General	It is not clear if the Guidance was drafted with the involvement of people affected by brain and CNS tumours and their carers and families, and we would like to ensure that there are opportunities for them to participate in the development of the Guidance.	People affected by brain and CNS tumours were included within the GDG and their participation will be acknowledged in the second draft of the guidance.
Macmillan Cancer Relief	General	We believe that there is scope for the guidance to reflect the significant and central role of the Neuro-Oncology Clinical Nurse Specialist (CNS) in the care and management of these patients, carers and families. Overall we felt the pivotal role of the nurse specialist is played down, particularly in respect of the capacity of the CNS to meet what may be long-term needs of patients and their carers.	Thank you for your comment. This was discussed by the GDG. The guidance has been revised and the clinical nurse specialist is now one of the key recommendations to reflect the importance of their role.
Macmillan Cancer Relief	General	Brain tumours throughout the Draft Guidance are referred to as either “benign”, “malignant” or “uncertain”. Should all brain tumours be described as “benign, low grade, malignant or uncertain” throughout the Guidance?	Thank you for your comment. This was discussed by the GDG and we have made the appropriate amendments – tumours are now referred to as high or low grade
Macmillan Cancer Relief	Key Recommendations	The Nurse Specialist role should be reflected in the Key Recommendations.	Thank you for your comment. A key recommendation on clinical nurse specialists has been added to the second draft of the guidance manual
Macmillan Cancer Relief	7	Whilst we acknowledge the role of the Palliative Care Specialist, we would question their inclusion so high in the list of specialists, as many patients (especially those with low-grade tumours) may not need palliative care input in the initial stages of their disease. Patients who have low-grade, slow-growing tumours, with or	The GDG agreed that brain tumours are the majority of CNS tumours and that in general CNS tumours have a poor prognosis. The GDG also agreed that it is important to encourage closer collaboration with, earlier referral to, and utilisation of, specialist palliative care skills. The Key Recommendation supports and promotes these aims. The Palliative Care Specialist is already a member of the neuroscience brain and other CNS tumours MDT.

		without neurological deficits, do not come within the palliative care remit and receive little in the way of long term continued support except that provided by the specialist nurse. They may be followed up by surveillance imaging over years before tumour progression requires further intervention. This obviously has implications when looking at service needs.	The Palliative Care Specialist is not a core member in those rarer CNS tumour MDTs where the majority of patients have benign tumours and/or a long prognosis. Palliative care is not exclusive to cancer patients. Patients with low-grade long-term tumours have been identified as a group that lacks support from all professionals at the moment. We have tried to address this in the guidance. Within the GDG there was a clear process for deciding the key recommendations to be included in the final document and it is felt that this priority should remain.
Macmillan Cancer Relief	8	We suggest adding to the first sentence "... and has urgent access to an MRI to confirm the suspected diagnosis".	It is felt that MRI is not needed to confirm a diagnosis and not appropriate for this document. It is also clear in the key recommendations that the confirmation of the radiological diagnosis is confirmed by the MDT.
Macmillan Cancer Relief	22	We suggest adding to the last sentence "... particularly through support for both patient and their carer in what is often a short and intensely traumatic experience".	We do not intend to alter paragraph 22.
Macmillan Cancer Relief	64	We suggest adding to the end of this paragraph: "A delay of the magnitude of 8-12 weeks may involve a doubling of the size of a highly malignant brain tumour.", thus indicating that a waiting time of 8-12 weeks is not acceptable.	This comment is not appropriate for the background section.
Macmillan Cancer Relief	71	We suggest that an important factor of brain tumours is their potential to impair the patient's mental capacity, which adds a complication to treatment of these cancers which is absent from other cancers.	We feel that the mental capacity of the patient is covered in this background section. The bullet points have equal weighting. There is no intention of inferring priority.
Macmillan Cancer Relief	90	We suggest that it might be beneficial to involve a Consultant Neurologist and an Epilepsy Nurse more specifically as members of the neuroscience brain and other CNS tumours MDT. We believe their involvement should have a higher priority than they currently have as 'others as required' .	Thank you for this comment. The guidance has been revised and the neurologist is now a core member of the neuroscience MDT. However, the epilepsy nurse remains an extended member of the MDT
Macmillan Cancer	95	We would welcome clarification about the role of the 'key	We feel that cover for the key worker when absent from work will

Relief		worker', especially as it is suggested that it is a role which might be undertaken by a number of professionals during the course of someone's cancer experience. Consideration also needs to be given to how patients and carers can access key workers or an equivalent level of support out of hours or whilst the key worker is absent from work. Trusts must also be required to allocate sufficient resources to enable the delivery of this role.	be the same as cover for any other healthcare professional. We consider that key worker advice on non life-threatening issues should be available in regular hours.
Macmillan Cancer Relief	After 103	Under 'Structure', fifth bullet point: amend to read "Establishment of secure internet based database for central data collection."	Point acknowledged and noted. We have revised the guidance to take account of data protection issues.
Macmillan Cancer Relief	165	We suggest that this paragraph is reworded to reflect the needs of those patients with rapidly growing tumours or significant symptoms, for example "…although there may be some patients with rapidly growing tumours or significant or worsening symptoms of a physical or psychological nature who will need treatment much more quickly." Use of the words "pressing symptoms" might be confused with only one of the many symptoms of a brain tumour (pressure on the brain).	Thank you for your comment. We have made the appropriate amendment.
Macmillan Cancer Relief	190	We recommend that patients are carers are also provided with information about out-of-hours emergency contacts.	We will not add details about who to contact in out of hours emergency situations as this implies that there should be specific services for these patients out of hours. We do not think this would be appropriate.
Macmillan Cancer Relief	316	Social care and information professionals also have a role in providing supportive care, not just healthcare professionals. We are pleased to see recognition of the value of the NICE Supportive and Palliative Care Guidance, but feel that this section could be greatly strengthened to reflect the importance of this type of support. We attach a copy of the leaflet for the public which sets out the range of support needs which patients and their carers and families have. The core elements of supportive care which we would like to see reflected in this guidance comprise: • Involvement of patients and carers in decisions about	We have cross-referred to the NICE Supportive and Palliative Care guidance and feel this is sufficient. We have described additional services for this group of patients.

		treatment and care - Clear communication between patients, carers and health and social care professionals - Clear communication between the professionals providing care to patients - Guidance and advice about the support which is available to patients and their carers and families - Information which is comprehensive, timely and appropriate to patients' and carers' needs - Recognition of the importance of social and practical needs and how these can be met - Recognition of the importance of emotional and spiritual needs - Help with living with the effects of cancer and its treatment - Help for carers and families - Services which are responsive to individual needs and readily available - Support to enable people to die in their preferred place of dying - An opportunity for patients and carers to be involved in improving cancer services	
Macmillan Cancer Relief	319	All professionals involved in the provision of supportive care also need to know how to signpost patients and carers to information about statutory benefits and how their practical and social needs can be met. There may well be financial hardship as the symptoms of the brain tumour may affect the patient's ability to continue to earn a living, or require a carer to give up work to care for the patient.	We feel that we have covered this area in para 341. However, we are mindful that we cannot make recommendations for organisations outside the NHS.
Macmillan Cancer Relief	323	We would strongly recommend that healthcare professionals have face-to-face communication with patients and carers at whatever times the patients and carers deem to be necessary, not just at 'critical' times. We would also like patients and carers to be able to raise whatever issues are of concern to them, so would recommend that the end of the	Thank you for your comment. We have added 'carers' to this paragraph but have not added 'any other matters'.

		sentence is amended to read: "…recurrence, end-of-life care and any other matters."	
Macmillan Cancer Relief	325	It is important that the needs of carers are also met, and we therefore recommend amending the sentence to read: "Good communication will improve the experience for patients and carers and healthcare professionals throughout the patient pathway and ensure that, whenever possible, patients and carers can participate in the decision-making process."	Thank you for your comment. We have amended the paragraph as appropriate.
Macmillan Cancer Relief	326	We recommend that that communication skills training should encompass elements of how to relay distressing news to patients and carers in an appropriate manner.	This paragraph summarises the current available evidence.
Macmillan Cancer Relief	335	A website based in the USA www.virtualtrials.com is universally regarded by patients as containing some of the most up to date and comprehensive information for brain tumour patients and carers. The Yahoo e-mail discussion group for UK patients and carers, BTUK, provides a forum for support and information. See: http://groups.yahoo.com/group/btuk/	It is not appropriate for the guidance to recommend specific websites, as we have no control over their content.
Macmillan Cancer Relief	336	We would like to suggest that this information is provided at a time appropriate to patients and carers and that it is supplemented with verbal follow-up with healthcare professionals if desired by the patient and/or carer.	We feel that 'relevant' is sufficient.
Macmillan Cancer Relief	346	We suggest amending this 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."	Thank you for your comment. However, we do not feel the suggested sentence adds anything to the paragraph.
Macmillan Cancer Relief	348	Amend sentence to read: "Regular assessment of patients' psychological needs and monitoring of cognitive and personality changes are an important part of their continuing care.	Thank you for your comment. We have amended the paragraph as appropriate.

Macmillan Cancer Relief	352	We would also like to see the needs of carers reflected in this section. We therefore suggest an additional sentence, for example: "In addition, support should be made available to carers who may also require psychological support in order to sustain their role throughout the patient's pathway."	Thank you for your comment. We have amended the paragraph as appropriate.
Macmillan Cancer Relief	422, 430 and 434(D)	We would like to repeat the necessity of data collection systems to be secure, and suggest amending the relevant sentences as follows: "Consideration should be given to a secure web-based information system that will allow easy but safe data sharing across the service." (422); "A secure web-based database and data collection system will enable members of the MDT…" (430); and "Compatible secure local, regional and, eventually national electronic information systems." (434(D)	Point acknowledged and noted. We have revised the guidance to take account of data protection issues.
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 but e.g. 375	Lack of clarity on 'commissioners' – specialist, PCT, cancer network commissioning group or all 3?	Because of the changing position of specialist commissioners, PCTs and cancer network commissioning groups, there seems to be no alternative for the GDG other than to use a generic term of commissioners in this regard.
National Cancer Network Clinical	55	Complex mapping re NSUs and networks recognised, but big issue- should all NSUs do brain and CNS cancers is not	The question of whether all neurosurgical units should do brain and CNS cancer work is acknowledged. Within the document

Directors Group		tackled	there are clear definitions of specialist teams, including neuropathology, on-site neuropathology, and two neurosurgeons on the core team committing more than 50% of their time to this work. These definitions automatically result in some units being unable to fulfil the criteria and continue with brain and CNS cancer work.
National Cancer Network Clinical Directors Group	74	Core time for MDTs is crucial	We agree with this comment.
National Cancer Network Clinical Directors Group	78	2 surgeons as core members- how many attend each MDT?	Attendance at each MDT will be as defined in the Manual of Cancer Services measures. However, the GDG will be reinforcing the message of attendance at MDT meetings.
National Cancer Network Clinical Directors Group	85–7 Box 1	Who should be Trust lead- radiologist for initial diagnosis or neurologist for ongoing care?	We feel that the definition of the designated lead is quite clear enough.
National Cancer Network Clinical Directors Group	90–97	The requirement for 2 MDTs is complex. We believe we could make it work in Sussex but this will vary between CNs and NSUs and whether co-located. Are all these team members really required at both meetings? Need to recognise emergency nature of surgery for many of these tumours, so some NSMDMs will be retrospective.	The requirement for two MDTs is essential because of their different roles and responsibilities. Where they are co-located, clearly membership will overlap. We have revised the guidance recognising the emergency nature of surgery for some patients.
National Cancer Network Clinical Directors Group	96	Evidence for requirement for 5-15 new cancers per month per MDT?	Five to fifteen new cancers per month per MDT was considered to be the likely incidence of cancers per cancer network.
National Cancer Network Clinical Directors Group	97 (Box 3, p. 39)	'Specialist neurosurgeon who spends at least 50% of their clinical programmed activities in neuro-oncological surgery' - there are likely to be very few of these in the UK Specialist palliative care is a scarce resource and coverage of MDTs is challenging- why need for sp pall care presence at initial surgical MDT?- even less community nursing input, given wide area covered by NSU- see also paras 405-11	The GDG considers both of these issues to be very important and the guidance should stand.
National Cancer Network Clinical Directors Group	98 (p. 45)	Timescales for communication between MDTs in Box 6 are far too prescriptive when many patients present are treated as emergency referrals	We feel that the timescales are an important standard, we have revised the guidance elsewhere to take account of patients who may require emergency treatment.
National Cancer	102	Recognises there is no evidence for above	Thank you for your comment.

Network Clinical Directors Group		recommendations!	
National Cancer Network Clinical Directors Group	103 (page 48)	'Evidence that MDTs audit individual clinicians actions against MDT decisions' – This is totally impractical and questions responsibility for treatment.	We feel that MDTs should audit treatment interventions against MDT decisions and have revised this sentence accordingly. The mechanism for recording this will be through data collection at the MDT meeting.
National Cancer Network Clinical Directors Group	151 (page 61 and others)	In 'outcome' ' Patient and Carer satisfaction' is mentioned a number of times with no guidance as to what this means	We would be very grateful to receive further guidance on patient and carer satisfaction.
National Cancer Network Clinical Directors Group	216 (page73)	Hospital Case Volume - comparisons with the US system are not appropriate as case volumes have a very different distribution to UK	We note this comment. However, we have included US research data elsewhere in the document.
National Cancer Network Clinical Directors Group	231	No guidance given on population base or national number of dedicated specialist MDTs for rarer CNS tumours- eg box 10' dedicated time to skull base tumours'	No guidance has been given on population base or national number of dedicated teams. This is because we have carefully defined membership of these specialist MDTs and feel that this will ultimately determine their number. This will require collaboration of commissioners as is included in our recommendations.
National Cancer Network Clinical Directors Group	240 (page 86)	on Intra-dural spinal cord tumours principles of care the statement 'Intra-operative neuro-physiological recording helps to identify and therefore preserve normal spinal cord and should be available' is unreferenced and unsubstantiated.	Thank you for your comment. We will check the evidence and revise the paragraph as appropriate during the second consultation period.
National Cancer Network Clinical Directors Group	282, c.f. 238 Box 8, etc.	The radiotherapy recommendations re cranio-spinal treatments seem inconsistant to me. If it's for medulloblastoma the IOG says this must be done in a centre that treats paediatric medullo patients - but doesn't specify that the oncologist must treat kids as well as adults.For other indications (some equally as rare) this isn't specified. If there is real concern over the physics / planning aspects and evidence that this is warrented then it should apply to all patients. Similarly, the appropriate level of provision of super- specialised oncology needs to be defined	Thank you for your comment. We will discuss these paragraphs with the GDG and address any amendments during the second consultation period.
National Cancer Network Clinical	372–373	Is this feasible?	The point we are trying to make in these sections is that patients should have access to these services.

Directors Group			
National Cancer Network Clinical Directors Group	405–411	See above	We recognise that the recommendations will require additional resources but stand by them.
National Cancer Network Clinical Directors Group	417–429	Info requirements challenging without C4H!	We recognise these are challenging requirements but we stand by them.
National Patient Safety Agency		This organisation was approached but did not respond.	
National Public Health Service – Wales		This organisation was approached but did not respond.	
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	In general this is a commendable attempt at improving quality of care.	Thank you for your comment.
Royal College of General Practitioners	General	There are two general points I wish to make.	Thank you for your comment
Royal College of General Practitioners		1 It is not clear whether the neurosurgeons who will be looking after patients will be members of the MDT. Page 30 point 78 implies that 2 will be core members but others need not be, but must be members, but may not attend. This could mean that the surgeon attending the MDT may not have seen the patient, and indeed, neither the radiologist nor pathologist need have seen the patient. The recommendation in point 78 seems to apply only to neurosurgeons specialising in tumours. Non-specialist neurosurgeons also operate on brain tumours, and indeed as pointed out in the evidence section, there is no evidence that they perform worse for common types of tumour. The issues are therefore: What is the value of an MDT where none of the major contributors have or ever will see the patient? See point 114. Will there be a mechanism to enforce MDT decisions on those clinicians looking after the patient but not present at the MDT? The lack of clarity may have been avoided if, in the introduction, the problem for which the MDT is the solution had been better clarified.	1. Part 1 was discussed at GDG meeting. It is the intention of the GDG that there will be two core neurosurgical members of the neuroscience MDT. Their role is to define protocols and advise on management of the majority of patients. However, there will be occasions when for instance patients managed in an emergency will have been operated on by neurosurgeons other than core members. In this instance it would be expected that the neurosurgeon would present the case to the MDT. With regard to the value of the MDT, where none of the major contributors have ever seen the patient it is acknowledged that by registering all patients through the MDT and advising on their management plan (in the presence of adequate clinical information) an audit trail will exist and protocol-driven management will be the norm. There is, of course, no method of enforcing MDT decisions. This is true for brain and other CNS tumours and in other IOGs similar MDT-based decisions. However, by introducing a process of decision-making through MDTs and strict audit the standard management of patients will evolve over a period of time as has happened in more common malignancies.

		2 There is a neglect of the role/importance of general practice. GP's are still the focus/keyworkers of general practice. They are the only professional who has a lifelong duty of care for any patient, and they are skilled in supportive care, counselling, coordination, referral as well as the straightforward diagnostic and treatment skills. Examples:	2. Thank you for your comment. Nothing in this guidance is meant to negate the important role of primary care in the management and continuing care of all patients and their carers. However, we wish to: 1. Highlight their important role in diagnosis and referral; 2. Avoid giving explicit duties to GPs in circumstances in which only a few of them would wish to have them bestowed; 3. Avoid giving responsibilities to GPs for coordination in circumstances when they usually will not have appropriate relationships with regional and supra-regional services.
Royal College of General Practitioners	Point 45	final sentence, GP's not mentioned	The phrase 'healthcare professional' encompasses general practitioners and others.
Royal College of General Practitioners	Point 54	This unreasonably downplays the role of GP's: it is true that primary tumours are rare, but it is pointed out elsewhere that 20-40% of cancers have cerebral mets- so this could amount to 10 times the incidence of primary tumours. Since the symptomatology of primary and secondary tumours is similar, GP's and phcts have indeed reasonable experience	The wording of paragraph 54 is felt to emphasise the importance of the primary healthcare team as it stands. There are specialist requirements and access to specialist services are acknowledged, but they are in their proper context and the wording does not need to be changed.
Royal College of General Practitioners	Point 76	GP's not mentioned in relation to rehab, supportive and palliative care near the patient's home	We feel that it is not appropriate to specifically mention GPs in the section.
Royal College of General Practitioners	Point 95	I accept that G.P. mentioned here	Thank you for your comment.
Royal College of General Practitioners	Page 37	Key worker is a contentious issue. Each PHCT determines its policy and it wouldn't be true that the key worker in the community would necessarily normally be a nurse	Thank you for your comment.
Royal College of General Practitioners	Point 364	Here complimentary therapists and chaplains are included but not GP's	We will be grateful if you would clarify the role of the GP in the provision of rehabilitation services.
Royal College of General Practitioners	Point 385	Palliative care isn't a small part of the workload of GP's- after all every patient dies, and about a quarter from cancer.	This paragraph provides factual information about the rarity of CNS tumours. It acknowledges that GPs and other healthcare

		In any case, just because something is infrequent doesn't mean that specialist care is needed.	professionals deliver the majority of care but it does not imply that this responsibility should be taken away from them. It raises awareness of and signposts the way to specialist palliative care services.
Royal College of General Practitioners	Point 401	The care can also be provided in the G.P. surgery	The sentence referred to here describes the different settings in which continuing care is provided not the service provider.
Royal College of General Practitioners	Other points	There are suggestions for many audits: it would be important that there are national templates for the audits so that the performance of different units can be compared more accurately	Thank you for your comment. National templates for audits are beyond our remit. We would welcome RCGP's support to include such measures within the Quality and Outcomes Framework.
Royal College of General Practitioners	Point 112	This is unclear: is the tumour really identified from the Gap's request, or from the investigation resulting from it? Is it proposed to fast-track the investigation or alternatively to make an early appointment with the specialist?	Thank you for this comment. The guidance has been revised accordingly.
Royal College of General Practitioners	Page 53	Ensure that imaging delay audits are split so that G.P. referrals can be separated out	Your comment is acknowledged and the guidance has been revised accordingly.
Royal College of General Practitioners	Point 186	I don't think that the hospital key worker is the point of contact for GP's. Normally I wish to speak to whoever saw the patient in the recent outpatients, or the consultant when I wish to communicate clinically important news/seek advice on a complicated problem.	We acknowledge that the key worker is not the only point of contact for the GP.
Royal College of General Practitioners	Point 332	A dedicated information lead would be nice, but is it really intended that this is a full post? It would be achievable if the post-holder also gave information on other tumours. If information officers had to be appointed for each tumour group, then my network would have to employ 10 times more. If the officers were employed on the basis of the number of patients affected by the tumour, then the figures would be even higher since brain tumours are relatively rare compared with breast, lung etc.	We do not feel this should be a full-time post and therefore do not say so.
Royal College of General Practitioners	Point 388	This may be true, but a basic principle of good palliative care is anticipation, so that place of care can be identified at an early stage.	This paragraph reflects the fact that patients do not always wish to address end of life care or placement issues at an early stage. Patients' preferred place of care may also change or not be feasible due to cognitive impairment, personality changes, etc.
Royal College of	Point 16	Not all networks take part in all trials. Patients with specific	There is currently a website available with all national accredited

General Practitioners		conditions may not have access or information about the trials. Patients may be willing to travel to more distant centres to take part in trials. There is therefore an issue of where the patient/G.P. can obtain information about trials outside the network. A national website containing data on what trials are available where should be made available. This would also help populate trials.	trials through the NCRN including information on centres participating. We feel that this fulfils the requirements as requested through this comment.
Royal College of General Practitioners Wales		This organisation was approached but did not respond.	
Royal College of Nursing (RCN)	88	Welcome the recognition that there should be a member of the MDT who is responsible for obtaining scans, notes etc, however, we feel that stronger emphasis should be placed on this, in particular the practicalities of obtaining records within an appropriate time scale in order to optimise the efficiency with which support is delivered.	We think that the emphasis is made in Box 6 within the communication framework and will make reference to this in the document.
Royal College of Nursing (RCN)	95	Welcome the recognition that the key worker is not automatically presumed to be the clinical nurse specialist and could be another member of the MDT who is more suited to a particular patient.	Thank you for the comment.
Royal College of Nursing (RCN)	321 and 327	Important to ensure that patient is told of diagnosis in private, comfortable environment with adequate support from key worker and with relatives in attendance if the patient wishes them to be.	Thank you for your comment.
Royal College of Nursing (RCN)	317	Must also recognise the needs of carers and family members who can often feel isolated and powerless.	We feel that the opening statement in paragraph 316 adequately covers this.
Royal College of Nursing (RCN)	334	How will information be assessed as high quality and appropriate? The Centre for Health Information Quality (CHIQ) which did provide a quality standard triangle mark no longer exists.	This comment applies to all tumours. We would welcome advice from the RCN on this topic.
Royal College of Nursing (RCN)	335	National organisations and websites must be regularly reviewed in order to ensure accuracy and relevancy, who will do this?	This comment applies to all tumour sites and is not the remit of the guidance.
Royal College of Nursing (RCN)	General	Overall this guidance will be very helpful in co-coordinating care and increasing the support that CNS tumour patients	Agreed.

		and their families receive. However, it is the responsibility of each NHS trust to implement the guidelines and ensure that minimal provision has been made for regular auditing to ensure that services are delivered in accordance with the guidance.	
Royal College of Paediatrics and Child Health	General	We are aware of the more detailed response from UKCCSG submitted to NICE on behalf of Cancer Research UK. The RCPCH shares their concerns about the need to: 1. include some guidance on liaison between children's and adults' services; 2. include some guidance on the needs of adolescents and young adults; 3. mention the specific tumours they refer to; and 4. consider age stratification in some of the guidance.	It is explicit in this document that the guidance refers to adult services. For this reason these comments do not relate to this guidance although where relevant cross-reference has been made to the Children and Young People with Cancer guidance and we feel that this is more appropriate covered within this document. The UKCCSG submission has not been received to date.
Royal College of Pathologists	20	It may be helpful to include a little more information about the distinction between benign and malignant tumours as this applies to the central nervous system, where the criteria are not nearly as clear-cut as they are for tumours in most other parts of the body. Benign tumours outside of the CNS are generally characterised by expansile growth and an absence of distant metastases, and malignant tumours by infiltrative growth and a propensity to metastasise. In the CNS most benign tumours show infiltrative rather than expansile growth, and some metastasise along cerebrospinal fluid pathways. Most malignant tumours CNS tumours kill as a result of local spread rather than metastasis.	Thank you for your comment. This was discussed by the GDG and the malignant/benign tumour description has been amended.
Royal College of Pathologists	139	As most of these techniques are best performed on unfixed tumour tissue, I suggest that the guidelines should emphasise the desirability of freezing a sample of fresh (unfixed) tumour tissue at the time of initial biopsy, whenever possible without compromising patient safety or diagnostic accuracy.	Thank you for your comment. We feel that we have reinforced this in paragraph 446.
Royal College of Pathologists	274	I agree that for pathological assessment of CNS tumours it is important to have a neuropathology service on-site,	We think that we have made it clear that the lymphoreticular pathology service does not have to be on site.

		particularly for intra-operative diagnosis. However, the need for an on-site service for CNS tumours does not apply to specialist lymphoreticular pathology. At present, this is not entirely clear in the guidance. It would be helpful to note that specialist lymphoreticular pathology services need not necessarily be provided on site, provided that they are readily accessible through a local pathology network.	
Royal College of Pathologists	General	This first draft still includes quite a number of typographical and grammatical errors (e.g. in table 5, box 3, paragraph 109, paragraph 199, paragraph 202, paragraph 209 and several others).	Thank you for your comment. We will make the appropriate amendments.
Royal College of Physicians of London and ABN – joint response	General	A generally comprehensive and thorough document. Congratulations!	Thank you for your comments.
Royal College of Physicians of London and ABN – joint response	General	Resource implications are substantial and not quantified	Thank you for your comment – this will be covered in the second draft.
Royal College of Physicians of London and ABN – joint response	General	Our Stakeholder Panel was struck by the relative paucity of commentary on the involvement of neurologists. There are some centres in the UK where there is a neurologist with a special interest (e.g. neuro-oncologist) involved in the MDT, and others where a nominated neurologist deals with the common problem of epilepsy. There is a desire to develop these roles for neurologists and this should be recognised in the text and in Box 3. This is important because audits have shown that epilepsy is not well managed in people with brain tumour, and the input of expert neurologists should be encouraged. It is also important to write into the guidance appropriate comments concerning neurologists at diagnosis. Many patients with brain tumour first present to a neurologist who will establish the diagnosis and discuss this with the patient	Thank you for your comment. This was discussed by the GDG, the guidance has been revised and the neurologist is now a core member of the neuroscience MDT. Thank you for your comments. This will be discussed by the GDG and addressed during the second consultation period.

		and family before referral to the neurosurgeon/MDT.	
Royal College of Physicians of London and ABN – joint response		XXX is a member of the ABN/RCP Stakeholder Panel and he has made a number of comments sent separately, as copied below. So as to avoid duplication, the ABN/RCP Panel with the permission of XXX would like to associate themselves with most of these observations, with some reservations about his comments on Point 39 .	Thank you for your comments.
Royal College of Physicians of London and ABN – joint response	General	Role of neuroscience MDT and cancer network MDT seems blurred and basically determined by local resources and in particular availability of neurosurgeons and oncologists on one site. May not be applicable to a number of neuroscience centres where oncologists work side by side with neurosurgeons	Paragraph 82 in the guidance covers this issue. Where appropriate it is acknowledged that all care may be coordinated and delivered in one location but that this is not the case in some geographical areas within the country.
Royal College of Physicians of London and ABN – joint response	7	While the idea of palliative care practitioners attending MDTs is a good one, I think it will be unrealistic to expect them to be present at all MDTs. Many palliative care practitioners do not work in hospitals and are based at hospices. In our MDT, the Clinical Nurse Specialist acts as liaison between the neurosurgery or oncology team and the palliative care service.	The GDG acknowledge this. However the GDG agreed to put what is *needed* in the guidance, so as to stimulate commissioning and support specialties in obtaining extra resources.
Royal College of Physicians of London and ABN – joint response	10	It is not always possible in emergency situations to discuss the case preoperatively as most MDTs occur weekly or fortnightly. Furthermore I do not believe that the surgeon's decisions should be over-ruled by an MDT where the patient has not been seen by other members.	This issue has been addressed by rewording paragraph 91 to take into consideration the patients presenting as an emergency needing urgent intervention. The MDT cannot overrule a decision. But if the surgeon decides to act contrary to their advice then he may find himself exposed if things go wrong. It is his decision.
Royal College of Physicians of London and ABN – joint response	Table 5	Typo: Should be glial hamartomata not hamartia	Thank you for your comment. We have made the appropriate change.
Royal College of Physicians of London and ABN – joint response	39	Better to subdivide presentation into headache with raised intracranial pressure, epilepsy, progressive neurological deficit including cranial nerve palsies, mental state changes (rarely associated with headache) and an increasingly important group, the incidental finding in patients scanned for headaches e.g. migraine and tension headache	Thank you for your comment. This will be discussed with the GDG and addressed during the second consultation period.

Royal College of Physicians of London and ABN – joint response	40	Disagree. In Thomas and McKeran's series this accounted for only 16% of presentations and in a more recent series (Grant 2004 Your Ref 27), only 1.6% had a personality problem as a presenting symptom	Thank you for your comment. The Grant paper (reference 27) shows that behavioural changes as a *first* symptom is rare (1.6%). However, by hospital presentation they are quite common and virtually always associated with headache. We feel that this paragraph should remain unchanged
Royal College of Physicians of London and ABN – joint response	49	Use vestibular instead of acoustic to maintain consistency	Thank you for your comment. We have made the appropriate changes.
Royal College of Physicians of London and ABN – joint response	Reference 27	Neurosurgery and Psychiatry is part of the journal title	Thank you for your comment. This will be amended in the second consultation period.
Royal College of Physicians of London and ABN – joint response	72	'brain gliomas' is a tautology – suspect you mean malignant gliomas	Brain gliomas is not a tautology as gliomas can also occur in the spine.
Royal College of Physicians of London and ABN – joint response	89	Regarding the responsibility of the lead clinician, it is not realistic to expect him/her to know which of his/her colleagues have requested imaging on a patient which has subsequently turned out to have a tumour. I am a lead clinician yet I cannot know which of my colleagues have recently diagnosed a tumour case until that patient is referred into the MDT usually via neurosurgery	Thank you for this comment. We have revised this comment to so that it is not an individual responsibility but rather to ensure that processes are in place.
Royal College of Physicians of London and ABN – joint response	91	Not sure how the cancer network MDT, which in our network is primarily an administrative body, would be involved with individual patient management. Suggest that it should be the responsibility of the responsible clinician to refer the patient back to the neuroscience MDT at relapse. An MDT cannot take responsibility for individual patients	Thank you for your comment. We suggest that you review Box 4.
Royal College of Physicians of London and ABN – joint response	95	This seems contradictory – if the Key Worker is likely to be CNS or AHP, then why include neurologist, neurosurgeon etc. In practice it is unlikely to be one of the medical team as they often only contribute to the patients care at certain points in the pathway	The neurologist and neurosurgeon were included because there are occasions when they will be the key workers.

Royal College of Physicians of London and ABN – joint response	Box 3	I am a Consultant Neurologist and a Lead Clinician for Neuro-oncology.There is a great deal to be said for increasing neurology involvement in MDTs particularly as many patients with CNS tumours are originally referred to the neurologist and many of their ongoing problems e.g. epilepsy, neurological deficit are managed better by a neurologist than an oncologist or neurosurgeon. I believe there is a case to be made for nominating one or two consultant neurologists to each neuroscience MDT	Thank you for your comment. The guidance has been revised and the neurologist is now a core member of both the neuroscience MDT and cancer network MDT.
Royal College of Physicians of London and ABN – joint response	Box 6	These timelines seem too harsh and are unrealistic. There is often no way that a patient can be seen and communicated their diagnosis and management plan within a working week let alone one working day. Also it may not be clinically relevant particularly for low-grade gliomas or benign tumour with long natural histories	We do not feel the timescales are too harsh or unrealistic and stand by them.
Royal College of Physicians of London and ABN – joint response	112, 113	The responsibility for informing the GP or hospital clinician that a scan is suspicious for brain tumour should be with the reporting radiologist who has all the information rather than the lead clinician of the Trust who may be working in a different building and department.	Thank you for your comment. The paragraph has been amended accordingly.
Royal College of Physicians of London and ABN – joint response	115	Emphasises the need for a neurologist to be a core member of the neuroscience MDT	Thank you for your comment. The guidance has been revised and the neurologist is now a core member of both the neuroscience MDT and cancer network MDT.
Royal College of Physicians of London and ABN – joint response	146	There is such limited availability of PET that it should only be mentioned as an ancillary investigation in a few centres. It cannot become a nationally available resource and there is not enough evidence to support its widespread adoption in neuro-oncology	This paragraph summarises the current available evidence.
Royal College of Physicians of London and ABN – joint response	147	Risk of stereotactic biopsy quoted here (4% permanent morbidity) is higher than we quote (1-2%)	If the RCP/ABN send us their data, we will assess them and possibly include them in the evidence.
Royal College of Physicians of London	151	Typo temozolomide not temozolimide	Thank you for your comment. We will make the appropriate amendment.

and ABN – joint response			
Royal College of Physicians of London and ABN – joint response	158	Low-grade gliomas are often not initially biopsied as their management may be surveillance for many years. Should rephrase "All patients need to have a confirmed histopathological diagnosis…" to "All patients need to have adequate discussion at the neuroscience MDT about the pros and cons of biopsy/resection versus watch-and-wait"	The GDG have given considerable consideration to this particular sentence and feel that further revision is not appropriate.
Royal College of Physicians of London and ABN – joint response	165	Not clear what point is being made here. Figures seem unrealistic e.g. time to radiotherapy treatment may be 8-12 weeks in some centres	We agree these are indeed challenging targets.
Royal College of Physicians of London and ABN – joint response	172	Need to mention BR12 trial comparing PCV against temozolomide in patients with malignant glioma at first relapse	It is not appropriate to mention this specific trial.
Royal College of Physicians of London and ABN – joint response	198	This whole paragraph is misleading and inaccurate – there is no good quality evidence linking extent of resection with survival, early radiotherapy prolongs progression-free survival but not overall survival and there is no clear evidence that early radiotherapy is associated with a higher risk of late radiation damage compared with delayed radiation therapy. This has never been looked at principally because patients treated with delayed radiotherapy usually have low grade glioma that have undergone malignant transformation and therefore have a significantly reduced life expectancy.	This paragraph summarises the current available evidence. We agree there is no good quality evidence.
Royal College of Physicians of London and ABN – joint response	199	As with low-grade gliomas no clear evidence to link extent of resection with prolonged survival in malignant gliomas. That is why there is such a variation in neurosurgical practice across the country. The main and undisputed indications for surgery in malignant glioma is relief of intracranial pressure and tissue diagnosis.	This paragraph summarises the current available evidence. We agree there is no clear evidence to link extent of resection with prolonged survival.

Royal College of Psychiatrists	Box 3	Although paragraph 13 acknowledges that patients should have ready access to specialist neuropsychiatric services, the membership of "extended MDT" does not include psychiatry/neuropsychiatry.	Thank you for your comment. The guidance has been appropriately amended.
Royal College of Psychiatrists	Box 5	Although paragraph 13 acknowledges that patients should have ready access to specialist neuropsychiatric services, the membership of "extended MDT" does not include psychiatry/neuropsychiatry.	Thank you for your comment. The paragraph has been amended appropriately.
Royal College of Psychiatrists	22	Although this paragraph acknowledges cognitive dysfunction to be a problem and notes that this may lead to the need for "psychological, social and physical support", it is also the case that cognitive dysfunction may require psychiatric intervention, possibly for the management of depression arising from a realisation of cognitive decline.	It is felt that this point is covered within the document under paragraph 350, but psychiatry will be added to paragraph 22 in addition.
Royal College of Psychiatrists	347	I suggest that the nature of the expertise of neuropsychiatrists be further specified by the introduction of the text "in the context of organic brain disease", such that paragraph 347 would now read "therefore clinical psychologists, neuropsychologists with specialist training and expertise in the assessment and management of cognitive and personality change and neuropsychiatrists with specialist training and expertise in the management of patients with severe mental health problems in the context of organic brain disease, have a key contribution to the care of patients with CNS tumours".	Thank you for your comment. We have amended the paragraph accordingly.
Royal College of Radiologists		This organisation was approached but did not respond.	
Royal College of Speech and Language Therapists	General	Overal,l we welcome this guidance, which we consider will be very helpful to commissioners and service providers for this client group. However, whilst we appreciate it is not the remit of the guidance to focus on resources, we are concerned that the considerable issues that the level of resourcing needed for the implementation of the recommendations to ensure an adequately trained and	We feel the recommendations are based on what we feel we should be achieved for these patients. We acknowledge the fact that this is not the job of the guidance to focus on resources.

		experienced workforce may be prohibitive to the delivery of the quality of services this guidance seeks to promote for all the patients of this relatively small client group.	
Royal College of Speech and Language Therapists	General	Throughout the document please use the term 'speech and language therapy' when referring to the profession and 'speech and language therapist' when referring to the practitioner and not the terms speech therapy or speech therapist.'	Thank you for your comment. The appropriate changes have been made to the guidance.
Royal College of Speech and Language Therapists	General	Where the document refers to 'speech and language problems' we suggest "and swallowing" is added	Thank you for your comment. The appropriate changes have been made to the guidance.
Royal College of Speech and Language Therapists	P. 5, para 13 and throughout	There are many references made to changes in cognition. We suggest that aphasia is specifically mentioned as the patients may be trying to make sense of their diagnosis & treatment management by the very modality that is impaired i.e. language.	It is felt that these issues are dealt with paragraphs 321, 361 and 363 and it is not necessary to be more explicit than has already been indicated in the document. It is outside the remit of the guidance to indicate explicit funding.
Royal College of Speech and Language Therapists	Paras 13, 42, 80, 192 and throughout	We welcome the acknowledgment that patients may have speech and language problems, the references to AHPs and their contribution to patient care, and the strong emphasis on multidisciplinary working. Given patients' potential for speech and language problems, it is essential that speech and language therapy is one of the key AHPs within the multidisciplinary team to guide the management of patients communication problems and to advise members of the multidisciplinary team and others on strategies etc. to facilitate communication between the patient and professionals etc. throughout the patients journey.	We believe this has been addressed by the identification of speech and language therapy both in the neurosciences and the cancer network core MDT membership under specialist AHP.
Royal College of	P. 5, para	We recommend mention is made of communication aids	It is felt that these issues are dealt with paragraphs 321, 361 and

Speech and Language Therapists	14 and throughout the document	where access to specialist equipment is mentioned. These are being used more often primarily for patients with speech (e.g. person with medulloblastoma) rather than language problems. However, the determination of the appropriacy and provision of a communication aid should always be based on a thorough assessment and discussion with the patient. Funding of equipment is consistently an ongoing issue, and we welcome guidance on how this will be addressed. If a multi-agency approach is recommended we hope there will be clear guidance about who has responsibility to fund to avoid wasted time and effort in trying to identify who is responsible often at a cost to patient care and well being.	363 and it is not necessary to be more explicit than has already been indicated in the document. It is outside the remit of the guidance to indicate explicit funding.
Royal College of Speech and Language Therapists	P. 23, para 62	We are pleased to note that the issues of resourcing have been highlighted and look forward to the second consultation where they are to be considered.	Thank you for your comment.
Royal College of Speech and Language Therapists	Para 74	We agree with this paragraph, but suggest that additionally there is often the need for pre-operative and post-operative assessment by the multidisciplinary team. This is not explicitly stated in paragraph 80 although the term “ all stages” is incuded	We feel that the paragraph does in fact include pre-operative and post-operative assessment and further clarification is not necessary.
Royal College of Speech and Language Therapists	Paras 76, 77	We are in agreement that services need to be provided as close as possible to patients’ homes. We suggest however that account also needs to taken of patient choice /preference for where their on going treatment is provided. We would also wish to note that service provision as close as possible to the patient’s home may not be possible without significant resource allocation for small professional groups such as speech and language therapists, as well as other AHP professions, who may be experiencing retention and recruitment difficulties as well as other competing priorities across the client groups they provide services to.	We do not that it is appropriate to make reference to patient choice in this background section. Noted. Noted.

		Also the time to 'grow' specialists may delay the provision of the required / desired service. This is mentioned in para 77 in relation to neurosurgeons, but we suggest this will be a key concern across the majority, if not all professional groups working with the client group.	
Royal College of Speech and Language Therapists	P. 45, para 98	We welcome guidance on expected timescales and are pleased that they are set to demonstrate the speed of response required. However, we have serious concerns about how realistically they can be implemented especially if there are staff shortages due to recruitment or insufficiently trained staff.	We acknowledge this comment. However, we feel that it is an important standard to work towards.
Royal College of Speech and Language Therapists	P. 49, para 104 onwards and throughout	Early referral is essential. High grade tumours usually indicate a poor prognosis. Ongoing impairment based therapy may not be appropriate but information about communication, practical strategies for patients & their carers is vital. Many factors, for example tumour site and grade, the location, surgery, radiotherapy and side effects, medication etc almost guarantee a fluctuating presentation. There is an essential role for the speech and language therapist to be present at initial consultation and at certain points on the pathway e.g. tumour recurrence, tumour progression, transformation to higher grade tumour. Our recommendation is therefore that the speech and language therapist must be flexible in their approach to service delivery within multidisciplinary teams throughout the patients journey.	This comment is noted and the importance of the SALT throughout the patient journey is acknowledged.
Royal College of Speech and Language Therapists		We are of the opinion that specialist experience is essential. This patient group may present with constantly changing levels of communication & swallowing difficulties. They are also likely to have to make huge adjustments within a very limited time in dealing with terminal & end of life issues. Similarly professionals will be involved with the management of patients terminal & end of life issues. It is emotionally very demanding and therefore good support networks for both	We feel that this is dealt with in the explicit responsibilities as defined under the definitions of membership in Box 3 and Box 5 and that there is an education and liaison responsibility for specialist AHPs.

		patients / carers and professionals is vital.	
Royal College of Speech and Language Therapists	Psychological Support services including Neuropsychology and Neuropsychiatry, pp. 112–116	We consider this to be well covered. As with out comment above (para 13 etc) speech and language therapy has vital role where patients present impaired speech / language skills. This is our area of specialty so we suggest it would be essential to have joint working with the range of other professionals currently involved with the patients. At times, and depending on the patients difficulties, psychology assessments can sometimes be of limited value especially if they are too time consuming fail to take into account that the patients abilities can fluctuate. Therefore where these assessments are being considered, we recommend that there is information sharing between the speech and language therapists and the psychologist on issues that could affect patients performance, for example the patient's ability to tolerate testing, their concentration levels, attention span, distractibility etc as well as the patients actual speech / language and communication abilities	Thank you for this comment. We have revised para 348 as appropriate.
Royal College of Speech and Language Therapists	Rehabilitation services/Neurorehabilitation teams	The timing of referral to these services is important, as patients may be unable to tolerate intensive rehabilitation if it coincides with the extreme fatigue patients can experience post radiotherapy treatment.	Thank you for your comment. We hope we have made this clear in para 368.
Royal College of Speech and Language Therapists	Supportive Care/Rehabilitation services/Neurorehabilitation teams/General Palliative Care/Specialist	We consider the role of speech and language therapists in such services / teams would be to advise their colleagues of the common issues *relating* to this patient group. Below are listed suggested key roles: Key roles for SLT: • be an advocate for the patient throughout and provide support to manage speech / language / communication and swallowing difficulties • suggest strategies / methods to the multi professional team to support and facilitate their	No reference paragraph provided. We consider that the key roles for the Speech and Language Therapist are included our definition of the AHP. We do not feel that it would be helpful to give key roles for individuals within the AHP team. We have previously noted your comment about swallowing.

	Palliative Care	communication with the patient • attendance at regular multi professional meetings a crucial role given the speech and language therapists potential role as patient advocate and for the team in providing mutual support when dealing with sensitive issues • to maintain regular communication with speech and language therapists in the community, in the neuro rehab teams' of other hospitals & hospices, and palliative care teams ensure information of the patients communication needs are conveyed and managed at transition points of the patient's journey.	
Royal College of Surgeons of England		This organisation was approached but did not respond.	
Royal College Patient Liaison Groups		This organisation was approached but did not respond.	
Royal Liverpool Children's NHS Trust		This organisation was approached but did not respond.	
Royal Pharmaceutical Society of Great Britain		This organisation was approached but did not respond.	
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	Pp. 168–169	As this is planned for publication during June'06, which is the same timelines as the NICE technology appraisal (TA) on High Grade Glioma. That TA should be incorporated into these guidelines.	The document is guidance for commissioners and does not incorporate NICE technology appraisals.
Schering Plough Ltd	P. 170	The MGMT and resource section should be split into 2 separate paragraphs. The MGMT information we have was performed retrospectively and a Phase III trial is currently in development to evaluate prospectively this. The information that we have in the Hegi paper showed significant difference in PFS but this was not translated into an OS benefit. This	We have revised this paragraph.

		study was not designed or powered to detect this and so it should not be used to influence clinical decision making.	
Schering Plough Ltd	P. 199	As in P162, extent of resection is important and should be mentioned	Thank you for your comment. We do not feel the sentence needs revision.
Schering Plough Ltd	P. 200	Should talk about RT treatment prolonging survival in all patients with or without histological diagnosis.	We have given this due consideration and feel that the paragraph stands as it is.
Schering Plough Ltd	P. 204	Could be more specific re. longer term survival; should include % patients alive at 2 years in the study – 26.5% (RT & TMZ) vs 10.4% (RT). Also include information on patients who are progression free at 2 years, 10.7% (RT & TMZ) vs 1.5% (RT)	Thank you for your comment. This level of detail will be considered for the evidence review that accompanies the second draft of the guidance.
Schering Plough Ltd	P. 205	Similar parameters should be included for carmustine implants (CI) – Note should be made of the differences in baseline characteristics of pts in TMZ and CI trials.	Thank you for your comment. We will review the level of detail in the evidence sections during the second consultation period.
Schering Plough Ltd	P. 207	Evidence should be included giving the support of treatment at relapse.	Thank you for your comment. We will review the level of detail in the evidence sections during the second consultation period.
Schering Plough Ltd	P. 223	One year and Five year survival data is mentioned - OS and PFS data should also be mentioned.	We feel that one and five year survival rates are sufficient for service monitoring purposes.
Schering-Plough Ltd	Pp. 168–169	These should be re-ordered, concomitant RT & Chemo will always come prior to adjuvant treatment and so this guidance should word these in that order.	We feel that re-ordering these is unnecessary.
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		This organisation was approached but did not respond.	
Society and College of Radiographers		This organisation was approached but did not respond.	
Society for Endocrinology	P. 82, section 236	Radiosurgery may also be used for non-functioning tumours, not just hyperfunctioning	Thank you for your comment. We have revised the paragraph accordingly.

Society for Endocrinology	P. 12, Table 1	Here it is indicated that there are 29 malignant pituitary tumours per annum with the mortality of 7.8 per annum. This presumably includes parasellar tumours such as mengiomas and possibly metastases as this is far in excess of the incidence of pituitary carcinomas. Inclusion of such tumours means the document should explicitly state in the introduction that when referring to pituitary tumours this is taken to include parasellar tumours including meningiomas and metastases.	Thank you for your comment. Pituitary data includes craniopharyngeal tumours and a footnote has been added to Table 1 to explain this.
Society for Endocrinology	P. 20, section 50	This section should be amended to explicitly acknowledge that patients can present not only with evidence of hypersecretion and mass effects but also hypopituitarism.	Thank you for your comment. We have made the appropriate changes.
Society for Endocrinology	P. 22, section 59	We fully endorse the notion that pituitary tumours require a high level of specialisation with only one or two surgeons performing procedures in most units	Thank you for your comment.
Society for Endocrinology	Pp. 80–85	The general and specific recommendations for the care of pituitary tumours should be supported as they define the appropriate structure for patient care.	Thank you for your comments.
Society for Endocrinology	P. 83, section 236	Regular assessment of visual field by perimetry with access to a neuro-ophthalmologist as clinically indicated as the majority of patients have normal or stable visual fields and deterioration is an indication for referral to a neurosurgeon. There is no need for routine involvement of a neuro-ophthalmologist. There is no need for involvement of palliative care in a pituitary MDT.	Thank you for your comment. We have revised the paragraphs accordingly.
Society of British Neurological Surgeons	General	We have concerns as to the relationship between the guidance and existing requirements for 'referral for suspected cancer' 'decision to treat' and 'first definitive treatment' where a, there is such a wide variation in pathways for management and b, there is likely to be a significant impact on treatment speed for the same diagnosis as a result. For example patients with a high grade glioma may have a biopsy (diagnostic period) and the 31 day period becomes the waiting time for radiation to commence. Equally a a patient with the same diagnosis may	The role of the guidance and GDG is to define patient pathways and management pathways for patients. In addition there are explicit guidance on collection of data that would allow identification of 31- and 62-day targets to be extracted for such patients. It is not the responsibility of the GDG to define which tumour types fall within the groups necessary for such data collection.

		have resective craniotomy (diagnosis, and first definitive treatment) and then have to compete for radiation treatment with no target date specified, eg less then 31 days. As best treatment often includes both processes (surgery and radiotherapy closely allied), networks may have difficulty implementing this process without the guidance giving explicit support for expedient handling of these two pathways. How do NICE propose to advise on this as it is crucial to the delivery process agreed between Trusts and Networks. The 31/62 day process is complex to deliver if all NICE scoped tumours are included as 'cancer' for this purpose. Is this what the Guidance intends? If so how does the wide range of pathways fir with the government requirements for 31/62 targets?	
Society of British Neurological Surgeons	8	We recognise the importance placed on early referral especially for high grade intrinsic tumours, but are unclear as to the pathway envisaged by the guidance for non-neuroradiologists to effect this process, nor how it can be regulated, audited and enforced.	The process whereby this is achieved is clearly defined within the document on paras 87 and 88 where it is an explicit responsibility of the designated lead and the designated coordinator for the MDTs.
Society of British Neurological Surgeons	9	Does this mean that the Guidance will expect all Neurosurgical Units to have on site pathologists for all biopsies, in case difficulties occur or as a planned exercise?	Yes.
Society of British Neurological Surgeons	10	We believe this is a useful comment but may still lead to significant variations in service delivery across the UK without specific models for networks to follow that can be expected to represent an improved service for these patients.	We request further information on which specific models for networks you are referring to. The statement as it currently stands appears to be as explicit as possible within the clinical context.
Society of British Neurological Surgeons	11	We support this recommendation and suggest that it should take at least the form of a networked data-base of patients supported (financially) at a national level as hard evidence of commitment to improving the status of these patients.	Thank you for your comment.
Society of British Neurological Surgeons	15	There is no national collective for data on survival of patients with these cancers. There must be specific demands from the guidance that all units providing this service are	It is felt that this is covered in the explicit responsibilities of the neurosciences MDT and the cancer network MDT, which include data collection. It is not within our remit to impose targets of time

		supported with database recording not only of 'cancer dataset' but of quality and outcome data. This should have time target to implement eg one year from publication of Guidance	on the implementation of this guidance.
Society of British Neurological Surgeons	16	In principle patients with high grade gliomas have such a poor outcome that all should be included in clinical trials. We believe that if the outcome for these patients is to be improved the evidence from recent trials eg Stupp et al is that they do better in a clinical trials structure, and that units should be requested to show how they are achieving this by default to the NCRI and local Cancer Networks.	We feel this issue is addressed under paragraphs 444 and 445, but that it would not be ethical to insist that all patients be entered into clinical trials.
Society of British Neurological Surgeons	General 24-36	We are grateful to NICE for the compilation of this data and recognise how difficult it was to collect given the poor data collecting capacity of most units. A recommendation acknowledging this and that service delivery nationwide would be reviewed by NICE for delivery of the intended improvement using a similar tool.	The GDG is fully supportive of this comment and it is acknowledged in para 15 as a key recommendation for data collection and also in the section on information management from paragraph 417 onwards.
Society of British Neurological Surgeons	55	The recognition that Brain and CNS cancer patients deserve a more coordinated management of their care pathway via the NSU and locally is valuable and important, but it is difficult to see how this will be coordinated where Network, Trust and MDT areas do not coincide. Web based clinical information systems are a priority here.	An explicit responsibility of the MDTs both at the neuroscience centre and at the cancer network is to have site-specific group meetings on a regular basis to define pathways of care and protocols (see Box 2). This process will aid coordination of care across networks, trusts and MDTs. There are explicit requirements within the document for the development of a web-based clinical information system and recording is also a responsibility of the MDTs.
Society of British Neurological Surgeons	59	Up to 30% of individual NSU activity is related to the Guidance, with High Grade Gliomas predominating. Usually such a workload is spread through the neurosurgeons service as a whole. We recognise that the intent of the Guidance is to ensure that those delivering service to patients are bound by their commitment to MDT working as defined by the guidance. We recognise that delivery of this principal will need changes in many units to deliver a service that is sub-specialist for these patients, and welcome this initiative.	Thank you for your comment.

Society of British Neurological Surgeons	60	The feedback from many units is that the establishment of MDT for these patients has lead to these patients at least achieving equivalence with other cancer sufferers eg breast , lung for recognition of service needs and support but not yet for equivalence in drug treatment costs or CNS support.	Thank you for your comment.
Society of British Neurological Surgeons	63-67	There are anomalies in the definition of Brain Cancer patients and their timely access to radiation as defined by urgency of treatment. As timely radiation eg in four weeks from surgery/biopsy is so crucial to outcome, the guidance should recognise this from the RCR statements and show how Brain and CNS patients will not end up in competition with other patients for access dependent on their classification as treatment, urgent, palliative etc	The Department of Health defines waiting times so changes to these definitions are outside the remit of this guidance.
Society of British Neurological Surgeons	65	The poor supply of CNS in this area is noted eg only 65% of units.	Thank you for your comment.
Society of British Neurological Surgeons	69	Stereotactic radiosurgery has as a result of technical developments become a local possibility for many units to deliver treatments for eg metastases. We recognise the vital role of Sheffield at delivering the National Service and the demands of local clinicians to provide a local service and follow-up. The SBNS will be examining and updating its own guidance and standards for this service over the next 12 months.	Thank you for your comment.
Society of British Neurological Surgeons	73	We recognise that no patient has a brain tumour until imaging confirms it and that until this has been done the patients do not belong to any 'tumour management pathway'. We have concerns about referral processes as a result see 8 above. We also note the delay element highlighted in BJC 3rd May 2005 University of Leeds and would ask for comments from the Guidance team suggesting that according to this paper an intrinsic delay of a minimum of 30 days was seen for many cancers and in many cases much more. Such delays are crucial to patients with high grade gliomas. How will the guidance deliver more	We agree that this point is very important. Unfortunately, it has not been possible to find the reference. We would be grateful if you could send us the complete reference.

		rapid entry to the correct pathway given these issues?	
Society of British Neurological Surgeons	75	We applaud this recommendation but are concerned that many patients with low grade tumours are currently managed by neurologists, and referral to an MDT may firstly be outside their understanding of their role towards these patients, and secondly could result in a substantial increase in the Brain and CNS cancer follow-up services if all these patients end up by being transferred for their care to this team as is likely to occur.	We note the comment, but feel the paragraph should remain as it is.
Society of British Neurological Surgeons	76	The nature and timing of follow-up for Brain and CNS patient together with the need for imaging surveillance is insufficiently precise in the Guidance to effect improvement in this aspect of the service. We recognise that imaging is crucial and that changes in pathology can often be seen before neurology occurs, hence a more specific standard across the UK is needed. This is a particularly important issue for patients and their families and carers as delays in follow-up imaging contribute hugely towards their quality of life.	The GDG feel that there is no evidence to support developing a specific standard across the UK for frequency of imaging. Therefore this should be left to local determination as in Box 2 describing the responsibilities of the neuroscience brain and other CNS tumours MDT.
Society of British Neurological Surgeons	77	Up to 30% of individual NSU activity is related to the Guidance, with High Grade Gliomas predominating. Usually such a workload is spread through the neurosurgeons service as a whole. We recognise that the intent of the Guidance is to ensure that those delivering service to patients are bound by their commitment to MDT working as defined by the guidance. We recognise that delivery of this principal will need changes in many units to deliver a service that is sub-specialist for these patients, and welcome this initiative.	Noted with thanks.
Society of British Neurological Surgeons	81	As said above 81/1 needs to be strengthenedd from a platitude to a firm auditable statement	We feel that 81/1 should remain as it is in the background section. However, para 88 endorses this statement and audit is included in section D in the first chapter.
Society of British Neurological Surgeons	Fig. 4	This is helpful at explaining the relationship between an MDT in an NSU and a local MDT. We suspect that in many cases the linkage is poor and often unutilised from lack of	The definition of the key worker in paragraph 95 has been enhanced to reflect the importance of this role of the key worker.

		recognition that the interplay of care at any one time can be either way. Perhaps the guidance could be stronger at explaining this interplay rather than hoping that 'Keyworkers' will facilitate this.	
Society of British Neurological Surgeons	87	There is a large variety of pathways to and MDT for patients belonging to the scope of this guidance, and these are as yet unclearly recognised and documented. Guidance here would be helpful. An increased referral rate for comments to the MDT will need support for the MDT to be ensured eg Coordinators eg as in 88	We feel that because of the complexity there is a need for a designated lead in each trust. We agree with your second comment.
Society of British Neurological Surgeons	88	This role needs to be more precisely defined and IT support may need to be included for these roles to enable documentation to cover guidance information, targets and outcome, as well as ongoing web based clinical data.	Thank you for this comment. This was discussed by the GDG and we feel it is not necessary to describe the role of the MDT coordinator in such detail
Society of British Neurological Surgeons	94	How these decisions fit with the Cancer Target waiting times needs to be considered	We do not feel that this paragraph has any impact on the cancer target waiting times.
Society of British Neurological Surgeons	95	There is a danger that the Keyworker role will be by default be ascribed to the CNS and this may add additional and unreasonable burdens to an already complex multitasking nature of this job. We were disappointed that the role of the CNS was not individually explored as it is central to the working of this service and to the facilitation of the patients pathway. Whilst 65% of units may have a CNS in this area, less than half of these will for example have any cover arrangements in their absence. We would recommend that a specific section is devoted to this crucial role and the needs to support the role in action.	We acknowledge the importance of the CNS that is why this individual is included as a core member of both the neuroscience MDT and cancer network MDT. Furthermore, we have enhanced the role by cross-referring to the *Manual of Cancer Services* measures.
Society of British Neurological Surgeons	Box 3	The supply of Palliative care support for MDT's is poor and in demand. Greater emphasis needs to be placed on this for this group opf patients to ensure that pathway delays later do not lead to an impoverished service at crucial times.	We agree that great emphasis needs to be placed on palliative care and that is why palliative care is included in the membership of MDTs.
Society of British	Box 6	This process would be expedited and made more useful by	Comment acknowledged. We have included this in the information

Neurological Surgeons		having it web based and hence in real time.	management section.
Society of British Neurological Surgeons	106	a. We recognise the importance placed on early referral especially for high grade intrinsic tumours, but are unclear as to the pathway envisaged by the guidance for non-neuroradiologists to effect this process, nor how it can be regulated, audited and enforced. b. We recognise that no patient has a brain tumour until imaging confirms it and that until this has been done the patients do not belong to any 'tumour management pathway'. We have concerns about referral processes as a result see 8 above. We also note the delay element highlighted in BJC 3rd May 2005 University of Leeds and would ask for comments from the Guidance team suggesting that according to this paper an intrinsic delay of a minimum of 30 days was seen for many cancers and in many cases much more. Such delays are crucial to patients with high grade gliomas. How will the guidance deliver more rapid entry to the correct pathway given these issues?	a) We feel that the process for registering these patients is clear. b) We have not been able to obtain the paper mentioned – please could you let us have the full bibliographic reference.
Society of British Neurological Surgeons	111	We accept this need but see a conflict between the variety of referral pathways for patients with Brain and CNS tumours and the Trusts interpretation of target referral and treatment times. For example is Neurological Cancer by the DOH target definition the same as that used by NICE? If not then there will be considerable confusion when the guidance is published.	We do not see how the comment relates to paragraph 111. NICE and the GDG will comply with the Department of Health target definitions.
Society of British Neurological Surgeons	113	Our comments are above as in 106. Here we draw attention to the open statement 'without delay' what are the limits to this? How does this mechanism work so that general radiologists can be expected to satisfy this requirement? Are they to carry the responsibility for ensuring that unusual but suspicios lesions are referred?	We have clarified this by adding a cross-reference to Box 6.
Society of British Neurological	121	We applaud the requirement for these measures but emphasise that the implementation will require considerable	Comment acknowledged.

Surgeons		resource increase, as these tumour types do not have equivalence in service support funding now or in the foreseeable future.	
Society of British Neurological Surgeons	124	See comments 106 and 113	See our responses to your comments 106 and 113.
Society of British Neurological Surgeons	127	We support the comments and are pleased to see recognition for how important accurate diagnostic information is for the the surgeon to manage and for the patient and carers to know.	Thank you for your comment.
Society of British Neurological Surgeons	122-140	We strongly endorse the intent of these statements. We are concerned as to what ‘a timely and efficient manner’ is (138) A service standard should be stated eg a tissue diagnosis within 48hrs of biopsy in 75% of cases. This would encourage Trusts to look seriously at current delays, and to realise that keeping patients waiting (perhaps in a hospital bed increasing LOS) is stressful for patients and carers as well as staff.	We have revised para 138 to take account of this comment.
Society of British Neurological Surgeons	139	We strongly support initiatives in this area, but recognise that confusion exists at the Trust level concerning the retention of tissues for future unspecified use. There is a national need for a clear statement obligating trusts to support this activity that protects them under the conditions of the Human Tissue Act . In addtion the extra costs for this process must be realised and supported.	Thank you for your comment. We feel we have reinforced this in para 446.
Society of British Neurological Surgeons	148	Both the recent studies Westphal (gliadel) and Stupp (Temozolomide) have shown that patients undergoing extensive resection in a RCT setting have derived most benefit from the therapy. Units will need to consider this data when planning for future service delivery, and that that they can perform such surgery with equivalently low morbidity as in the two studies. The data from these two studies MUST be included in NICE’s deliberations on improving outcomes for the guidance to be considered useful.	These studies are currently being considered by NICE in the development of the appropriate clinical guideline. We feel it is not appropriate to include these studies in service guidance.
Society of British	151	Support for this will be needed. This data needs to be	This paragraph summarises the current available evidence.

Neurological Surgeons		flagged for consideration by D&T groups of Networks.	
Society of British Neurological Surgeons	158	The EORTC criteria should be included	Thank you for your comment. The EORTC criteria will be included in the appendices. This will be addressed during the second consultation period.
Society of British Neurological Surgeons	161	Without tissue diagnosis the management of these patients is difficult, and without tissue diagnosis, entry into trials is very difficult. We recognise that improvements to this group of patients will come from expert management of the uncertainties that exist by experienced personnel. Watching and waiting for deterioration without intervention, or treatment is very difficult for most patients and is probably becoming unacceptable.	We assume this comment refers to paragraphs 158 and 159. The GDG gave these issues considerable consideration and feels that further revision is not appropriate.
Society of British Neurological Surgeons	165	See general comments above.	See comment to the general comment above.
Society of British Neurological Surgeons	169	Both the recent studies Westphal (gliadel) and Stupp (Temozolomide) have shown that patients undergoing extensive resection in a RCT setting have derived most benefit from the therapy. Units will need to consider this data when planning for future service delivery, and that that they can perform such surgery with equivalently low morbidity as in the two studies. The data from these two studies MUST be included in NICE's deliberations on improving outcomes for the guidance to be considered useful. It should be added that the Stupp trial showed for the first time a doubling of two year survival for patients with glioblastoma. We will not be able to exclude discussion of this treatment from our discussions with patients, and such an improvement in outcome will need a comment from NICE stronger than 169, or these patients outcomes will be significantly poorer than in the rest of the EC and USA.	Thank you for your comment. However, it is not appropriate to include the results of NICE technology appraisals in guidance for commissioners.
Society of British Neurological Surgeons	170	This data needs further verification especially with respect to methylation status but does represent an important indicator that this area of Cancer will need treatment support for the	This paragraph has been revised in the light of comments from another stakeholder.

		improved outcomes to be realised.	
Society of British Neurological Surgeons	184	Patients may see rapid changes in their tumours behaviour. Unfortunately waiting for clinical deterioration means that it is often already too late to offer effective further treatment. A clear definition of surveillance imaging would be helpful not only for demand planning but also for achieving improvements in patient handling (scans and reports on time for outpatient appointments etc) . Patients recognise the need for scanning to manage their disease and early detection of tumour growth (tumour disease control) by imaging allows treatment before neurology (overall disease control). We recognise that the options for disease control are limited but the scope of this guidance is improvement in outcome for the future and without the mechanisms for appropriate imaging surveillance in place, no new treatments will be able to be introduced. Interval MRI scanning of eight weeks for glioblastoma has been accepted in USA, Canada and EC for trials work and more widely for routine management. Changes in tumour appearance are used to 'alter management ' . A national standard here is needed as local constraints will not always guarantee that the service provision is consistent across the UK.	We note this comment. However, the GDG have had extensive discussions on this area and feel that a clear definition of surveillance imaging would not be helpful as there is so little evidence in this area. It is more appropriate for local determination by the specialist MDT.
Society of British Neurological Surgeons	190	A national standard here is needed as local constraints will not always guarantee that the service provision is consistent across the UK. A specialist for example may be in part defined by their commitment to holding regular eg weekly 'glioma' or similar clinics.	We don't understand your question with regard to this paragraph. Please may we have some clarification.
Society of British Neurological Surgeons	199	See comments above especially 169	See our response to paragraph 169.
Society of British Neurological	204, 205	These comments are on their own now obsolescent and need rewriting to provide a more rigorous consideration and	This paragraph summarises the current available evidence.

Surgeons		recommendation	
Society of British Neurological Surgeons	212	The role of stereotactic radiosurgery versus surgical excision of accessible lesions is established and the further need for WBRT in question. The additional role of SRS for unaccessible lesions used alone is also well established. This message needs to be reinforced and we are pleased to see the evidence given here.	Your comment is acknowledged.
Society of British Neurological Surgeons	220–223	The guidance overall indicates the need for specialists commanding a wide knowledge of not only the surgical treatment of brain tumours but also the complexity of providing the service across the chronological and geographical pathway, in conjunction with other specialities, and tailored to individual issues of patients at different periods in their disease path way. Improvements in service will only come from implementation of these recommendations through local leadership above simple measures of surgical outcome and morbidity, although important (see 169 above) We acknowledge that patient are demanding a more informed and responsive service that acknowledges the information available to them from many different sources including the internet. We also are aware that the service provision for these patients varies across the UK. Hence we endorse the need for the portfolio of neurosurgical sub-specialisation in this area to be recognised, but are aware that service support and professional training must be maintained. To this end the modernisation of medical careers and the recruitment of new consultants into this sub-speciality must be supported.	Your comment is acknowledged.
Society of British Neurological Surgeons	224–315	We have asked specific stakeholders to comment as are own comments have been fed to the GDG through our representative.	Thank you for your comment.
Society of British Neurological	316–328	We support the recommendations and would value in the measurement process increased explanation of the	We feel that the involvement of patients and carers in the monitoring process is the responsibility of all cancer networks and

Surgeons		methodology for patient and carer involvement in the process.	applies to all tumour types.
Society of British Neurological Surgeons	329–344	We recognise the need of patients for information but are concerned that this should be realistic and useful to them. We consider our comments in 220-223 together with those in 190 to be relevant here.	Please see the responses to your comments about paragraphs 220–223 and 190 above.
Society of British Neurological Surgeons	435–451	We strongly endorse these statements and would emphasise the importance of all parties showing support for strengthening the research base for these patients. The current expenditure on basic research in the UK is in the greater part supported by charities, and the funding for clinical research well below that for other cancers. The impact of the guidelines should also be to enable workers in all provider areas for these cancers to simply and easily become involved in recruiting patients. Setting the service delivery standards to a uniform high level comparable with our international colleagues will give a considerable boost to this process and encourage patients, carers and staff to participate. We would confirm the SBNS Academic Committee's resolve and actions to implement these issues.	Thank you for your comment.
South West Peninsula Strategic Health Authority		This organisation was approached but did not respond.	
Southampton University Hospitals NHS Trust		This organisation was approached but did not respond.	
Teenage Cancer Trust, The		This organisation was approached but did not respond.	
Thames Valley Strategic Health Authority		This organisation was approached but did not respond.	
The Medway NHS Trust		This organisation was approached but did not respond.	
The Royal Society of		This organisation was approached but did not respond.	

Medicine			
The Royal West Sussex Trust		This organisation was approached but did not respond.	
UK Children's Cancer Study Group		This organisation was approached but did not respond.	
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	The Walton Centre for Neurology & Neurosurgery welcomes the guidelines and is very happy with much of the contents and their conclusions. The recommendations should also include a comment about access to neurogenetics, especially as a considerable number of CNS tumours are related to neurofibromatosis. The same advice may be necessary for patients with haemangioblastomas (von Hippel-Lindau syndrome), multiple endocrine neoplasia and tuberous sclerosis, etc.	Thank you for your comments. We would direct you to paragraphs 311–314, which we think address this issue and explicitly arrange appropriate referrals and follow-up for these patients.
Walton Centre for Neurology and Neurosurgery NHS Trust	6	The document refers to a neuroscience MDT and then in the next paragraph to a cancer network, brain and other CNS tumours MDT. It is appreciated that both teams need to be multidisciplinary but it would be helpful if some different terminology could be used to make a clearer differentiation between the neuroscience MDT and the cancer network MDT. The use of the term cancer network must imply a multidisciplinary group and therefore perhaps the term “MDT” could be deleted from this title i.e. it must involved surgeons, radiotherapists, oncologists, nurses, etc i.e. the term “MDT” in the “cancer network” is superfluous. The neuroscience MDT is important to be stated as such so that	The GDG has already spent a considerable amount of time considering the titles for the two separate MDTs. Changes to these titles are not felt to be appropriate.

		one avoids this being the sole province of the Neurosurgeon. In summary, it would be better to use the terms "neuroscience brain and other CNS tumours MDT" AND "cancer brain and other CNS Tumours Network".	
Walton Centre for Neurology and Neurosurgery NHS Trust	93 and 94, Box 2	If the neuroscience MDT has protocols in place that address the issues of oncology and radiotherapy, then it would seem unnecessary to refer the care back to protocols devised by the cancer network MDT. The question of surgery or no surgery is not always as straightforward as the separation implies in the document between neuroscience care and cancer network care. Indeed some patients may move backwards and forwards between the two more than once. I am concerned that some aspects of this document make this process unnecessarily cumbersome, and will result in significant delays in treatment. Indeed there seems to be some considerable blurring of the margins as one bullet point under the neuroscience MDT states "to develop and maintain evidence-based local management protocols covering all aspects of the patient pathway" – this MDT includes oncologists, pathologists, palliative care and specialist AHPs amongst others.	We acknowledge your comment, but feel that the guidance takes account of the complexity of some patients' care.
Walton Centre for Neurology and Neurosurgery NHS Trust	Box 4 and 198	The first bullet point states the following "Implement the non surgical aspects of the management plan produced by the neuroscience MDT". While the separation between the cancer network and neuroscience network may be appropriate for those with metastatic disease, who happen to have a brain tumour it seems unnecessarily complicated for those with primary brain tumours.	We have reviewed this and feel that the separation is not unnecessarily complicated.
Walton Centre for Neurology and Neurosurgery NHS Trust	39, 158 and 159	There are some patients that present with epilepsy going back many years in which a brain tumour may be suspected on scanning. Sometimes these patients are merely followed up by a neurologist and have repeat scanning every six to twelve months. Such cases are not always referred for	It is a clear standard in the guidance that all patients are discussed at the neurosciences MDT. This is not a neurosurgical group but multidisciplinary and will provide a global view of patient management. The standard will remain unchanged.

		surgical opinions or for any further procedure and the diagnosis of a brain tumour remains provisional. The management of this group of patients needs to be allowed for in the document. It is not always in their best interest to be referred into a brain tumour or cancer network, in spite of what most neurosurgeons say!!	
Walton Centre for Neurology and Neurosurgery NHS Trust	91 and 189	NICE should consider the logistics of putting all neoplasms through the MDT group e.g. precisely what numbers are involved in a Regional Neuroscience Unit covering 3 million people. The large numbers of patients involved will seriously limit the time for discussion in each and every case. Whilst it is accepted that neuroscience MDT discussion may be important in the processing of all patients, one wonders whether the statement that "preoperative discussions should take place at neuroscience MDT" is necessary in all cases. This would surely delay the surgical treatment of brain tumours.	The GDG feels strongly that all patients should be reviewed by the neuroscience MDT. However, the guidance has been revised to take account of patients requiring emergency intervention.
Walton Centre for Neurology and Neurosurgery NHS Trust	140	Are NICE saying that all patients with brain tumours should be entered into research trials so that specimens can be stored (with patient consent) I am personally in agreement with this statement providing specimens are then usefully investigated but it has far reaching consequences.	Thank you for your comment. This statement is further expanded in paragraph 446.
Walton Centre for Neurology and Neurosurgery NHS Trust	220–223	Although the data suggests there is no improvement from subspecialisation in neurosurgery, it would be helpful to have a comment which states how big the number would need to be to detect a 10% or 20% difference in survival. I suspect the number would need to be far bigger than any of the trials quoted and therefore the data regarding subspecialisation in surgery should be treated with great suspicion. Proving that there is no difference in treatment often requires very large studies, especially if one is looking for a 10% or 20% change.	This paragraph summarises the current available evidence. We agree the evidence is not strong.
Walton Centre for	Boxes 7, 8,	I am concerned by the number of specialist MDTs	We agree with your comment and feel that is exactly what we are

Neurology and Neurosurgery NHS Trust	9 and 10	suggested by the guidelines. The guidelines suggest not only MDT in neuroscience centres looking at brain tumours but also having separate MDTs for spinal, skull base and pituitary tumours. While I appreciate that these conditions are very different, many of the individuals who make up the MDT are similar e.g. neuroradiology, specialist nurses, neuropathology, and I would have thought that these MDTs should all be subsections of the neuroscience MDT. The extra individuals required for pituitary, skull based and spinal decision making could be drafted as and when appropriate.	saying in the guidance.
Walton Centre for Neurology and Neurosurgery NHS Trust	11 and Box 2	The guidelines recommend the setting up of various National Tumour groups for medulloblastoma, pineal tumours and optic gliomas amongst others. The make-up of these groups needs to be independently chosen.	Thank you for your comment.
Walton Centre for Neurology and Neurosurgery NHS Trust	General	Many of the neurosciences tumours are sufficiently rare that it is highly relevant to discuss them at a neuroscience MDT meeting but a cancer network would add little to this.	We would accept that the specialist needs of rare tumours would not need to be discussed at the cancer network MDT, but that the generic continuing care needs would appropriately be discussed within this group.
Walton Centre for Neurology and Neurosurgery NHS Trust	General	Many of the measurements relate to process and structure but more emphasis should be placed on survival and quality of life – the latter are mentioned but should be as important if not more so than process.	The measurement of survival and quality of life are consistently commented on in all sections of the document. The order of layout with process at the front of each section is determined by NICE and is compatible with layout of all previous IOGs. This is not intended to convey a priority for these measurements.
Walton Centre for Neurology and Neurosurgery NHS Trust	435–451	The recommendations in the NICE guidelines for research are to be applauded.	Thank you for your comment.
Welsh Assembly Government (formerly National Assembly for Wales)	General	Thank you for giving the Welsh Assembly Government the opportunity to 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.	Thank you for your comment.
West Midlands Specialised Services		This organisation was approached but did not respond.	

Agency			