Appendix 1 - Surveillance review consultation

Surveillance review consultation comments table
4 November 2014 – 18 November 2014

Stakeholder	Do you agree that the guidance should not be updated?	Do you agree that the guidance should be put on the static list?	Comments on equality issues or areas excluded from the original scope	Comments If you disagree please explain why	Response
Dr Charles Davis, past president BNOS. Professor Neurosurgery and neurooncology, lancs teaching hospitals, director largest brain cancer research uk/preston				The opinion that guidance should become static flies in the face of the biggest change in cancer over an equivalent period- ever. It is a pity that the tick box approach appears to have ignored metasatic brain disease since the IOG 2006 and that practice has changed in the majority of new brain tumours-About 13,000 new cases of metastases, should be being treated in what is the most rapidly increasing cancer-again ever. The IOG 2006 is essentially yesterdays news with clinicians wallowing in the mire of unevidenced treatment. a complete reappraisal and new evidence is required urgently.	Thank you for your comment. Following consultation feedback on the proposal not to update the guidance and subsequent consideration of stakeholder comments, NICE has been in discussion with the Department of Health and NHS England about how best to meet the needs of patients with intracerebral tumours and how best to take this forward. Following these discussions, it has been agreed that NICE will formally request a referral from NHS England to develop a guideline on primary brain cancers. A decision on whether the guidance on improving outcomes for people with brain and other CNS tumours should be updated will be deferred pending the

Stakeholder	Do you agree that the guidance should not be updated?	Do you agree that the guidance should be put on the static list?	Comments on equality issues or areas excluded from the original scope	Comments If you disagree please explain why	Response
					finalisation of the scope of new guidance on primary and secondary brain tumours. In light of this decision the proposal is not to put the guidance on the static list at this time.
GDG member	There is scope for including more information on the impact of molecular diagnostics in the next few years.		The 2007 WHO classification of central nervous system tumors is about to be updated, and several entities will be defined as much by their molecular genetic alterations as by their histopathology. Reference to this and the necessity for expertise in clinical genomics at the MDT meeting could be useful in an updated guidance document.		Thank you for your comment. Following consultation feedback on the proposal not to update the guidance and subsequent consideration of stakeholder comments, NICE has been in discussion with the Department of Health and NHS England about how best to meet the needs of patients with intracerebral tumours and how best to take this forward. Following these discussions, it has been agreed that NICE will formally request a referral from NHS England to develop a guideline on primary brain cancers. A decision on whether the guidance on improving outcomes

Stakeholder	Do you agree that the guidance should not be updated?	Do you agree that the guidance should be put on the static list?	Comments on equality issues or areas excluded from the original scope	Comments If you disagree please explain why	Response
					for people with brain and other CNS tumours should be updated will be deferred pending the finalisation of the scope of new guidance on primary and secondary brain tumours. In light of this decision the proposal is not to put the guidance on the static list at this time.
The Society and College of Radiographers	NO	NO		We believe that the guidance for improving outcomes for people with brain and other central nervous system tumours needs to be updated and therefore reject the decision to stay as is. In particular the Stereotactic Radiosurgery section which states that much of the Radiosurgery work is undertaken by Sheffield. This was true in 2005/2006 but not now. The Multi-disciplinary Team section is not reflective of the modern skill mix required to deliver technical advancements e.g. Radiosurgery, IMRT, Rapid Arc etc for both high grade, low grade tumours in both the Neuro-oncology and Skull Base Pathway. Therapeutic Radiographers/ Advanced Practitioners/Consultant Radiographers - technical and clinical skills in providing these services for continuity of care, patient experience and patient centred care- especially in preparation for	Thank you for your comment. Following consultation feedback on the proposal not to update the guidance and subsequent consideration of stakeholder comments, NICE has been in discussion with the Department of Health and NHS England about how best to meet the needs of patients with intracerebral tumours and how best to take this forward. Following these discussions, it has been agreed that NICE will formally request a referral from NHS England to develop a

Stakeholder	Do you agree that the guidance should not be updated?	Do you agree that the guidance should be put on the static list?	Comments on equality issues or areas excluded from the original scope	Comments If you disagree please explain why	Response
				protons in the next 2 years and the need for them to be core members of the MDT in Specialist centres - with guidance on their role and responsibility and where this fits into service improvement and service need. Additional increased number of patients through the pathway should be noted and the change in way services are delivered Research Trials - increased number of trials available to the elderly neuro patient which would be reflective of our ageing population an increased demand on services. Overall, we think considering the improvements that have occurred in the last 9 years and plans for the future it would be wrong to accept the 2006 version as still current.	guideline on primary brain cancers. A decision on whether the guidance on improving outcomes for people with brain and other CNS tumours should be updated will be deferred pending the finalisation of the scope of new guidance on primary and secondary brain tumours. In light of this decision the proposal is not to put the guidance on the static list at this time.
Brainstrust	Disagree			New research (RTOG 9802) shared at the Society of Neuro-Oncology Conference November 2014 suggests that the treatment protocol for low grade high risk brain tumours should be changed. Patients who have had radiation should be offered PCV post radiotherapy. This updates the recommendation on p59 of the guideline: *The exact role of chemotherapy is uncertain; the research evidence is not strong and the results of recent trials are awaited.*	Thank you for your comment. Following consultation feedback on the proposal not to update the guidance and subsequent consideration of stakeholder comments, NICE has been in discussion with the Department of Health and NHS England about how best to meet the needs of patients with intracerebral tumours and how best to take this

Stakeholder	Do you agree that the guidance should not be updated?	Do you agree that the guidance should be put on the static list?	Comments on equality issues or areas excluded from the original scope	Comments If you disagree please explain why	Response
				For more information: http://am.asco.org/adjuvant-chemotherapy-after-radiation-improved-overall-survival-low-grade-glioma	forward. Following these discussions, it has been agreed that NICE will formally request a referral from NHS England to develop a guideline on primary brain cancers. A decision on whether the guidance on improving outcomes for people with brain and other CNS tumours should be updated will be deferred pending the finalisation of the scope of new guidance on primary and secondary brain tumours. In light of this decision the proposal is not to put the guidance on the static list at this time.
The Royal College of Radiologists (RCR) / British Society of Neuroradiologists (BSNR)	Agree	Agree		The RCR and BSNR note that radiological diagnosis of CNS tumours was not specifically included in the evidence review for this guidance. With regard to the conclusion of the review that MDTs do improve outcomes, the RCR and BSNR note that they will require an increasing amount of neuroradiological time for both preparation and participation in MDT meetings. The RCR and BSNR feel that this should be realistically reflected in job plans and without consultant	Thank you for your comment. Following consultation feedback on the proposal not to update the guidance and subsequent consideration of stakeholder comments, NICE has been in discussion with the Department of Health and NHS England about how best to meet the

Stakeholder	Do you agree that the guidance should not be updated?	Do you agree that the guidance should be put on the static list?	Comments on equality issues or areas excluded from the original scope	Comments If you disagree please explain why	Response
				expansion this has had, and will continue to have, a detrimental effect on capacity for other areas of practice The RCR notes that the increased use of post-operative MRI and the use of MRI to minimise delayed diagnoses of cerebral abcesses require rapid access to MRI scanners – ideally within 24 hours (48 maximum) post-tumour surgery and at the earliest non-emergency opportunity for suspected abscesses. The RCR and BSNR are concerned that, as the demand for urgent and elective MRI is increasing from just about every clinical area, this is a very significant additional pressure point on scanner time and list organisation, and adds to the acute reporting burden.	needs of patients with intracerebral tumours and how best to take this forward. Following these discussions, it has been agreed that NICE will formally request a referral from NHS England to develop a guideline on primary brain cancers. A decision on whether the guidance on improving outcomes for people with brain and other CNS tumours should be updated will be deferred pending the finalisation of the scope of new guidance on primary and secondary brain tumours. In light of this decision the proposal is not to put the guidance on the static list at this time.
Association of British Neurologists	Disagree	Disagree	Standard treatment has changed significantly over the last 8 years. **There is inequality in how elderly patients are managed across UK**. There is a cost associated in provision and interpretation of molecular testing required for consistent treatment of elderly.	**Disagree** Standard management has changed significantly since the last IOG. The guidelines do not take into account the pathology / molecular testing expertise and resources required to diagnose glioma (or medulloblastoma) patients.	Thank you for your comment. Following consultation feedback on the proposal not to update the guidance and subsequent consideration of stakeholder comments, NICE has been in discussion with the

Stakeholder	Do you agree that the guidance should not be updated?	Do you agree that the guidance should be put on the static list?	Comments on equality issues or areas excluded from the original scope	Comments If you disagree please explain why	Response
			Pathology – Units should check 1p 19q, IDH1, MGMT (elderly) which influences treatment decision in virtually all glioma patients. http://onlinelibrary.wiley.com/doi/10.1111/bpa.12171/full There is inequality in the consistent provision of these services in Neuro-pathology Units across the UK. Testing is haphazardly done with poor techniques in some centres and is not done in all centres in appropriate patients. Inequality in the provision of Neuro-rehabilitation for glioma and spinal cord patients with benign and resected high grade glioma patients. Huge disparity of acceptance of brain/spinal tumour patients across the UK.	Standard Treatment now involves Chemo-radiation for patients under 65 – requiring more frequent and intense follow up. New RCT Evidence for treatment in Elderly (chemotherapy/short course RT). http://www.ncbi.nlm.nih.gov/pubmed/24912512 New RCT evidence for treatment of patients with poor outcome) low grade Oligodendroglioma and Anaplastic Oligodendroglioma based on molecular techniques to determine Ch1p19Q deletions. Diagnosis of Medulloblastoma has changed based on molecular characterisations (WNT and Sonic Hedgehog) Molecular testing is not well supported across all sites resulting in equality issues. There is a commissioning requirement for this to be generally implemented The IOG did not emphasise the benefit of early neuro-rehabilitation with requirement for neurosurgery to refer to Neuro-rehab after surgery. This has been identified as a source of inequality within Eng & Wales, with only a few centres providing satisfactory care to maximise patients ability. There is a	Department of Health and NHS England about how best to meet the needs of patients with intracerebral tumours and how best to take this forward. Following these discussions, it has been agreed that NICE will formally request a referral from NHS England to develop a guideline on primary brain cancers. A decision on whether the guidance on improving outcomes for people with brain and other CNS tumours should be updated will be deferred pending the finalisation of the scope of new guidance on primary and secondary brain tumours. In light of this decision the proposal is not to put the guidance on the static list at this time.

Stakeholder	Do you agree that the guidance should not be updated?	Do you agree that the guidance should be put on the static list?	Comments on equality issues or areas excluded from the original scope	Comments If you disagree please explain why	Response
				commissioning requirement for this for this to be generally implemented Early involvement of Palliative Services does not occur in many sites – therefore huge inequalities. There is a commissioning requirement for this for this to be generally implemented	
NHS England	Disagree	Needs minor revision		The major change in brain tumour management that was not considered in detail previously relates to the increased use of molecular markers in diagnosis and the impact these have on treatment of gliomas (low and high-grade). A review of this subject is enclosed from the CRG policy statement. Specifically, as a minimum, LOH 1p19q should be routinely tested for any tumour with oligodendroglial morphology as it is an indicator of chemosensitivity and may well alter treatment, as well as being a more reliable indicator of prognosis. MGMT methylation status is also recommended in patients with GBM as it also indicates chemosensitivity and improved prognosis. This appears most valuable in the context of elderly patients where chemotherapy alone may be chosen for those methylated patients who aren't suitable for full Stupp regime. IDH-1 is also a useful indicator of prognosis and easily performed on imuunohistochemistry for the common mutation. (see refs enclosed)	Thank you for your comments. Following consultation feedback on the proposal not to update the guidance and subsequent consideration of stakeholder comments, NICE has been in discussion with the Department of Health and NHS England about how best to meet the needs of patients with intracerebral tumours and how best to take this forward. Following these discussions, it has been agreed that NICE will formally request a referral from NHS England to develop a guideline on primary brain cancers. A decision on whether the guidance on improving outcomes for people with brain and other CNS tumours

Stakeholder	Do you agree that the guidance should not be updated?	Do you agree that the guidance should be put on the static list?	Comments on equality issues or areas excluded from the original scope	Comments If you disagree please explain why	Response
					should be updated will be deferred pending the finalisation of the scope of new guidance on primary and secondary brain tumours. In light of this decision the proposal is not to put the guidance on the static list at this time.
				New evidence is now available to support the routine use of 5-ALA to aid resection of high-grade gliomas – full review with evidence enclosed. This should be included as represents a major new body of evidence that is changing practice for the management of the most common surgical neuro-oncology cases. We feel it should be included as a recognised treatment option. (see refs) The CNS Tumours CRG and peer review received data and feedback on the utility or otherwise of the "cancer network MDT". Very few, if any, centres in UK have a fully functioning cancer network MDT, with feedback indicating that the overall purpose of this MDT as a separate entity is unclear and a financial burden without significant perceived benefit in its current form. To make this option more useful for patients the CNS Tumours CRG along with the peer review team devised a fourth model, whereby the cancer network or	Thank you for your comment. Following consultation feedback on the proposal not to update the guidance and subsequent consideration of stakeholder comments, NICE has been in discussion with the Department of Health and NHS England about how best to meet the needs of patients with intracerebral tumours and how best to take this forward. Following these discussions, it has been agreed that NICE will formally request a referral from NHS England to develop a guideline on primary brain cancers. A decision

Stakeholder	Do you agree that the guidance should not be updated?	Do you agree that the guidance should be put on the static list?	Comments on equality issues or areas excluded from the original scope	Comments If you disagree please explain why	Response
				rehabilitation issues can be merged with each of the specialist MDTs (neuroscience brain & CNS tumours, pituitary, skull-base or spine), rather than run as a separate entity. Clearly this has never been subject to a clinical trial and unlikely ever will, hence no evidence is likely to be published in this area, however, it would seem a pragmatic alternative for many centres.	on whether the guidance on improving outcomes for people with brain and other CNS tumours should be updated will be deferred pending the finalisation of the scope of new guidance on primary and secondary brain tumours. In light of this decision the proposal is not to put the guidance on the static list at this time.
				The value of routine collection of PROMs including quality of life data in patients with brain tumours could now be emphasised on the basis of research evidence and the increased recognition of the importance of quality of life for these patients. This forms one of the core service specification standards released by NHS England in 2013 and should be reflected in the NICE IOG in order to promote usage in the future. EORTC QLQ-C30 and BN20 are recommended based on evidence review and are freely available at no cost.	Thank you for your comment. Following consultation feedback on the proposal not to update the guidance and subsequent consideration of stakeholder comments, NICE has been in discussion with the Department of Health and NHS England about how best to meet the needs of patients with intracerebral tumours and how best to take this forward. Following these discussions, it has been agreed that NICE will formally request a referral from NHS

Stakeholder	Do you agree that the guidance should not be updated?	Do you agree that the guidance should be put on the static list?	Comments on equality issues or areas excluded from the original scope	Comments If you disagree please explain why	Response
					England to develop a guideline on primary brain cancers. A decision on whether the guidance on improving outcomes for people with brain and other CNS tumours should be updated will be deferred pending the finalisation of the scope of new guidance on primary and secondary brain tumours. In light of this decision the proposal is not to put the guidance on the static list at this time.
				The core membership of many MDTs is still debated. There is general consensus that certain members of the MDT are absolutely essential for optimising patient care, however, concern has been expressed by many specialists in a number of units that some of the MDT members may offer just as much value as extended members of the MDT. In this context these valuable team members could attend MDTs as required or can be accessed outside of MDT meetings without the need to routinely attend all of every meeting. This would not negatively impact on patient care and would reflect a more sustainable and logical model from both a financial and clinical perspective. The suggestion would be	Thank you for your comment. Following consultation feedback on the proposal not to update the guidance and subsequent consideration of stakeholder comments, NICE has been in discussion with the Department of Health and NHS England about how best to meet the needs of patients with intracerebral tumours and how best to take this forward. Following these discussions, it has been

Stakeholder	Do you agree that the guidance should not be updated?	Do you agree that the guidance should be put on the static list?	Comments on equality issues or areas excluded from the original scope	Comments If you disagree please explain why	Response
				as follows: Neurosciences MDT/skull base/spine/ pituitary Essential core members: Neurosurgeons (&ENT for skull-base +/- pituitary) Oncologists Neuropathologists Neuroradiologists CNSs MDT coordinator (Endocrinoligist – for pituitary) Extended members: Neuropsychologist AHPs Palliative care Neurologists (Therapy radiographer – for combined cancer network MDT)	agreed that NICE will formally request a referral from NHS England to develop a guideline on primary brain cancers. A decision on whether the guidance on improving outcomes for people with brain and other CNS tumours should be updated will be deferred pending the finalisation of the scope of new guidance on primary and secondary brain tumours. In light of this decision the proposal is not to put the guidance on the static list at this time.
				The section on cerebral metastases could be revised in line with current evidence and national clinical commissioning policies in England (SRS ref enclosed). It would be better worded that patients could be considered for treatment (surgical or SRS) with solitary or oligometastatic disease provided the KPS was >/= 70, overall prognosis from systemic disease is > 6months anticipated survival. SRS is an option where the total tumour volume is <20cc.	Thank you for your comment. Following consultation feedback on the proposal not to update the guidance and subsequent consideration of stakeholder comments, NICE has been in discussion with the Department of Health and NHS England about

Stakeholder	Do you agree that the guidance should not be updated?	Do you agree that the guidance should be put on the static list?	Comments on equality issues or areas excluded from the original scope	Comments If you disagree please explain why	Response
					how best to meet the needs of patients with intracerebral tumours and how best to take this forward. Following these discussions, it has been agreed that NICE will formally request a referral from NHS England to develop a guideline on primary brain cancers. A decision on whether the guidance on improving outcomes for people with brain and other CNS tumours should be updated will be deferred pending the finalisation of the scope of new guidance on primary and secondary brain tumours. In light of this decision the proposal is not to put the guidance on the static list at this time.
				Further evidence in support of the volume-outcome debate has been missed and is now included. We agree with statements made in that regard. (see refs)	Thank you.
Royal College of Nursing				Nurses working in this area of health have reviewed this proposal and have no comments to submit at this present time.	Thank you.

Stakeholder	Do you agree that the guidance should not be updated?	Do you agree that the guidance should be put on the static list?	Comments on equality issues or areas excluded from the original scope	Comments If you disagree please explain why	Response
Department of Health				The Department of Health has no substantive comments to make, regarding this consultation.	Thank you.
The Brain Tumour Charity – Rebecca Shortt	Disagree	Disagree		Comments If you disagree please explain why **About The Brain Tumour Charity** The Brain Tumour Charity is at the forefront of the fight to defeat brain tumours. We fund pioneering research to find new treatments, improving understanding to bring us closer to a cure. We raise awareness of symptoms to aid earlier diagnosis and so that the needs of people affected by brain tumours are understood and can be met. We provide support for anyone affected so that they can have the best quality of life. Brain tumours are the highest cause of cancer related death for children and adults under 40. The disease presents a global challenge to world health and an incredible burden on economies. Yet progress in treatment has stagnated. As a charity we are committed to having the biggest possible impact for every person affected by a brain tumour, to defending the most amazing part of the human body, so that getting a diagnosis no longer means a death sentence. **Comments** Unfortunately we observe that the guidance is not being followed consistently across England with significant differences in care still being	Thank you for your comment. Following consultation feedback on the proposal not to update the guidance and subsequent consideration of stakeholder comments, NICE has been in discussion with the Department of Health and NHS England about how best to meet the needs of patients with intracerebral tumours and how best to take this forward. Following these discussions, it has been agreed that NICE will formally request a referral from NHS England to develop a guideline on primary brain cancers. A decision on whether the guidance on improving outcomes for people with brain and other CNS tumours should be updated will be deferred pending the finalisation of the scope of new guidance on primary and secondary

Stakeholder	Do you agree that the guidance should not be updated?	Do you agree that the guidance should be put on the static list?	Comments on equality issues or areas excluded from the original scope	Comments If you disagree please explain why	Response
				experienced by patients across the country[1]. Additionally there seems to have been little improvement in outcomes, despite the guidance, as well as a number of issues raised around poor experience. For example poor communication between healthcare professionals and patients is outlined as an area for improvement in the guidance at page 108, an observational study referred to in the guidance reports that 25% of patients with a brain tumour have expressed concerns about the way in which clinicians communicated. Yet in the most recent National Cancer Patient Experience Survey, in response to question 39 (being talked about as if not there) brain cancer patients reported results in the bottom 4. In respect of question 69 (being treated as a set of cancer symptoms) brain cancer patients reported the worst experience across all cancer types, with 24% of respondents reporting that they felt they were treated like a set of symptoms. The National Peer Review Report on Brain and CNS Services 2012/2013 reported attendance of healthcare professionals at the National Advanced Communications Skills Training as 33%. Given this review is 8 years on from	brain tumours. In light of this decision the proposal is not to put the guidance on the static list at this time.

[1] The National Peer Review Report on Brain and CNS Services 2012/2013 lists the percentage of Neuroscience MDT services with serious concerns at 70% Overall compliance varies regionally, see table on page 7 of the National Peer Review Report: Brain and CNS Cancer Services Report 2012/2013 which shows that 19 services are performing at below 50% with the very best services performing at 100%
http://www.cquins.nhs.uk/documents/resources/reports/2013/Brain%20and%20CNS%20NCPR%20Report%20September%202013.pdf

Stakeholder	Do you agree that the guidance should not be updated?	Do you agree that the guidance should be put on the static list?	Comments on equality issues or areas excluded from the original scope	Comments If you disagree please explain why	Response
				publication of the improving outcomes guidance, this is very disappointing. We would like to see the guidance reinforced by a NICE 'Quality Standard' and would be very keen to work with NICE in the development of a quality standard, which would likely result in better care for patients in our disease group, whilst reinforcing the NHS commitment to improving patient experience and quality of life. This is because we know from the National Peer Review Cancer Services 2012/2013 report that those disease areas which have a quality standard are performing better under review than those which do not with, for example, MDT performance in brain at 60-62% compared with breast at 94% and lung at 89%. With regard to the decision to place the guidance on the 'static list' we would be strongly opposed to this happening. Whilst progress is slow in terms of the guidance being reflected in every patient pathway, work is taking place at a national and regional level to implement the guidance and use this as a basis to ensure resources are made available to patients in line with best practice[2]. Reference to the guidance in this	

[2] We (The Brain Tumour Charity) were recently involved in supporting an application of a Consultant to obtain a CNS post at his centre where the Guidance was cited, the bid was successful.

Stakeholder	Do you agree that the guidance should not be updated?	Do you agree that the guidance should be put on the static list?	Comments on equality issues or areas excluded from the original scope	Comments If you disagree please explain why	Response
				manner only holds validity if it is seen as relevant and current, placing the guidance on the static list risks a perception that it is no longer relevant or that there is no further work to be done in improving outcomes. We would also refute the assertion that there is unlikely to be any relevant research evidence in the next 3-5 years. As outlined below there have been advances which are not currently reflected in the guidance. Given NHS commitment to continual improvement and the NICE improving outcomes guidance setting the benchmark for best practice, in our view the guidance no longer reflects best practice in some areas which we outline below in order of the corresponding section of the guidance: **2. Multidisciplinary Teams** • In respect of MDT, the Central Nervous System Clinical Reference Group (CRG) and peer review team received data and feedback on the utility or otherwise of the "cancer network MDT". Very few, if any, centres in UK have a fully functioning cancer network MDT, with feedback indicating that the overall purpose of this MDT as a separate entity is unclear with little perceived benefit, particularly in light of financial	

Stakeholder	Do you agree that the guidance should not be updated?	Do you agree that the guidance should be put on the static list?	Comments on equality issues or areas excluded from the original scope	Comments If you disagree please explain why	Response
				constraints. To make this option more useful for patients the CRG along with the peer review team devised a fourth model whereby the cancer network or rehabilitation issues can be merged with each of the specialist MDTs (neuroscience brain & CNS tumours, pituitary, skull-base or spine), rather than run as a separate entity. Clearly this has never been subject to a clinical trial and unlikely ever will, hence no evidence is likely to be published in this area. We would however like NICE to work with the CRG and peer review in including this in the guidance or to form part of a quality standard. **4. Diagnosis: radiology and pathology** • Diagnosis –There has been one major change in brain tumour management that has not been considered in detail previously, this relates to the increased use of molecular markers in diagnosis and the impact these have on treatment of gliomas (low and high-grade). We would refer you to the review of this subject from the CRG policy statement[3]. Specifically, LOH	

[3] Attached

Stakeholder	Do you agree that the guidance should not be updated?	Do you agree that the guidance should be put on the static list?	Comments on equality issues or areas excluded from the original scope	Comments If you disagree please explain why	Response
				1p19q should be routinely tested for any tumour with oligodendroglial morphology as it is an indicator of chemosensitivity and may well alter treatment, as well as being a more reliable indicator of prognosis. MGMT methylation status is also recommended in patients with Glioblastoma Multiforme as it also indicates chemosensitivity and improved prognosis. This appears most valuable in the context of elderly patients where chemotherapy alone may be chosen for those methylated patients who aren't suitable for full Stupp regime. IDH-1 is also a useful indicator of prognosis and easily performed on imuunohistochemistry for the common mutation. These tests should appear within the guidance as they now reflect best practice in terms of diagnosis. Additionally we would draw your attention to the following method of diagnosis: Stereotactic biopsy[4] which should arguably be included in the section on diagnosis as an alternative to intraoperative biopsy.	

[4] Shooman, D, Belli, A and Grundy, P.L.. Image-guided frameless stereotactic biopsy without intraoperative neuropathological examination: Clinical article. Journal of Neurosurgery, 113.2 (2010): 170-178.

Stakeholder	Do you agree that the guidance should not be updated?	Do you agree that the guidance should be put on the static list?	Comments on equality issues or areas excluded from the original scope	Comments If you disagree please explain why	Response
				5. Treatment and Follow–up: brain tumours • Specialisation of Surgical Practice - We note that there is now an increasing body of evidence that surgical sub-specialisation results in better outcomes. We would direct you to further articles which add weight to that argument[5]. The guidance currently suggests a lead MDT surgeon involved in treating these patients should spend at least 50% of his or her clinical programmed activities in neuro-oncology surgery we would suggest this should be higher, as sub-specialisation has been shown to result in better outcomes; the guidance should be amended to reflect this. • Quality of Life and Patient Reported Outcomes Measures - With routinely poor experiences and quality of life being reported by those with brain tumour in the National Cancer Patient	

[5] Trinh, V. T., Davies,J.M. and Berger, M.S.. Surgery for primary supratentorial brain tumors in the United States, 2000–2009: effect of provider and hospital caseload on complication rates. Journal of neurosurgery (2014): 1-17.

Khan, U. A., *et al*. Treatment by specialist surgical neurooncologists improves survival times for patients with malignant glioma. Journal of Neurosurgery, (2014): 1-6.

Stakeholder	Do you agree that the guidance should not be updated?	Do you agree that the guidance should be put on the static list?	Comments on equality issues or areas excluded from the original scope	Comments If you disagree please explain why	Response
				Experience Survey and elsewhere[6], emphasis on the value of routine collection of quality of life data and patient reported outcome measures in patients with brain tumours should now be included in the guidance on the basis of research evidence and the increased recognition of the importance of quality of life for these patients particularly. This is because where overall survivorship is low a poor quality of any survivorship is amplified. It is vital therefore that quality of life measures are considered with other outcome measures[7]. This forms one of the core service specification standards released by NHS England in 2013. **8. Supportive Care** • Clinical Research- Improving outcomes is dependant upon	

[6] http://www.thebraintumourcharity.org/Resources/SDBTT/news/documents/the-brain-tumour-charity-report-on-improving-quality-of-life-final-report dec2013.pdf

[7] Dirven, Linda, et al. "The level of patient-reported outcome reporting in randomised controlled trials of brain tumour patients: A systematic review." European Journal of Cancer 50.14 (2014): 2432-2448.

Kotronoulas, G, et al. "What Is the Value of the Routine Use of Patient-Reported Outcome Measures Toward Improvement of Patient Outcomes, Processes of Care, and Health Service Outcomes in Cancer Care? A Systematic Review of Controlled Trials." Journal of Clinical Oncology (2014): JCO-2013.

Stakeholder	Do you agree that the guidance should not be updated?	Do you agree that the guidance should be put on the static list?	Comments on equality issues or areas excluded from the original scope	Comments If you disagree please explain why	Response
				research. The NHS is demonstrating a commitment to a vision of integrated research to support the development of high quality commissioning, to provide a culture that values and promotes research and is patient centred.[8] However we also know that pitifully few brain tumour patients (3.5%) are taking part in clinical trials.[9] The requirement to signpost patients to relevant research should be added to the guidance in the section about information giving (pages 104-107).	

[8] NHS Research and development strategy, currently in consultation http://www.england.nhs.uk/ourwork/gov/research-dev-strategy/

[9] The proportion of those brain tumour patients taking part in clinical trials has not risen above 3.5% in any single year since 2006/2007 NIHR statistic (personal communication).

Stakeholder	Do you agree that the guidance should not be updated?	Do you agree that the guidance should be put on the static list?	Comments on equality issues or areas excluded from the original scope	Comments If you disagree please explain why	Response
The Brain Tumour Charity	No	No		From the patients perspective, we certainly want to prevent this going on the static list as it will remain there untouched for a number of years. Although there have not been many major Development, I believe that the progress on biological markers for the IDH mutation, MGMT methylation and 1p19q is a major reason for updating the Guidance. All relevant brain tumour patients should be tested for these markers as it gives a much more accurate prediction of their outcomes. The scientific evidence is strong enough to make this a special case for not going on the static list.	Thank you for your comment. Following consultation feedback on the proposal not to update the guidance and subsequent consideration of stakeholder comments, NICE has been in discussion with the Department of Health and NHS England about how best to meet the needs of patients with intracerebral tumours and how best to take this forward. Following these discussions, it has been agreed that NICE will formally request a referral from NHS England to develop a guideline on primary brain cancers. A decision on whether the guidance on improving outcomes for people with brain and other CNS tumours should be updated will be deferred pending the finalisation of the scope of new guidance on primary and secondary brain tumours. In light of this decision the proposal is not to put the guidance

Stakeholder	Do you agree that the guidance should not be updated?	Do you agree that the guidance should be put on the static list?	Comments on equality issues or areas excluded from the original scope	Comments If you disagree please explain why	Response
					on the static list at this time.
GDG member	**Agree**	**Yes**	There is increasing evidence that it will be difficult to see improvements in survival for some cancers which have a high primary diagnostic rate from A& E admissions. This indicates delay in diagnosis through the usual primary care pathways. Recent data suggests that UK Brain and CNS diagnosis through A& E is very high >70% and may be associated with worse outcome. The original IOG did not focus on this area, but mainly on pathway delivery. Although recent NIHCE work has provided new draft guidance to GP's across the whole range of Cancer diagnosis and referral, it may be that more creative approaches to attacking this problem are needed to match our European colleagues. (eg: Natalwala A, Bharkhada V, Noel G, Cruickshank G. Comparison of time taken from initial presentation to histological diagnosis of Glioblastoma Multiforme (GBM) in Birmingham, United Kingdom and Strasbourg, France. Clin Neurol Neurosurg. 2011 Jun;113(5):358-61. doi: 10.1016/j.clineuro.2010.10.001. Epub 2011 Apr 5. PubMed	Organisation: a. The relationship between Local brain and CNS neuro MDTs and Network NSSGs and NSDGs is a problem at the moment as local structures have now dissembled, since the loss of Cancer Networks. This means that there is little or no local strategic planning structure available for this cancer type. This will need to be clarified as it is now substantially at variance from the IOG description but perhaps should form a component of Local Commissioning plans. b. The defined MDT structures submitted for agreement and then designated for peer review lack a clear mechanism for updating. This is likely to become much more important when the issues of reconfiguration begin to take shape after the next election, as intimated by NHS England. This issue was assumed to form part of the IOG review but could perhaps from part of the CRG on Brain and CNS tumours work program.	Thank you for your comment. Following consultation feedback on the proposal not to update the guidance and subsequent consideration of stakeholder comments, NICE has been in discussion with the Department of Health and NHS England about how best to meet the needs of patients with intracerebral tumours and how best to take this forward. Following these discussions, it has been agreed that NICE will formally request a referral from NHS England to develop a guideline on primary brain cancers. A decision on whether the guidance on improving outcomes for people with brain and other CNS tumours should be updated will be deferred pending the finalisation of the scope of new guidance on primary and secondary

Stakeholder	Do you agree that the guidance should not be updated?	Do you agree that the guidance should be put on the static list?	Comments on equality issues or areas excluded from the original scope	Comments If you disagree please explain why	Response
			PMID: 21470768) Further exploration of the Post Code access of GP's to scanning needs consideration. Definition of imaging needs to ensure that MRI is the standard for MDT decision making .		brain tumours. In light of this decision the proposal is not to put the guidance on the static list at this time.
				Current Structures: Neuroscience MDT's should remain more or less as they are. This process has made a profound impact on the delivery of the IOG intentions and allowed the establishment of a universal access structure for all UK patients. However these teams are threatened by their own success to become very busy with increasing referrals especially form other cancer types (cerebral mets). We need to ensure that the IOG description of the MDT does not become diluted and that sufficient clarity is given to the roles of the individuals to attend and deliver. For example we would argue that best care for patients is delivered by an MDT where there is a quorum of all the talents to ensure that each patient is reviewed appropriately. This means that continuous (meeting)attendance from the Core team is essential to ensure that patients know that the decision on their care has truly been reached from a compliant MDT.	Thank you for your comment. Following consultation feedback on the proposal not to update the guidance and subsequent consideration of stakeholder comments, NICE has been in discussion with the Department of Health and NHS England about how best to meet the needs of patients with intracerebral tumours and how best to take this forward. Following these discussions, it has been agreed that NICE will formally request a referral from NHS England to develop a guideline on primary brain cancers. A decision on whether the guidance on improving outcomes for people with brain and other CNS tumours

Stakeholder	Do you agree that the guidance should not be updated?	Do you agree that the guidance should be put on the static list?	Comments on equality issues or areas excluded from the original scope	Comments If you disagree please explain why	Response
					should be updated will be deferred pending the finalisation of the scope of new guidance on primary and secondary brain tumours. In light of this decision the proposal is not to put the guidance on the static list at this time.
				MDT Problem Areas: a. Fair representation of all patients irrespective of age. b. Ensuring full core complement in decision making c. Core surgeons attending MDT doing the operating. d. CNS overload form increased MDT activity e. Prolonged MDT meetings – decision fatigue	Thank you for your comment. Following consultation feedback on the proposal not to update the guidance and subsequent consideration of stakeholder comments, NICE has been in discussion with the Department of Health and NHS England about how best to meet the needs of patients with intracerebral tumours and how best to take this forward. Following these discussions, it has been agreed that NICE will formally request a referral from NHS England to develop a guideline on primary brain cancers. A decision on whether the guidance

Stakeholder	Do you agree that the guidance should not be updated?	Do you agree that the guidance should be put on the static list?	Comments on equality issues or areas excluded from the original scope	Comments If you disagree please explain why	Response
					on improving outcomes for people with brain and other CNS tumours should be updated will be deferred pending the finalisation of the scope of new guidance on primary and secondary brain tumours. In light of this decision the proposal is not to put the guidance on the static list at this time.
				Pathology-Updating of Molecular Diagnostic Needs: ie Mandatory access to support Diagnosis, Prognosis, and Prediction of response to treatment. a. MGMT assay for all patients with Glioblastoma- sensitivity to Temozolomide b. 1p 19q LOH assays for patient with Oligodendroglioma- prognosis and drug sensitivity c. IDH1 assays for all gliomas- prognosis and confirmation of diagnosis in equivocal biopsy specimens d. EGFR status for confirmation of true Grade in equivocal Grade III tumours	Thank you for your comment. Following consultation feedback on the proposal not to update the guidance and subsequent consideration of stakeholder comments, NICE has been in discussion with the Department of Health and NHS England about how best to meet the needs of patients with intracerebral tumours and how best to take this forward. Following these discussions, it has been agreed that NICE will formally request a referral from NHS England to develop a

Stakeholder	Do you agree that the guidance should not be updated?	Do you agree that the guidance should be put on the static list?	Comments on equality issues or areas excluded from the original scope	Comments If you disagree please explain why	Response
					guideline on primary brain cancers. A decision on whether the guidance on improving outcomes for people with brain and other CNS tumours should be updated will be deferred pending the finalisation of the scope of new guidance on primary and secondary brain tumours. In light of this decision the proposal is not to put the guidance on the static list at this time.
				Neurosurgical Centres: As well as current IOG technology should also be able to provide: a. Access to awake craniotomy and mapping (De Witt Hamer et al Impact of intraoperative stimulation brain mapping on glioma surgery outcome: a meta–analysis. Journal of Clinical Oncology 30:2559-2565 2012) b. Access to 5 ALA for glioma surgery (Stupp R, Tonn JC, Brada M et al ESMO Clinical Practise Guidelines for diagnosis, treatment and follow-up Ann Oncol 21: 190-193 2010) c. Access to SRS from MDT for deciding about metastatic	Thank you for your comment. Following consultation feedback on the proposal not to update the guidance and subsequent consideration of stakeholder comments, NICE has been in discussion with the Department of Health and NHS England about how best to meet the needs of patients with intracerebral tumours and how best to take this forward. Following these discussions, it has been agreed that NICE will

Stakeholder	Do you agree that the guidance should not be updated?	Do you agree that the guidance should be put on the static list?	Comments on equality issues or areas excluded from the original scope	Comments If you disagree please explain why	Response
				disease management. (National Guidelines for SRS commissioning)	formally request a referral from NHS England to develop a guideline on primary brain cancers. A decision on whether the guidance on improving outcomes for people with brain and other CNS tumours should be updated will be deferred pending the finalisation of the scope of new guidance on primary and secondary brain tumours. In light of this decision the proposal is not to put the guidance on the static list at this time.
Eleanor Grogan on behalf of the Association for Palliative Medicine of Great Britain and Ireland				On behalf of the Association for Palliative Medicine of Great Britain & Ireland, I am happy to agree with the NICE proposal.	Thank you for your comment.
The Walton Centre NHS Foundation Trust	Disagree	Disagree		MGMT is a prognostic biomarker for glioblastoma that can be used in clinical practice to guide treatment (1) and define those patients that will benefit from repeat treatment with temozolomide (2). MGMT status is also relevant to elderly patients with glioblastoma who derive equal benefit from temozolomide alone compared to radiotherapy alone with fewer side	Thank you for your comment. Following consultation feedback on the proposal not to update the guidance and subsequent consideration of stakeholder comments, NICE has been in

Stakeholder	Do you agree that the guidance should not be updated?	Do you agree that the guidance should be put on the static list?	Comments on equality issues or areas excluded from the original scope	Comments If you disagree please explain why	Response
				effects (3). Fluorescence-guided resection has been shown to improve the extent of resection in glioblastoma, which translates to better clinical outcomes (4). References 1. MGMT gene silencing and benefit from temozolomide in glioblastoma. Hegi ME, Diserens AC, Gorlia T, Hamou MF, de Tribolet N, Weller M, Kros JM, Hainfellner JA, Mason W, Mariani L, Bromberg JE, Hau P, Mirimanoff RO, Cairncross JG, Janzer RC, Stupp R. N Engl J Med. 2005 Mar 10;352(10):997-1003. 2. Effects of radiotherapy with concomitant and adjuvant temozolomide versus radiotherapy alone on survival in glioblastoma in a randomised phase III study: 5-year analysis of the EORTC-NCIC trial. Stupp R, Hegi ME, Mason WP, van den Bent MJ, Taphoorn MJ, Janzer RC, Ludwin SK, Allgeier A, Fisher B, Belanger K, Hau P, Brandes AA, Gijtenbeek J, Marosi C, Vecht CJ, Mokhtari K, Wesseling P, Villa S, Eisenhauer E, Gorlia T, Weller M, Lacombe D, Cairncross JG, Mirimanoff RO; European Organisation for Research and Treatment of Cancer	discussion with the Department of Health and NHS England about how best to meet the needs of patients with intracerebral tumours and how best to take this forward. Following these discussions, it has been agreed that NICE will formally request a referral from NHS England to develop a guideline on primary brain cancers. A decision on whether the guidance on improving outcomes for people with brain and other CNS tumours should be updated will be deferred pending the finalisation of the scope of new guidance on primary and secondary brain tumours. In light of this decision the proposal is not to put the guidance on the static list at this time.

Stakeholder	Do you agree that the guidance should not be updated?	Do you agree that the guidance should be put on the static list?	Comments on equality issues or areas excluded from the original scope	Comments If you disagree please explain why	Response
				Brain Tumour and Radiation Oncology Groups; National Cancer Institute of Canada Clinical Trials Group. Lancet Oncol. 2009 May;10(5):459-66. 3. Temozolomide chemotherapy alone versus radiotherapy alone for malignant astrocytoma in the elderly: the NOA-08 randomised, phase 3 trial. Wick W, Platten M, Meisner C, Felsberg J, Tabatabai G, Simon M, Nikkhah G, Papsdorf K, Steinbach JP, Sabel M, Combs SE, Vesper J, Braun C, Meixensberger J, Ketter R, Mayer-Steinacker R, Reifenberger G, Weller M; NOA-08 Study Group of Neuro-oncology Working Group (NOA) of German Cancer Society. Lancet Oncol. 2012 Jul;13(7):707-15. 4. Fluorescence-guided surgery with 5-aminolevulinic acid for resection of malignant glioma: a randomised controlled multicentre phase III trial. Stummer W, Pichlmeier U, Meinel T, Wiestler OD, Zanella F, Reulen HJ; ALA-Glioma Study Group. Lancet Oncol. 2006 May;7(5):392-401.	

Appendix 2 - Decision matrix

The table below provides summaries of the evidence/intelligence that were identified.

Conclusion from the previous surveillance reviews	Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion?	Clinical feedback from the GDG at the 8-year point	Conclusion of this 8-year surveillance review (2014)
Multidisciplinary team (MDT) functioning			
Not applicable	No. One study[1] evaluated the change in practice as a result of implementing the Improving Outcomes Guidance from NICE. Patients were identified from the local cancer registry and hospital databases. Time from diagnosis to treatment, proportion of patients discussed at MDT meetings, treatment received, length of inpatient stay, survival and inpatient and imaging costs were compared. Results showed that service reconfiguration and implementation of NICE guidance resulted in significantly more patients being discussed by the MDT, reduced emergency admission in favour of elective surgery, reduced median hospital stay, increased use of post-operative MRI facilitating early discharge and treatment planning, and reduced cost of inpatient stay. The authors concluded that implementation of the neuro-oncology service reconfiguration in accordance with NICE guidance provided enhanced clinical care for patients. One study[2] investigated the safety of referral of people with suspected brain tumours to a dedicated neuro-oncology MDT in accordance with NICE guidance. Results showed that pre-operative MDT did not lengthen time to operation for patients with brain tumour, however there was a delay in time to operation for abscesses that were inadvertently	One GDG member indicated that they were not sure if all neuroscience centres have capacity for a neuropsychologist to be a core part of the main MDT. However, no references were provided.	The new evidence suggests that MDTs lead to improved outcomes for patients with brain tumours in terms of more patients being discussed by the MDTs, reduced emergency admission in favour of elective surgery, reduced median hospital stay, increased use of post-operative MRI facilitating early discharge and treatment planning, and reduced cost of inpatient stay. Patients' and staff's experiences of MDT follow-up for high-grade glioma after radical radiotherapy were also positive. This is consistent with the evidence presented in the guideline which advocated that multimodal treatment is often necessary for people with brain and other CNS tumours.

Conclusion from the previous surveillance reviews	Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion?	Clinical feedback from the GDG at the 8-year point	Conclusion of this 8-year surveillance review (2014)
	referred via the MDT route. Also, no lesion imaged with MRI was misdiagnosed. The authors advocated the use of MRI to minimise the risk of misdiagnosis of cerebral abscesses One UK study[3] explored the experiences of patients and staff at one UK centre where regular MDT clinics and brain scanning was provided for high-grade glioma after radical radiotherapy. In-depth interviews were conducted with patients and staff. These were transcribed and analysed qualitatively. Patients reported supportive, individualised care with familiar staff; good communication; and that regular scanning was reassuring. Staff believed that team follow-up facilitated immediate decision-making and referral, and reduced visits; they felt that patients valued seeing their scans.		
Not applicable	No. One US retrospective cohort study[4] showed that larger-volume centres had lower mortality rates for patients who underwent craniotomy for meningioma. Complications following discharge were also less likely at high-volume hospitals. With respect to surgeon caseload, there was a trend toward a lower rate of mortality after surgery when higher-caseload providers were involved, and a tendency towards significantly less frequent adverse discharges. The authors concluded that mortality and rates of complication following hospital discharge were lower when meningioma surgery was performed by high-volume providers. One US study[5] analysed the effect of centralisation of caseload for primary brain tumour surgeries.	No clinical feedback was provided through the questionnaire for this section of the guidance.	The new evidence suggests that high-volume hospitals and surgeons lead to improved outcomes for brain and other CNS tumour patients in terms of improved survival/reduced risk of death, fewer complications and decreased length of stay. This is consistent with the evidence presented in the guideline linking higher patient volumes and better surgical care and lower mortality rates.

Conclusion from the previous surveillance reviews	Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion?	Clinical feedback from the GDG at the 8-year point	Conclusion of this 8-year surveillance review (2014)
	Length of stay (LOS), mortality and discharge status were the main outcomes of interest. Results showed that surgeries in high-caseload hospitals increased, while those in low-caseload centres declined. Overall, there was a decrease in mortality but the rate of decrease was higher in high- as compared to low-caseload hospitals; high-caseload centres had lower LOS than hospitals with lower caseload centres. Multivariate analysis showed that patients treated in low-volume hospitals had an increased risk of death and complications following discharge. The authors concluded that there was a trend towards improved in-hospital mortality, LOS and discharge status for all hospitals, however, the trend was convincingly favourable for high-caseload hospitals. A retrospective cohort study[6] investigated recent trends in surgical volume and associated patient outcomes in the treatment of acoustic neuromas in the US. Among others, results showed that high surgical caseload significantly reduced the risk of non-routine discharge and complications.		

References

1. Guilfoyle MR, Weerakkody RA, Oswal A et al. (7-6-2011) Implementation of neuro-oncology service reconfiguration in accordance with NICE guidance provides enhanced clinical care for patients with glioblastoma multiforme. British Journal of Cancer 104:1810-1815.

2. Rittman T, Corns R, Kumar A et al. (2012) Is referral to the neuro-oncology MDT safe? British Journal of Neurosurgery 26:321-324.

3. Catt SLA. (2011) Patients' and staff's experiences of multidisciplinary follow-up for high-grade glioma after radical radiotherapy. Psychology, health & medicine 16:357-365.

4. Curry WT, McDermott MW, Carter BS et al. (2005) Craniotomy for meningioma in the United States between 1988 and 2000: decreasing rate of mortality and the effect of provider caseload. Journal of Neurosurgery 102:977-986.

5. Nuno M, Mukherjee D, Carico C et al. (2012) The effect of centralization of caseload for primary brain tumor surgeries: trends from 2001-2007. Acta Neurochirurgica 154:1343-1350.

6. Patel S, Nuno M, Mukherjee D et al. (2013) Trends in surgical use and associated patient outcomes in the treatment of acoustic neuroma. World Neurosurgery 80:142-147.