NATIONAL INSTITUTE FOR HEALTH AND   
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Quality standards

Briefing paper: Brain tumours and brain metastases in adults

**Quality Standards Advisory Committee meeting**: 16th June 2021

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1. Introduction

This briefing paper presents a structured overview of potential quality improvement areas for brain tumours (primary) and brain metastases in adults. It provides the committee with a basis for discussing and prioritising quality improvement areas for development into draft quality statements and measures for public consultation.

This briefing paper includes a brief description of the topic, a summary of each of the suggested quality improvement areas and supporting information.

Recommendations selected from the key development sources are included to help the committee in considering potential statements and measures.

* 1. Development source

The key development sources referenced in this briefing paper are:

* [Brain tumours (primary) and brain metastases in adults. NICE guideline NG99](https://www.nice.org.uk/guidance/ng99) (2018).
* [Suspected cancer: recognition and referral. NICE guideline NG12](https://www.nice.org.uk/guidance/ng12) (2015).
* [Improving outcomes for people with brain and other central nervous system tumours. NICE cancer service guideline CSG10](https://www.nice.org.uk/guidance/csg10) (2006). The guideline is available on the NICE website. The website indicates that recommendations will be updated and incorporated into the guideline on brain tumours (primary) and brain metastases in adults.

1. Overview
   1. Focus of quality standard

### This quality standard will cover diagnosing, monitoring and managing any type of primary brain tumour or brain metastases in people aged 16 or over.

* 1. Definition

Primary brain tumours come from the brain tissue or its coverings – the meninges. Malignant high-grade gliomas (anaplastic gliomas and glioblastomas) and pre-malignant low-grade gliomas come from the brain tissue glial cells and make up over 60% of primary brain tumours. Meningiomas make up a further 30%. Although often thought benign, meningiomas can have an acute presentation and are associated with significant long-term neurological morbidity. Because of this, they can behave in a malignant fashion in terms of recurrence and impact.

Cancers that have spread to the brain from somewhere else in the body are called secondary brain tumours, or brain metastases. Many different cancer types can spread to the brain, with lung and breast cancers being the most common.

There are many different types of brain tumour and they can cause a wide range of symptoms depending on the kind of tumour, where it is, where it has come from, if it is a metastasis and how quickly it is growing.

* 1. Incidence and prevalence

It is estimated there are around 10,000 new cases of primary brain tumours per year. The peak age of presentation of brain cancer is between 65 and 69. Although primary malignant brain tumours represent only 3% of all cancers, they result in the most life-years lost of any cancer. There is concern that the true incidence of these tumours is rising.

More people with systemic cancers are surviving longer and are referred to neuroscience multidisciplinary teams for management of their brain metastases. The number of people needing assessment for cranial treatment is now over 10,000 per year in the UK and rising.

The singular effects of brain tumours on mental performance (both psychological state and cognitive decline) are a particular challenge to carers and professionals alike, especially in delivering support to people at home.

* 1. Current service delivery and management

Over 60% of people with primary brain tumours present at, and are diagnosed by, accident and emergency services rather than from conventional GP or specialist referral. This causes a significant demand on these services.

The specialist nature of neuro-imaging and the need for complex diagnostic and reductive surgery emphasises the importance of well-organised service delivery by dedicated units. There are concerns that delivery of all services to older people is suboptimal. There are also concerns that the transition from paediatric to adult units could create a care gap.

Survival with malignant brain tumours has remained poor despite some improvements in surgery, radiotherapy and chemotherapy, and a greater understanding of molecular classification.

The management of a low-grade glioma that is likely to transform to high grade remains controversial and presents issues for ongoing care. Follow‑up for people with meningiomas after primary treatment is often long term, and there is variation in both follow‑up and treatments for recurrence.

Conventional whole-brain irradiation as optimal therapy for brain metastases is being challenged by concerns about its effectiveness and toxicity, as well as the availability and immediacy of surgery and stereotactic radiotherapy.

Neuro-oncology services are commissioned by NHS England. Providers are NHS hospital trusts.

See [appendix 1](#_Appendix_1:_Additional) for the visual summary for glioblastoma management from NICE’s guideline on brain tumours (primary) and brain metastases in adults.

* 1. Resource impact

We do not expect this quality standard to have a significant impact on NHS resource use. When the NICE guideline on Brain tumours (primary) and brain metastases in adults (NG99) was in development, the resource impact of the recommendations was assessed and it was anticipated that only one recommendation would have a significant resource impact, this was recommendation 1.2.36 on 5-ALA fluoroscopy guided resection. We do not anticipate that the resource impact of the quality standard will exceed the costs discussed when the resource impact tools were developed for that guideline.

1. Summary of suggestions
   1. Responses

In total 12 registered stakeholders responded to the 2-week engagement exercise.

* 12 registered stakeholders suggested areas

6 specialist committee members suggested areas

The responses have been summarised in table 1 for further consideration by the committee.

* 1. Priorities for committee discussion

Table 1 Summary of information available for suggested areas for improvement

| Suggested area for improvement | Stakeholder | In scope | Guideline recs | Current practice evidence | Existing QS statement | Priority to discuss? |
| --- | --- | --- | --- | --- | --- | --- |
| **Investigations**   * Rapid access to MRI * Additional imaging/testing | * BTR, BSNR, NHSE&I, P-CNS, RCN, SCMs, SCR * SCMs | Yes  Yes | Yes  Yes | Yes  Yes | Yes  No | **Yes**  **Yes** |
| **Management/Treatment**   * Multidisciplinary team * Treatment pathway * Maximal safe surgical resection * Stereotactic radiosurgery for multiple brain metastases | * BTC, NCRI-ACP-RCP, NHSE&I, SANON * SCM, SBNS * SCM, SANON, SBNS * SCM | Yes  Yes  Yes  Yes | Yes  No  Yes  Yes (consider) | Yes  Yes  Yes  Yes | No  No  No  No | **Yes**  **No**  **Yes**  **No** |
| **Follow-up**   * Imaging * Advanced imaging | * BTR, BSNR, SCM * BSNR, SCM | Yes  Yes | Yes (consider)  Yes (consider) | Yes  Yes | No  No | **No**  **No** |
| **Care needs of people with brain tumours**   * Holistic needs assessment * Named healthcare professional * Specific support | * BT, BTC, NCRI-ACP-RCP, NHSE&I, P-CNS, SBNS * BT, BTC, NHSE&I, SCMs * BTC, NCRI-ACP-RCP, NHSE&I, SCM, SANON | Yes  Yes  Yes | Yes  Yes  Yes | Yes  Yes  Yes | No  No  No | **Yes**  **Yes**  **Yes** |
| **Neurorehabilitation**   * Assessment for neurorehabilitation * Access to neurorehabilitation services | * SCMs * BT, NHSE&I, SBNS | Yes  Yes | Yes  Yes | Yes  Yes | No  No | **Yes**  **Yes** |
| **Surveillance for late-onset side effects of treatment** | * NHSE&I, SCMs | Yes | Yes | No | No | **Yes** |
| **Additional areas**   * Clinical trials/research * End of life care * Employment support * Quality of life questionnaires | * BSNR, BTC, NCRI-ACP-RCP, NHSE&I, SANON * BT, CiD * SCM * SCM | No  Yes  Yes  No | No  Yes  No  No | N/A  N/A  N/A  N/A | No  Yes  Yes  No | **No**  **No**  **No**  **No** |

Abbreviations:

* BT, Braintrust
* BTC, The Brain Tumour Charity
* BTR, Brain Tumour Research
* BSNR, British Society of Neuroradiologists
* CiD, Compassion in Dying
* NCRI-ACP-RCP, National Cancer Research Institute, Association of Cancer Physicians, Royal College of Physicians
* NHSE&I, NHS England and NHS Improvement
* P-CNS, Primary Care and Community Neurology Society
* RCN, Royal College of Nursing
* SANON, Scottish Adult Neuro-oncology Network
* SBNS, Society of British Neurological Surgeons
* SCM, Specialist Committee Member
* SCR, Society and College of Radiographers

Full details of all the suggestions provided are given in appendix 3 for information.

1. Suggested improvement areas

Section 4 presents a summary of the suggested improvement areas, with provisional recommendations that may support statement development and information on current UK practice.

* 1. Investigations

### Rapid access to Magnetic Resonance Imaging (MRI)

Stakeholders indicated that diagnosis of a brain tumour is often late following presentation in an emergency setting. It is therefore important to improve access to neuroimaging from primary care to support earlier diagnosis as some people attend primary care multiple times. Stakeholders indicated that there needs to be better recognition of the key signs and symptoms in primary care to support earlier referral for imaging. It is important that people with a suspected brain tumour have contrast enhanced MRI before referral to the multi-disciplinary team, however, some people attend the 2 week wait clinics without an MRI scan. It was noted that some people may have Computed Tomography (CT) initially which results in unnecessary radiation. It was suggested that there is currently considerable variation in speed of access to imaging and the imaging modality available.

#### Selected recommendations

NICE’s guideline on suspected cancer (NG12):

1.9.1 Consider an urgent direct access MRI scan of the brain (or CT scan if MRI is contraindicated) (to be performed within 2 weeks) to assess for brain or central nervous system cancer in adults with progressive, sub‑acute loss of central neurological function.

NICE’s guideline on brain tumours (primary) and brain metastases in adults (NG99):

1.1.1 Offer standard structural MRI (defined as T2 weighted, FLAIR, DWI series and T1 pre- and post-contrast volume) as the initial diagnostic test for suspected glioma, unless MRI is contraindicated.

1.4.1 Offer standard structural MRI (defined as T2 weighted, FLAIR, DWI series and T1 pre- and post-contrast volume) as the initial diagnostic test for suspected meningioma, unless MRI is contraindicated.

1.6.1 Offer standard structural MRI (defined as T2 weighted, FLAIR, DWI series and T1 pre- and post-contrast volume) as the initial diagnostic test for suspected brain metastases, unless MRI is contraindicated.

#### Statements in existing quality standards

NICE’s quality standard on suspected cancer (QS124), statement 1:

GPs have direct access to diagnostic endoscopy, ultrasound, MRI, X-ray and CT for people with suspected cancer.

#### Current UK practice

The [Diagnostic Imaging Dataset Annual Statistical Release 2019/20](https://www.england.nhs.uk/statistics/statistical-work-areas/diagnostic-imaging-dataset/diagnostic-imaging-dataset-2019-20-data/) indicated that GP direct referrals for brain MRI increased from 31,035 in 2012-13 to 90,970 in 2019-20. There was growth of 4.2% in the number of GP direct referrals for brain MRI between 2018-9 and 2019-20. In 2019-20 GP direct referrals were 11.3% of all referrals for brain MRI.

[NHS England’s National Cancer Patient Experience Survey 2019](https://www.ncpes.co.uk/) indicated that 44% of people with brain/central nervous system cancer (sample=299) went straight to hospital about their cancer, 20% saw their GP once before being referred to hospital and 20% saw their GP 3 or more times before being referred.

A British Journal of General Practice (2018) report on [Diagnosing cancer in primary care: results from the National Cancer Diagnosis Audit](https://bjgp.org/content/68/666/e63) indicated that in 2014, 9% of people diagnosed with brain cancer (sample=265) were referred through the two week wait route and 65% were diagnosed following an emergency referral. The report indicated that there was an avoidable delay in diagnosis in 17% of people with brain cancer. 9.3% of patients with brain cancer had primary-care led imaging as part of the diagnostic assessment prior to referral.

### Additional imaging/testing

Stakeholders suggested that there is a need to ensure that additional imaging and testing is carried out as follows:

* Good molecular marker testing can improve outcomes for people with glioma. This is a new and emerging area, and it is important to highlight best practice to clinicians.
* Extracranial imaging should be undertaken for people with metastases that is suitable for focal treatment to support decision making at the multidisciplinary team.

#### Selected recommendations

NICE’s guideline on brain tumours (primary) and brain metastases in adults (NG99):

1.1.4 Report all glioma specimens according to the latest version of the World Health Organization (WHO) classification of tumors of the central nervous system. As well as histopathological assessment, include molecular markers such as:

* IDH1 and IDH2 mutations
* ATRX mutations to identify IDH mutant astrocytomas and glioblastomas
* 1p/19q codeletion to identify oligodendrogliomas
* histone H3.3 K27M mutations in midline gliomas
* BRAF fusion and gene mutation to identify pilocytic astrocytoma.

1.1.5 Test all high-grade glioma specimens for MGMT promoter methylation to inform prognosis and guide treatment.

1.1.6 Consider testing IDH-wildtype glioma specimens for TERT promoter mutations to inform prognosis.

1.6.2 To help establish current disease status, offer extracranial imaging (appropriate to the primary tumour type) to people with any radiologically suspected brain metastases that may be suitable for focal treatment.

#### Current UK practice

The [Scottish Adult Neuro Oncology Network report of the 2019 clinical audit data for brain and central nervous system cancers](https://www.sanon.scot.nhs.uk/audit/) indicated that 48% of patients with biopsied or resected gliomas in Scotland underwent 1p/19q molecular analysis of tumour tissue within 21 days of surgery. This compared with 55% in 2018. Additionally, 84% of patients with biopsied or resected gliomas in Scotland in 2019 underwent MGMT promoter hypermethylation status testing within 21 days of surgery. This compared with 80% in 2018.

### Issues for consideration

**For discussion:**

* Can we add anything to the existing quality statement on direct access to diagnostic tests in QS124?
* What is the priority for improvement?
* What is the key action that will lead to improvement?
* Can we develop a specific, measurable statement?

**For decision:**

* Should this area be prioritised for inclusion in the quality standard?
  1. Management/treatment

### Multidisciplinary team (MDT)

Stakeholders suggested that it is important that the treatment and care for people with brain cancer is managed by a multidisciplinary team as this can improve patient outcomes and satisfaction and reduce costs. It was suggested that the team should include specialists and allied health professionals and that single consultant clinics/services should be avoided. Monitoring of treatment related morbidity and mortality was felt to be important to ensure that treatment is undertaken in people who can benefit from it.

#### Selected recommendations

NICE’s guideline on brain tumours (primary) and brain metastases in adults (NG99):

1.1.2 Refer people with a suspected glioma to a specialist multidisciplinary team at first radiological diagnosis for management of their tumour.

1.2.1 The surgical expertise in the multidisciplinary team should include:

* access to awake craniotomy with language and other appropriate functional monitoring and
* expertise in intraoperative neurophysiological monitoring and
* access to neuroradiological support and
* access to intraoperative image guidance.

NICE’s guidance on cancer services: improving outcomes for people with brain and other CNS tumours (CSG10, key recommendations):

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

* a designated lead in every acute trust (see [Table 6](https://www.nice.org.uk/guidance/csg10))
* a neuroscience brain and other CNS tumours multidisciplinary team (MDT), usually based at a neuroscience centre (see [Tables 7 and 8)](https://www.nice.org.uk/guidance/csg10)
* a cancer network brain and other CNS tumours MDT (see Tables [9 and 10](https://www.nice.org.uk/guidance/csg10))
* a key worker

#### Current UK practice

The [Scottish Adult Neuro Oncology Network report of the 2019 clinical audit data for brain and central nervous system cancers](https://www.sanon.scot.nhs.uk/audit/) indicated that 74% of patients with brain/CNS cancer in Scotland were discussed at MDT meeting before surgery. This compared to 77% in 2018.

### Treatment pathway

Stakeholders suggested changes to the treatment pathway to improve outcomes for people with brain cancer as follows:

* Include prehabilitation to improve treatment effectiveness and survival
* Schedule elective rather than emergency admission for surgery and plan discharge 24-48 hours post-surgery
* Reduce the time from MDT discussion to surgical clinic pathway to 1 week
* Reduce the pathway from decision for surgery to surgery from 31 to 14 days
* Reduce the post-surgery to radiotherapy pathway for primary brain cancer to 4 weeks

#### Selected recommendations

This area is not directly covered in NICE guidelines and no recommendations are presented.

#### Current UK practice

The 2018 [Getting it Right First Time (GIRFT) report on cranial neurosurgery](https://gettingitrightfirsttime.co.uk/surgical-specialty/cranial-neurosurgery/) indicated that several providers stated that they admit patients diagnosed with high-grade glioma on the point of referral. Once in the hospital, the patients are placed on the non-elective list for emergency surgery – theoretically providing the quickest route to removal. However, emergency surgery then proves hard to schedule. Glioma patients are invariably pushed down that list when other patients are admitted with more urgent conditions. This in turn means the glioma patients may find themselves in hospital for some days before they are operated on. On average, glioma patients admitted on referral waited three days in hospital before surgery. However, 18% of patients didn’t have surgery until six or more days after admission. The report recommended that there should be an urgent elective pathway for glioma as patients are managed more effectively via the elective stream with average length of stay of 6.4 days compared to 13.4 days for those admitted non-electively.

### Maximal safe surgical resection

Stakeholders highlighted the importance of maximal safe surgical resection for high grade glioma to improve prognosis and survival. Usage of 5ALA guidance can help to achieve this. Although all UK neurosurgery units now have access to 5ALA, rates of usage vary. A stakeholder also emphasised the importance of ensuring that surgical neuro-oncologists are up to date with the latest technology and the use of intraoperative ultrasound or MRI was also recommended. It was suggested that access to intra-operative imaging varies.

#### Selected recommendations

NICE’s guideline on brain tumours (primary) and brain metastases in adults (NG99):

1.2.36 If a person has a radiologically enhancing suspected high-grade glioma and the multidisciplinary team thinks that surgical resection of all enhancing tumour is possible, offer 5‑aminolevulinic acid (5‑ALA)-guided resection as an adjunct to maximise resection at initial surgery.

1.2.37 Consider intraoperative MRI to help achieve surgical resection of both low-grade and high-grade glioma while preserving neurological function, unless MRI is contraindicated.

1.2.38 Consider intraoperative ultrasound to help achieve surgical resection of both low-grade and high-grade glioma.

#### Current UK practice

The [Scottish Adult Neuro Oncology Network report of the 2019 clinical audit data for brain and central nervous system cancers](https://www.sanon.scot.nhs.uk/audit/) indicated that 75% of patients in Scotland with malignant glioma (with enhancing component on preoperative imaging) underwent surgical resection where 90% or greater reduction in tumour volume was achieved provided it was considered consistent with safe outcome. This compared with 59% in 2018.

The [2019/20 annual report for The Brain Tumour Charity](https://www.thebraintumourcharity.org/about-us/annual-report-and-accounts/) indicated that 5-ALA is now available in all treatment centres across the UK.

### Stereotactic radiosurgery for multiple brain metastases

It was suggested that focal treatment for brain metastases can provide lasting control without further neurocognitive impact. Stereotactic radiosurgery (SRS) can help people with multiple brain metastases, good performance status and controlled/controllable extra-cranial disease. It was reported that currently the number of centres offering SRS is limited and people may have to be referred to a centre outside their region which can be a barrier to accessing treatment.

#### Selected recommendations

NICE’s guideline on brain tumours (primary) and brain metastases in adults (NG99):

1.7.6 See [NHS England's clinical commissioning policy on stereotactic radiosurgery and stereotactic radiotherapy to the surgical cavity following resection of cerebral metastases](https://www.england.nhs.uk/publication/clinical-commissioning-policy-stereotactic-radiosurgery-srs-and-stereotactic-radiotherapy-srt-to-the-surgical-cavity-following-resection-of-cerebral-metastases-all-ages/).

1.7.7 Consider stereotactic radiosurgery/radiotherapy for people with multiple brain metastases who have controlled or controllable extracranial disease and Karnofsky performance status of 70 or more. Take into account the number and total volume of metastases.

#### Current UK practice

Stereotactic radiosurgery (SRS) or stereotactic radiotherapy (SRT), is often the primary treatment for cerebral metastases. In some cases, the cerebral metastasis is too large for SRS / SRT and surgical removal is the alternative treatment option. In most cases, surgery will result in the metastasis being completely removed. Where it is not possible to completely remove the metastasis with surgery (incomplete surgical removal), the standard practice is to offer SRS / SRT shortly after surgery, in accordance with [NHS England’s clinical commissioning policy on SRS / SRT for Cerebral Metastases](https://www.england.nhs.uk/commissioning/spec-services/npc-crg/group-b/b01/). Some centres offered SRS/SRT to the surgical cavity shortly following complete surgical removal of a metastasis, however, [NHS England's clinical commissioning policy on stereotactic radiosurgery and stereotactic radiotherapy to the surgical cavity following resection of cerebral metastases](https://www.england.nhs.uk/publication/clinical-commissioning-policy-stereotactic-radiosurgery-srs-and-stereotactic-radiotherapy-srt-to-the-surgical-cavity-following-resection-of-cerebral-metastases-all-ages/) (2021) indicates that SRS and SRT is not recommended to be available as a treatment option through routine commissioning for the treatment of the surgical cavity following resection of cerebral metastases (all ages).

The 2018 [Getting it Right First Time (GIRFT) report on cranial neurosurgery](https://gettingitrightfirsttime.co.uk/surgical-specialty/cranial-neurosurgery/) noted that based on Hospital Episode Statistics (HES) only 4 out of 24 cranial neurosurgery providers were undertaking a significant volume of stereotactic radiosurgery. The GIRFT review found that this is misleading as the procedure is conducted regularly by the majority of providers but many record stereotactic radiosurgery in HES as an oncology procedure rather than cranial neurosurgery.

### Resource impact

During development of NG99, recommendation 1.2.36 was highlighted as a significant change in practice with the use of 5-ALA guided resection expected to double following publication of the guidance. The increased costs associated with this procedure were weighed against an expected increase in the number of complete resections and consequent reduction in the number of follow-up surgeries. The net cost to the NHS of this recommendation was expected to be £2.58m per year for England.

### Issues for consideration

**For discussion:**

* Do you agree with our suggestion that treatment pathways and stereotactic radiosurgery for multiple brain metastases do not need to be discussed during the meeting given the recommendations available?
* What are the specific issues in relation to access to a multidisciplinary team e.g., access, membership, responsibilities?
* Are there concerns about the resource impact of 5-ALA?
* What is the priority for improvement?
* What is the key action that will lead to improvement?
* Can we develop a specific, measurable statement?

**For decision:**

* Should this area be prioritised for inclusion in the quality standard?
  1. Follow-up

### Imaging

Stakeholders emphasised the importance of improving the quality of and access to imaging to inform clinical management. The priorities highlighted were:

* Standardisation of MRI imaging protocols to improve accuracy in assessment of brain tumours
* Consistent imaging schedules during treatment and surveillance
* Improve clinical information on requests for imaging e.g., via an electronic referral system
* Ensure that imaging, reporting and consultation are carried out in one hospital visit to reduce delays

#### Selected recommendations

NICE’s guideline on brain tumours (primary) and brain metastases in adults (NG99):

1.3.3 Consider the follow‑up schedule given in table 3 for people with glioma.

Table 3 Possible regular clinical review schedule for people with glioma depending on grade of tumour

|  |  |
| --- | --- |
| **Grade of tumour** | **Clinical review schedule** |
| **Grade I** | Scan at 12 months, then:   * consider discharge if no tumour visible on imaging unless completely-resected pilocytic astrocytoma * consider ongoing imaging at increasing intervals for 15 years for completely-resected pilocytic astrocytoma * consider if ongoing imaging is needed at a rate of once every 1 to 3 years for the rest of the person's life if the tumour is visible on imaging. |
| **Grade II 1p/19q non-codeleted, IDH mutated**  **Grade II 1p/19q codeleted**  **Grade III 1p/19q codeleted** | * From 0 to 2 years, scan at 3 months, then every 6 months * From 2 to 4 years, review annually * From 5 to 10 years, review every 1 to 2 years * For more than 10 years and for the rest of life consider ongoing imaging every 1 to 2 years. |
| **Grade II IDH wildtype**  **Grade III 1p/19q non-codeleted**  **Grade IV (glioblastoma)** | * From 0 to 2 years, review every 3 to 6 months * From 2 to 4 years, review every 6 to 12 months * From 5 to 10 years, review annually * For more than 10 years and for the rest of life - consider ongoing imaging every 1 to 2 years. |

1.3.4 Consider standard structural MRI (defined as T2 weighted, FLAIR, DWI series and T1 pre- and post-contrast volume) as part of regular clinical review for people with glioma, to assess for progression or recurrence, unless MRI is contraindicated.

1.3.7 Consider a baseline MRI scan within 72 hours of surgical resection for all types of glioma.

1.3.8 Consider a baseline MRI scan 3 months after the completion of radiotherapy for all types of glioma.

1.5.3 Consider the follow‑up schedule given in table 7 for people with meningioma.

Table 7 Possible regular clinical review schedule by years after end of treatment for people with meningioma depending on grade of tumour

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | **Grade I: no residual tumour** | **Grade I: residual tumour** | **Grade I: after radiotherapy** | **Grade II** | **Grade III** |
| **0 to 1 years** | Scan at 3 months | Scan at 3 months | Scan 6 months after radiotherapy | Scan at 3 months, then 6 to 12 months later | Every 3 to 6 months |
| **1 to 2 years** | Annually | Annually | Annually | Annually | Every 3 to 6 months |
| **2 to 3 years** | Annually | Annually | Annually | Annually | Every 6 to 12 months |
| **3 to 4 years** | Once every 2 years | Annually | Once every 2 years | Annually | Every 6 to 12 months |
| **4 to 5 years** | Once every 2 years | Annually | Once every 2 years | Annually | Every 6 to 12 months |
| **5 to 6 years** | Once every 2 years | Once every 2 years | Once every 2 years | Once every 2 years | Annually |
| **6 to 7 years** | Once every 2 years | Once every 2 years | Once every 2 years | Once every 2 years | Annually |
| **7 to 8 years** | Once every 2 years | Once every 2 years | Once every 2 years | Once every 2 years | Annually |
| **8 to 9 years** | Once every 2 years | Once every 2 years | Once every 2 years | Once every 2 years | Annually |
| **>9 years (for the rest of life)** | Consider discharge | Consider discharge | Consider discharge | Consider discharge | Annually |

#### For asymptomatic incidental meningioma: scan at 12 months and if no change, consider discharge or scan at 5 years.

#### Note: the presence of any residual tumour can only be established after the first scan at 3 months.

1.5.4 Consider standard structural MRI (defined as T2 weighted, FLAIR, DWI series and T1 pre- and post-contrast volume) as part of regular clinical review for people with meningioma, to assess for progression or recurrence, unless MRI is contraindicated.

1.8.3 Consider the follow‑up schedule given in table 11 for people with brain metastases.

Table 11 Possible regular clinical review schedule for people with brain metastases

|  |  |
| --- | --- |
| **Years after end of treatment** | **Clinical review schedule** |
| 0 to 1 years | Every 3 months |
| 1 to 2 years | Every 4 to 6 months |
| 2 years and onwards | Annually |

1.8.4 Consider standard structural MRI (defined as T2 weighted, FLAIR, DWI series and T1 pre- and post-contrast volume) as part of regular clinical review for people with brain metastases, to assess for progression or recurrence, unless MRI is contraindicated.

#### Current UK practice

A study of current imaging practices amongst UK neuro-oncology centres ([Booth et al Glioblastoma post-operative imaging in neuro-oncology: current UK practice (GIN CUP study)](https://link.springer.com/article/10.1007/s00330-020-07387-3)) found that most centres routinely performed an early post-operative MRI (87%, 27/31), whereas only a third performed a pre-radiotherapy MRI (32%, 10/31). The number and timing of scans routinely performed during adjuvant TMZ treatment varied widely between centres. At the end of the adjuvant period, most centres performed an MRI (71%, 22/31), followed by monitoring scans at 3 monthly intervals (81%, 25/31). Additional short-interval imaging was carried out in cases of possible pseudoprogression in most centres (71%, 22/31).

The [Scottish Adult Neuro Oncology Network report of the 2019 clinical audit data for brain and central nervous system cancers](https://www.sanon.scot.nhs.uk/audit/) indicated that 95% of patients in Scotland with malignant glioma (with enhancing component on pre-operative imaging) received early post-operative imaging with MRI within 3 days (72 hours) of surgical resection. This compared with 92% in 2018 and 90% in 2017.

[The Brain Tumour Charity report Finding myself in your hands, the reality of brain tumour treatment and care](https://www.thebraintumourcharity.org/about-us/our-publications/finding-myself/) reported that, based on a survey of 927 people with a brain tumour in 2015, one in four did not feel the amount of time they had to wait for the results of tests or scans at review was reasonable.

### Advanced imaging

There was a suggestion that a more consistent approach is needed to the application of advanced imaging techniques. Some advanced techniques are widely available, but their use may not be routine. Access to other advanced techniques is more limited. It was suggested that it would be helpful to confirm the status of these techniques so that it is clear if they should be part of standard care. MR perfusion imaging was highlighted as a priority as there is variation in practice.

#### Selected recommendations

NICE’s guideline on brain tumours (primary) and brain metastases in adults (NG99):

1.3.5 Consider advanced MRI techniques, such as MR perfusion, diffusion tensor imaging and MR spectroscopy, if findings from standard imaging are unclear about whether there is recurrence and early identification is potentially clinically useful.

1.8.5 Consider advanced MRI techniques, such as MR perfusion, diffusion tensor imaging and MR spectroscopy, if findings from standard imaging are unclear about whether there is recurrence and early identification is potentially clinically useful.

#### Current UK practice

A study of current imaging practices amongst UK neuro-oncology centres ([Booth et al Glioblastoma post-operative imaging in neuro-oncology: current UK practice (GIN CUP study)](https://link.springer.com/article/10.1007/s00330-020-07387-3)) found that routine use of advanced imaging was infrequent; however, the addition of advanced sequences was the most popular suggestion for ideal imaging practice.

### Issues for consideration

**For discussion:**

* Do you agree with our suggestion that these areas do not need to be discussed during the meeting given the recommendations available?
  1. Care needs of people with brain tumours

### Holistic needs assessment

Stakeholders suggested that people with brain tumours and their carers should have holistic needs assessments following diagnosis and at transition points so that they can access the support they need to optimise their quality of life. The needs assessments should inform a regularly refreshed personalised care plan. The importance of supporting shared decision making was emphasised. For people at risk of cognitive decline the assessment should include neuropsychology assessments. It was highlighted that a completed needs assessment should be sent to the GP on completion of radiotherapy. It was suggested that it is a priority to ensure that people aged 16-25 years have holistic needs assessments to ensure they receive the long-term support they may need.

#### Selected recommendations

NICE’s guideline on brain tumours (primary) and brain metastases in adults (NG99):

1.9.2 Discuss health and social care support needs with the person with a brain tumour and their relatives and carers (as appropriate). Take into account the complex health and social care support needs people with any type of brain tumour and their relatives and carers may have (for example, psychological, cognitive, physical, spiritual, emotional).

1.9.3 Set aside enough time to discuss the impact of the brain tumour on the person and their relatives and carers (as appropriate), and to elicit and discuss their health and social care support needs.

#### Current UK practice

[Brainstrust summary of results from the national cancer patient survey 2019](https://brainstrust.org.uk/ncpes-2019/) for people with brain tumours highlighted that 27.5% were given a care plan and this figure has been consistent since 2014.

### Named healthcare professional

A named healthcare professional, such as a clinical nurse specialist, was felt to be important to coordinate health and social care support for people with brain tumours and their carers. This is a priority because individual needs are complex, care is provided across a number of services and it can improve patient experience. It was suggested that the role could also be managed by allied healthcare professionals or therapeutic radiographers with an advanced practice role. There is variation in access to a named healthcare professional and, it was suggested that people who are diagnosed following an emergency presentation are often left without this support. In addition, in some hospitals, people with a meningioma and other low-grade tumours are also not offered a named healthcare professional.

#### Selected recommendations

NICE’s guideline on brain tumours (primary) and brain metastases in adults (NG99):

1.9.5 Provide a named healthcare professional with responsibility for coordinating health and social care support for people with brain tumours and their relatives and carers, for example, a key worker (often a clinical nurse specialist) as defined in NICE cancer service guidance on improving outcomes for people with brain and other central nervous system tumours.

NICE’s guidance on cancer services: improving outcomes for people with brain and other CNS tumours (CSG10, Section 2 recommendations):

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

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

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

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

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

#### Current UK practice

[NHS England’s National Cancer Patient Experience Survey 2019](https://www.ncpes.co.uk/) indicated that 93% of people with a brain/central nervous system tumour were given the name of a clinical nurse specialist who would support them through treatment. [Brainstrust summary of results from the national cancer patient survey 2019](https://brainstrust.org.uk/ncpes-2019/) reported that 86% found it quite easy to contact their clinical nurse specialist.

[The Brain Tumour Charity report Finding myself in your hands, the reality of brain tumour treatment and care](https://www.thebraintumourcharity.org/about-us/our-publications/finding-myself/) reported that, based on a survey of 927 people with a brain tumour in 2015, 58% had a single point of contact with their healthcare team, 32% did not, and the remainder were unsure. 76% of respondents with a high-grade tumour said that they had a single point of contact, compared to 53% of those with a low-grade tumour.

### Specific support

Stakeholders highlighted the need to ensure that people with brain tumours are signposted/referred to the support they need following diagnosis and at key points in the treatment and care pathway. This should include:

* Ensuring people presenting with seizures are seen by a neurologist/ epilepsy specialist nurse for diagnosis of epilepsy
* Providing neuropsychology and clinical psychology support along the whole patient pathway
* Access to allied health professionals to support people through survivorship e.g., physiotherapy, speech and language
* Consistent advice on driving
* Signposting to support groups and charities

#### Selected recommendations

NICE’s guideline on brain tumours (primary) and brain metastases in adults (NG99):

1.9.4 Health and social care professionals involved in the care of people with brain tumours should address additional complex needs during or at the end of treatment and throughout follow‑up. These include:

* changes to cognitive functioning
* fatigue
* loss of personal identity
* loss of independence
* maintaining a sense of hope
* potential for change in personal and sexual relationships
* the challenges of living with uncertainty
* the impact of brain tumour-associated epilepsy on wellbeing (see the NICE guideline on epilepsies: diagnosis and management).

1.9.7 Explain to the person that they have a legal obligation to notify the Driver and Vehicle Licensing Agency (DVLA) if they have a brain tumour, and that this may have implications for their driving.

1.9.9 Offer supportive care to people with brain tumours and their relatives and carers (as appropriate) throughout their treatment and care pathway.

NICE’s guidance on cancer services: improving outcomes for people with brain and other CNS tumours (CSG10, Section 8 recommendations):

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

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

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

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

#### Current UK practice

[NHS England’s National Cancer Patient Experience Survey 2019](https://www.ncpes.co.uk/) reported that 83% of people with a brain/central nervous system tumour (sample=299) said that hospital staff gave them information about support or self-help groups for people with cancer. 14% said that they were not given enough care and support from health or social care services such as district nurse, home helps or physiotherapists during their treatment. 11% indicated that once their treatment finished, they were not given enough care and support from health or social services.

The [Scottish Adult Neuro Oncology Network report of the 2019 clinical audit data for brain and central nervous system cancers](https://www.sanon.scot.nhs.uk/audit/) indicated that 37% of patients with brain/CNS cancer presenting with seizures at diagnosis were seen by a neurologist or a named epilepsy specialist nurse within four weeks of diagnosis. This compared with 39% in 2018 and 76% in 2017.

[The Brain Tumour Charity report Finding myself in your hands, the reality of brain tumour treatment and care](https://www.thebraintumourcharity.org/about-us/our-publications/finding-myself/) reported that, based on a survey of 927 people with a brain tumour in 2015, 43% had not accessed support services, 30% had accessed physiotherapy, 29% occupational therapy, 25% a psychologist, 14% speech and language therapy, 11% dietitian and 12% other support. The most common response amongst patients with a low-grade tumour was to say that they had not accessed any support service at all.

### Issues for consideration

**For discussion:**

* Is it significant that the guideline does not refer to needs assessments and care plans?
* What does supportive care mean in practice?
* What is the priority for improvement?
* What is the key action that will lead to improvement?
* Can we develop a specific, measurable statement?

**For decision:**

* Should this area be prioritised for inclusion in the quality standard?
  1. Neurorehabilitation

### Assessment for neurorehabilitation

As neurorehabilitation can improve function (cognition, mobility and neuroplasticity) in people with brain tumours it was suggested that assessment for rehabilitation should be considered at every stage of treatment and follow-up and information should be provided about how to get an assessment and the local neurological rehabilitation options. It was suggested that assessment for rehabilitation is currently limited and patchy.

#### Selected recommendations

NICE’s guideline on brain tumours (primary) and brain metastases in adults (NG99):

1.10.1 Consider referring the person with a brain tumour for a neurological rehabilitation assessment of physical, cognitive and emotional function at diagnosis and every stage of follow‑up.

1.10.3 Give people with brain tumours and their relatives and carers (as appropriate) information on:

* neurological rehabilitation options in the community, as an outpatient, or an inpatient and
* how to get a neurological rehabilitation assessment.

#### Current UK practice

The [NICE guideline on brain tumours (primary) and brain metastases in adults](https://www.nice.org.uk/guidance/ng99) indicates that, based on committee experience, there is currently variation in practice in assessing whether people with a brain tumour need neurological rehabilitation. Some of this reflects the availability of neurological rehabilitation services.

### Access to neurorehabilitation services

Stakeholders highlighted the importance of ensuring that people with brain tumours can access neurorehabilitation services to improve outcomes and quality of life. It was suggested that community-based services are important to reduce pressure on hospitals. The availability of rehabilitation pre- and post-surgery was highlighted as a priority.

#### Selected recommendations

NICE’s guideline on brain tumours (primary) and brain metastases in adults (NG99):

1.10.2 Offer people with brain tumours and their relatives and carers (as appropriate) information on accessing neurological rehabilitation, and on what needs it can help address.

NB: The scope of NICE guideline NG99 did not include neurorehabilitation services as this will be covered in the NICE guideline on rehabilitation for chronic neurological disorders including traumatic brain injury which is expected to publish in 2023. We do not have a referral for a separate quality standard on this topic.

NICE’s guidance on cancer services: improving outcomes for people with brain and other CNS tumours (CSG10, Section 8 recommendations):

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

Multidisciplinary rehabilitation teams should be available for the continued management of patients with CNS tumours at home or in the community.

Where it is not feasible for patients with CNS tumours to be cared for by the existing neurorehabilitation team(s), commissioners should ensure that an equivalent service is provided by a cancer network neuro-oncology rehabilitation team.

#### Current UK practice

The [NICE evidence review for NG99 on supporting people living with a brain tumour](https://www.nice.org.uk/guidance/ng99/evidence/evidence-reviews-july-2018-4903134733?tab=evidence) indicated that there is good provision of neurorehabilitation services across the UK as they are used extensively by those with other brain injuries. However, there is variation across the UK in whether people with brain tumours can access these services since many neurological rehabilitation centres do not accept referrals for people with brain tumours (or accept referrals only for certain kinds of brain tumour). There is also variation in how long and how intensively those diagnosed with a brain tumour can use services even in areas where brain tumour patients are accepted into neurological rehabilitation pathways.

### Issues for consideration

**For discussion:**

* Are community-based neurorehabilitation services easier to access than specialist services?
* If someone has an assessment will they be able to access any support they may need?
* What is the priority for improvement?
* What is the key action that will lead to improvement?
* Can we develop a specific, measurable statement?

**For decision:**

* Should this area be prioritised for inclusion in the quality standard?
  1. Surveillance for late-onset side effects of treatment

Access to late-effects clinics, neurological surveillance, and neuropsychology were highlighted as priorities. As people with brain tumours can develop late effects of treatment months or years afterwards, the individual risk of late effects of treatment needs to be assessed and discussed with them. This will support ongoing surveillance and active management of these risks and will improve the quality of care provided and patient quality of life.

#### Selected recommendations

NICE’s guideline on brain tumours (primary) and brain metastases in adults (NG99):

1.11.2 Assess the person's individual risk of developing late effects when they finish treatment. Record these in their written treatment summary and explain them to the person (and their relatives and carers, as appropriate).

1.11.4 For people who are at risk of stroke, consider checking their blood pressure, HbA1c level and cholesterol profile regularly.

1.11.5 Consider ongoing neuropsychology assessment for people at risk of cognitive decline.

1.11.6 If a person has had a radiotherapy dose that might affect pituitary function, consider checking their endocrine function regularly after the end of treatment.

1.11.7 Consider referring people who are at risk of visual impairment for an ophthalmological assessment.

1.11.8 Consider referring people who are at risk of hearing loss to audiology for a hearing test.

1.11.9 Consider referring the person to stroke services if an MRI during active monitoring identifies asymptomatic ischaemic stroke.

#### Current UK practice

No published studies on current practice were highlighted for this suggested area for quality improvement; this area is based on stakeholder’s knowledge and experience.

### Issues for consideration

**For discussion:**

* When is an assessment of the risk of late effects carried out after treatment e.g., at the first follow-up review?
* What is the priority for improvement?
* What is the key action that will lead to improvement?
* Can we develop a specific, measurable statement?

**For decision:**

* Should this area be prioritised for inclusion in the quality standard?
  1. Additional areas

### Summary of suggestions

The improvement areas below were suggested as part of the stakeholder engagement exercise. However, they were felt to be either unsuitable for development as quality statements, outside the remit of this particular quality standard referral or need further discussion by the committee to establish potential for statement development.

There will be an opportunity for the committee to discuss these areas at the end of the Advisory Committee meeting.

Table 2 Summary of information available for additional areas

| Suggested area for improvement | Within remit of NICE QS | In scope | Guideline recs | Relevant  existing QS |
| --- | --- | --- | --- | --- |
| Participation in clinical trials/research | No | No | No | No |
| End of life care | Yes | Yes | Yes | Yes |
| Employment support | Yes | Yes | No | Yes |
| Quality of life questionnaires | No | No | No | No |

### Participation in clinical trials/research

This suggestion has not been progressed. Increasing the opportunities for patients and the public to participate in research is within the remit of the National Institute for Health Research.

### End of life care

End of life care including advance care planning for people with brain tumours was suggested as an area of quality improvement. This suggestion has not been progressed within this quality standard. There is an existing quality standard on end-of-life care and an update is expected to publish in September 2021.

**Employment support**

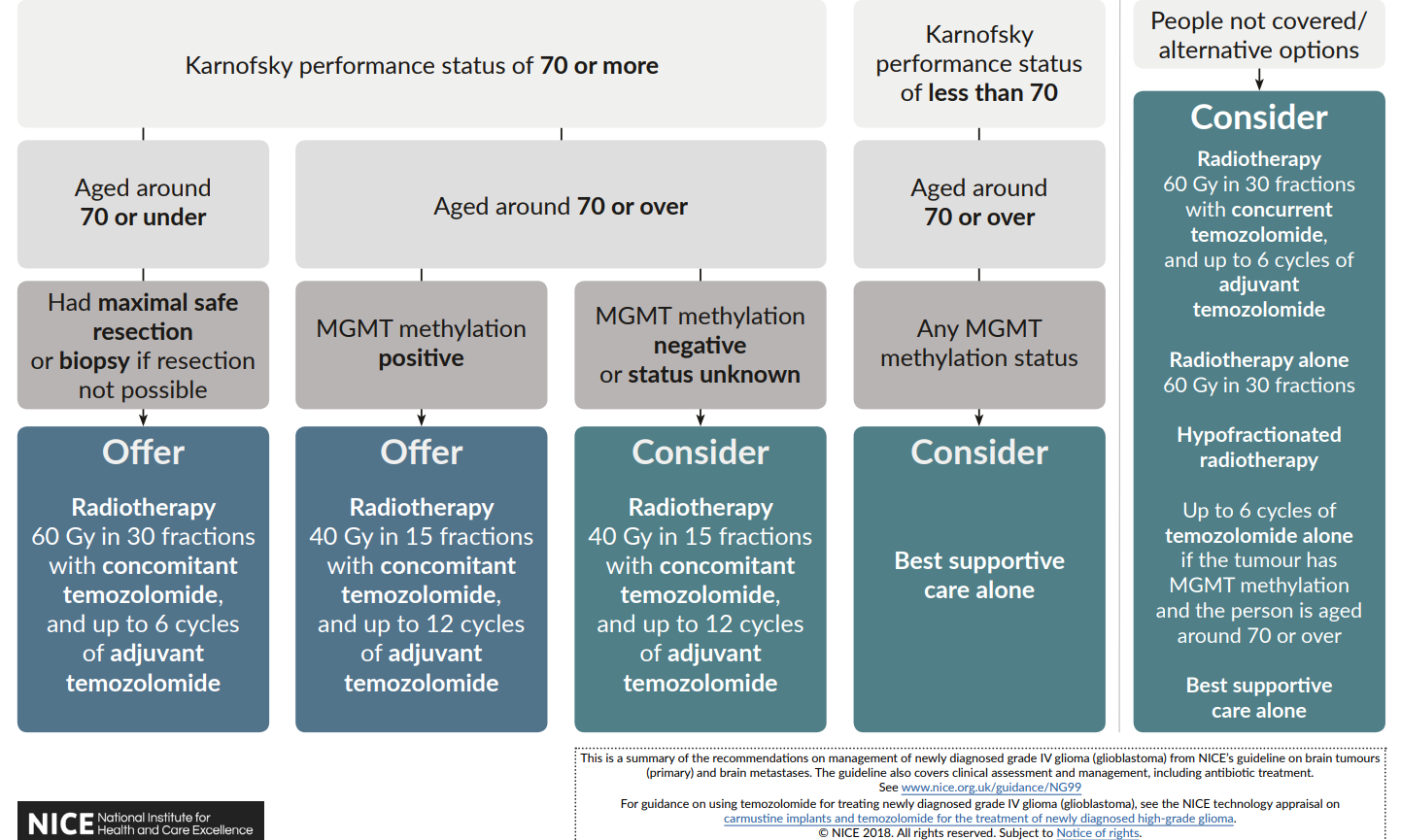
Support for returning to work after treatment with new disabilities for people with brain tumours was suggested as an area for quality improvement. This suggestion has not been progressed within this quality standard. A quality standard on workplace health: long-term sickness absence and capability to work is in development and is expected to publish in September 2021.

### Quality of life questionnaires

It was suggested that specific Quality of Life questionnaires for brain tumour patients are required to enable accurate data collection. This suggestion has not been progressed. Quality statements focus on actions that demonstrate high quality care or support, not the methods by which data is collated. However, suggested methods of data collection may be referred to in the data sources for quality measures.

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# Appendix 1: Brain tumours (primary) and brain metastases: management options for people with newly diagnosed grade IV glioma (glioblastoma)



# Appendix 2: Suggestions from registered stakeholders

| **ID** | **Stakeholder** | **Suggested key area for quality improvement** | **Why is this important?** | **Why is this a key area for quality improvement?** | **Supporting information** |
| --- | --- | --- | --- | --- | --- |
| **Investigations- Rapid access to MRI** | | | | | |
| 1 | Brain Tumour Research | Delay in Diagnosis | There is evidence that a higher than expected number of Brain Tumour patients obtain their diagnosis (60-70%) from an emergency scan performed at an ultimate visit to A and E depts. This implies that such tumours are not well investigated in Primary Care and that patients are presenting to A and E late with evolution of symptoms that may prejudice their access to treatment and impact on their survival. | There is a need for a new quality standard to reduce this delay in referral and hence reduce the negative impact on brain tumour patients and the inappropriate use of A and E services. | 1. There is evidence that in the case of malignant high-grade tumours delay in diagnosis can seriously adversely affect timely diagnosis and outcome 2. The Diagnostic pathway in Primary Care for people with brain tumour symptoms was specifically excluded from the NICE guidance on Primary CNS brain tumours and metastases 2018. [[1]](#endnote-1) 3. The current quality standard (as here) however implies that the whole clinical pathway maybe considered. 4. There is evidence that there are a few patients with seizures or stroke like symptoms that present as acute cases to A and E depts as result of a sudden obvious deterioration in their CNS status. ~ 10-15%. Seizure may represent early symptoms. 5. Some patients may develop slowly progressing focal CNS symptoms or other non-specific symptoms that do not point to a specific diagnosis. This results in either multiple consultations and/or with more than one doctor leading to delay in referral diagnosis. The evidence that this is indeed the case comes from the very low number of brain tumour patients referred for ‘Two Week Wait’ assessment (9% of 17,000) [[2]](#endnote-2) Notably 44% of patient with cancer were included in the safety netting process of which a high proportion were those with brain tumours. However, this Primary Care study was insensitive to those patients whose primary symptom was unclassified, who had multiple visits and who ultimately self – referred to A and E. 6. Relatively few patients develop headaches as their presenting symptom but more commonly as a late symptom indicating that the disease has grown to cause raised intracranial pressure. This is thus a late – too delayed symptom that impacts on the patient’s treatment. 7. There is evidence that that funding for early cancer diagnosis especially where this requires MRI imaging (NICE 2018) is variable in the UK with CCT’s actively limiting budgets for such diagnostic procedures despite the NICE suspected Cancer advice to allow a change from a 5% diagnostic threshold to a 2% threshold. 8. In addition, the existing guidelines to GP’s are unwieldy and complex (NICE Suspected Cancer: CNS. [[3]](#endnote-3) 9. A new set of guidelines is required to help GP’s select patients for early imaging. One suggestion would be “a patient with more than one CNS symptom lasting longer than one week should have an MRI of the head within two weeks” This would form a useful and practical tool to identify a new quality standard for primary care diagnosis and should be considered. (Reference ii uses the measure DI as the time from first symptom to the diagnosis of cancer being given to the patient.) 10. It is noted that the most recent Quality Standards on Suspected CNS disorders completely neglects patients with brain tumours [[4]](#endnote-4)   [Brain tumours (primary) and brain metastases in adults](https://www.nice.org.uk/guidance/ng99) (2018) NICE guideline NG99   1. British Journal of General Practice (2018) [Diagnosing cancer in primary care: results from the National Cancer Diagnosis Audit](https://bjgp.org/content/68/666/e63)   [Suspected cancer: recognition and referral](https://www.nice.org.uk/guidance/ng12) (2015, updated 2017) NICE guideline NG12  [Suspected neurological conditions](https://www.nice.org.uk/guidance/indevelopment/gid-qs10082) (2021) NICE quality standard 198 |
| 2 | British Society of Neuroradiologists | Key area for quality improvement 4 – Early access to imaging for patients with a suspected brain tumour. | Diagnosis of a brain tumour is frequently late and in an emergency setting, despite earlier presentations in primary care. Improving access to neuroimaging from primary care might promote earlier diagnosis. | Access to neuroimaging from primary care is variable across the UK, with differing availability of imaging odalities. Guidance on urgent referral may help to achieve earlier diagnosis. | Direct access CT for suspicion of brain tumour: an analysis of referral pathways in a population-based patient group. Zienius K, Chak-Lam I, Park J et al. BMC Fam Pract (2019) 20:18. <https://doi.org/10.1186/s12875-019-1003-y> |
| 3 | NHS England and NHS Improvement | (CAHPO)Key area for quality improvement 4  Patients with a brain tumour should have contrast enhanced Magnetic Resonance Imaging (MRI) prior to treatment. | MRI is the established investigation for patients with presumed low-grade tumours | Although contrast enhanced Computed Tomography (CT) will often be the initial investigation suggesting the diagnosis of brain tumour, MRI provides additional information in many cases. | Soffietti R, Baumert BG, Bello L, von Deimling A et al (2010) Guidelines on management of low-grade gliomas: report of an EFNS-EANO Task Force. European Journal of Neurology 2010; 9: 1124-33. |
| 4 | Primary care and Community Neurology Society (P-CNS) | Key area for quality improvement 1  Appropriate and rapid referral to scanning services | Linked to the existing NICE guidance, the P-CNS wishes to see improvement in appropriate and rapid referral to scanning services and therefore, improved recognition of the key signs and symptoms to ensure that prompt referral take place. | The person experiencing unusual and alarming signs and symptoms, (along with key family members) need to either receive reassurance that what they are experiencing is not of a sinister nature, or gain access to appropriate management asap to limit any of the damaging effects on the person’s health. | Direct access CT for suspicion of brain tumour: an analysis of referral pathways in a population-based patient group, Zienius et al, BMC Family Practice, 2019  <https://bmcfampract.biomedcentral.com/articles/10.1186/s12875-019-1003-y>  Missed opportunities for diagnosing brain tumours in primary care: a qualitative study of patient experiences,  Walter et al, BJGP, 2019  <https://bjgp.org/content/69/681/e224> |
| 5 | Royal College of Nursing | Key area for quality improvement 1 | Early detection – improved access for MRI/CT scanning | Improved outcomes |  |
| 6 | SCM1 | Key area for quality improvement 1  All people with suspected brain tumours should have appropriate imaging as per NICE guidance | Within NICE guidance, all people with suspected glioma, meningioma and brain metastases should be offered a standard structural MRI scan (unless contraindicated) and those with metastases suitable for focal treatment should have appropriate extracranial imaging. This enables timely decisions regarding diagnosis and potential treatments at the MDT. | People who are referred to the MDT without this imaging have delays to their care whilst this imaging is obtained. Despite publication of the NICE guidance, anecdotally there as still s significant proportion referred without this essential imaging. |  |
| 7 | SCM3 | Early imaging access | Brain tumours are often diagnosed late and in emergency care settings. Rapid access to neuroimaging via primary care may help in earlier tumour diagnosis | Access to neuroimaging particularly from primary care is heterogeneous across the UK, as is speed of access and imaging modality available (e.g. CT v MR). Consideration of standardised guidelines for urgent referral may improve early pick up rate and also improve patient-doctor trust – a significant proportion of patients attend primary care multiple times prior to diagnosis. | Walter FM, Penfold C, Joannides A et al. Missed opportunities for diagnosing brain tumours in primary care – a qualitative study of patient experiences. Brit J Gen Practice 2019; DOI: https://doi.org/10.3399/bjgp19X701861  Zienius, K., Chak-Lam, I., Park, J. et al. Direct access CT for suspicion of brain tumour: an analysis of referral pathways in a population-based patient group. BMC Fam Pract 20, 118 (2019). <https://doi.org/10.1186/s12875-019-1003-y> |
| 8 | SCM6 | Open access MRI scanning for patients with a suspected brain tumour | NG12 recommends – Consider an urgent direct access MRI scan of the brain (or CT scan if MRI is contraindicated) (to be performed within 2 weeks) to assess for brain or central nervous system cancer in adults with progressive, sub‑acute loss of central neurological function. **[2015]** | Although recommended, many patients are still seen in 2WW clinics rather than accessing MRI immediately. Almost inevitably these patients will need then to be referred for an MRI scan, incurring further delay. | NG12  NG99  Headsmart campaign literature |
| 9 | The Society and College of Radiographers | Key area for quality improvement 1 |  |  | Do these match the RCR iRefer guidelines in relation to MRI being the gold standard over CT? Some centres still perform post contrast CT which is largely inappropriate as MRI is always performed for possibility of tumour unless there are contraindications. This leads to an unnecessary radiation dose purely because of convenience/lack of education. |
| **Investigations- Additional imaging/testing** | | | | | |
| 10 | SCM4 | Key area for quality improvement 4 | **Molecular marker testing** and analysis for glioma patients is still relatively new, hence practice is not very cohesive. Evidence suggests some markers such as MGMT and TERT promoter mutations integration shows significant benefits if tested. | Molecular markers are a new and emerging area in the treatment of brain tumours, and so guidance is needed to bring best practice to the attention of clinicians. It is thought that good molecular profiling can help to improve outcomes for people with tumours, but to perform molecular profiling well is difficult. | <https://www.nice.org.uk/guidance/ng99/evidence/a-investigation-management-and-followup-of-glioma-pdf-4903134734> |
| **Management/treatment- Multidisciplinary team** | | | | | |
| 11 | NCRI-ACP-RCP | Key area for quality improvement 2 |  |  |  |
| 12 | NCRI-ACP-RCP | Key area for quality improvement 3 |  |  |  |
| 13 | NHS England and NHS Improvement | (CAHPO)Key area for quality improvement 2  Patients with brain/CNS cancer should be discussed by a multidisciplinary (MDT) team prior to any surgical procedures. | Evidence suggests that patients with cancer managed by a multi-disciplinary team have a better outcome. We propose this team also includes Allied Health Professionals (AHPs) | There is also evidence that the multidisciplinary management of patients increases their overall satisfaction with their care. | [The Value and Future Developments of Multidisciplinary Team Cancer Care – PubMed (nih.gov)](https://pubmed.ncbi.nlm.nih.gov/31099640/) |
| 14 | NHS England and NHS Improvement | **(Spec Comm)** Maintenance of specialisation & resilience in the care pathway with emphasis on multidisciplinary working, expansion of CNS role & avoidance of single consultant clinics/service provision | Dedicated specialist care pathways improve clinical outcomes, reduces morbidity and drives down costs to the NHS |  | NICE NG99 Sections 1.2, 1.4 & 1.7  NHSE MDT guidelines updated 2018: <https://www.england.nhs.uk/publication/making-it-happen-multi-disciplinary-team-mdt-working/>  GIRFT: <https://www.gettingitrightfirsttime.co.uk>  National Neurosurgery Audit Programme: <https://www.nnap.org.uk>  <https://www.sbns.org.uk/index.php/policies-and-publications/> |
| 15 | Scottish Adult Neuro-oncology Network | Key area for quality improvement 2  30 day mortality following treatment for brain / CNS cancer. | Treatment related mortality is a marker of the quality and safety of the whole service provided by the Multi Disciplinary Team (MDT)3. | Outcomes of treatment, including treatment related morbidity and mortality should be regularly assessed. Treatment should only be undertaken in individuals that may benefit from that treatment, that is, treatments should not be undertaken in futile situations. This QPI is intented to ensure treatment is given appropriately, and the outcome reported on and reviewed. | NICE (2006) Improving outcomes for people with brain and other CNS tumours – the manual (accessed on: 23rd August 2013); Update available from: https://www.nice.org.uk/guidance/csg10/resources/improving-outcomes-for-people-withbrain-and-other-central-nervous-system-tumours-update-pdf-27841361437 (accessed July 2017) 3. NHS Quality Improvement Scotland (2008) Clinical standards for the management of bowel cancer. Available from: http://www.healthcareimprovementscotland.org/programmes/cancer\_care\_improvement/ca ncer\_resources/standards\_for\_cancer\_services.aspx (accessed 3rd June 2013) |
| 16 | The Brain Tumour Charity | Key area for quality improvement 4  The treatment and care of all patients diagnosed with a brain tumour is reviewed and managed by an MDT | Increasingly, multidisciplinary teams (MDTs) have been established and utilised for the care and treatment of brain tumours. The use of MDTs was one of the key recommendations of the Cancer service guidelines CSG10, highlighted due to its importance in driving improvements in patient care. | The availability of MDTs to discuss treatment and care options for people living with a brain tumour has increased significantly in recent years, with a report from the Commission for Health Improvement citing widespread use as far back as 2003.  However, their implementation across the UK varies and MDTs still may not include certain healthcare professionals who play an active role in patient treatment and care, such as Allied Health Professional or Palliative Care Specialist, where appropriate. | As outlined in the [Tessa Jowell Centre of Excellence Designation of Standards](https://www.tessajowellbraincancermission.org/wp-content/uploads/2020/10/TJ-Centre-Designation-Standards-1.pdf).  The MDT should include relevant specialists, including:   * Neurosurgeon * Diagnostic Neuroradiologist * Neuropathologist * Clinical Oncologist * Medical Oncologist (optional) * Neurologist * Neuropsychologist * Neuro-oncology Nurse * Palliative Care Specialist\* * Allied Health Professional (e.g. neuro-oncology physiotherapist, Occupational Therapist, Speech and Language Therapist) * Geneticist (desired, or access when relevant) * Consultant in Rehabilitation (desired, or access when relevant) * MDT Coordinator   \*An MDT may include a Palliative Care Specialist who will provide the option to discuss palliative care from the point of diagnosis, if appropriate for the stage and aggressiveness of their tumour.  If such conversations take place in the early stages of the patient pathway, it is more likely that a person with a terminal diagnosis will have the choice and control to exercise important decisions in care. |
| **Management/treatment – Treatment pathway** | | | | | |
| 17 | SCM4 | Key area for quality improvement 3 | Prehabilitation aims at optimising patient’s physical and mental health through exercise, nutrition, and psychological interventions based on individual needs. It aims to improve treatment effectiveness and cancer survival. Clinics with neuro specific OT / Physio | Macmillan suggests that prehabilitation should underpin the whole cancer pathway. Any intervention that seeks to reduce harm, improve emotional and physical resilience, and improve long term health should be welcomed.  The principles and guidance will help you to:  •advance cancer care provision  •include prehabilitation in the cancer pathway.  •inform service provision and development  •inform and support a change policy. | <https://www.bmj.com/content/366/bmj.l5120.full>  <https://www.macmillan.org.uk/healthcare-professionals/news-and-resources/guides/principles-and-guidance-for-prehabilitation> |
| 18 | Society of British Neurological Surgeons | Key area for quality improvement 2  Swift and Scheduled elective rather than emergency admission for Brain Cancer patients and short length of bed stay post surgery. | * Shorten the cancer pathway.   Efficient use of hospital beds. | Evidence in the recent GIRFT and from more than one UK centre that scheduled elective admission for surgery and a planned discharge 24-48 hours post surgery results in reduced morbidity for patients with a shortened cancer pathway. | Getting it Right First Time (2018) [Cranial neurosurgery: GIRFT programme national specialty report](https://gettingitrightfirsttime.co.uk/surgical-specialty/cranial-neurosurgery/) |
| 19 | Society of British Neurological Surgeons | Key area for quality improvement 5   * Reduce overall length of cancer pathway for primary brain cancer. * MDT discussion to surgical clinic pathway to be reduced to 1 week. * The present 31 days pathway from decision for surgery to surgery needs to be reduced to 14 days.   For Primary brain cancer the post surgery to radiotherapy pathway has no well defined timeline and is variable for up to 4-8 weeks. This needs to be reduced to 4 weeks. | There is evidence that shorter patient pathways leads to improved outcomes in patients with primary brain cancer. | * There is still variability in practice and speed of pathway/ diagnosis/surgery which needs to be addressed.   Primary brain cancer outcomes remain poor in the UK. | Getting it Right First Time (2018) [Cranial neurosurgery: GIRFT programme national specialty report](https://gettingitrightfirsttime.co.uk/surgical-specialty/cranial-neurosurgery/)  NHSE Transformation Programme. |
| **Management/treatment – Maximal safe surgical resection** | | | | | |
| 20 | SCM6 | Usage of 5-aminolevulinic acid (5ALA) guided resection for high grade glioma | The NG99 guidance recommends the usage of 5ALA guidance to maximise resection at initial surgery for suspected high grade glioma. Evidence supports this as being associated with improved progression free survival. Funding is now agreed for the usage of 5ALA in all UK Neurosurgery units and all applicable patients should be offered the opportunity to benefit from 5ALA. | Although all units now have access to 5ALA it is thought that rates of usage vary and this may be unwarranted variation in practice. All appropriate patients should have access to 5ALA and associated survival benefit. | NG99 Guidance.  Stummer et al. Lancet Oncol 2006 7(5):392-401 |
| 21 | Scottish Adult Neuro-oncology Network | Key area for quality improvement 4  Maximal Safe Surgical Resection | It is important to develop and maintain engaged surgical neuro-oncologists, who are up to date with the latest technology so that they can aspire to maximal safe resection. Adjuncts that help achieve maximal safe resections need to be standardised – the use of 5 ALA, intraoperative ultrasound or MRI | The extent of surgical resection is an independent prognostic factor in Grade III and Grade IV malignant gliomas. Maximal safe surgical resection (≥90%) prolongs time to tumour recurrence9 and is associated with prolonged survival10 . Maximum safe surgical resection is recommended by several published guidelines4, | Soffietti R, Baumert BG, Bello L, von Deimling A et al (2010) Guidelines on management of low-grade gliomas: report of an EFNS-EANO Task Force. European Journal of Neurology 2010; 9: 1124-33. 8. Wen P, Macdonald DR, Reardon DA, Cloughesy TF et al (2010) Updated Response Assessment Criteria for High Grade Gliomas: Response Assessment in Neuro-oncology Working Group. Journal of Clinical Oncology 2010; 28:1163-72. 9. Stummer W, Pichlmeier U, Meinel T, et al (2006) Fluorescence-guided surgery with 5- aminolevulinic acid for resection of malignant glioma: a randomised controlled multicentre phase III trial. Lancet Oncol. 2006; 7(5):392-401. 10. Pichlmeier U, Bink A, Schackert G, et al (2008) Resection and survival in glioblastoma multiforme: An RTOG recursive partitioning analysis of ALA study patients. Neurooncology 2008; 10; 1024-1035. 11. Ryken TC, Frankel B, Julien T, Olson JJ (2008) Surgical management of newly diagnosed glioblastoma in adults: Role of cytoreductive surgery. Journal of Neuro-Oncology. 2008;(3):271-286. |
| 22 | Society of British Neurological Surgeons | Key area for quality improvement 3  Regular use of 5-ALA agent for primary brain cancer surgery where maximal removal is attempted. | Randomised control trial evidence that use of this results in maximal cancer resection, better prognosis and survival. | Despite NICE recommendation and clinical trials the use of this across surgical centres in the UK is variable. | * [Brain tumours (primary) and brain metastases in adults](https://www.nice.org.uk/guidance/ng99) (2018) NICE guideline NG99   [Fluorescence-guided surgery with 5-aminolevulinic acid for resection of malignant glioma: a randomised controlled multicentre phase III trial.](https://www.ncbi.nlm.nih.gov/pubmed/16648043)**Lancet Oncol**. 2006 May;7(5):392-401. |
| 23 | SCM6 | Usage of intra-operative imaging during resection of glioma | Intra-operative MRI, intra-operative ultrasound and navigated diffusion tensor imaging are all recommended for consideration by NG99 as adjuncts to improve the degree of resection of high and low grade gliomas, with subsequent likely survival benefit. | These are specialised techniques which have uneven availability around the UK, but most units should have access to at least one of them. It is therefore important to assess that all appropriate patients have access to intra-operative imaging of at least one modality to enhance resection and improve safety. | NG99 |
| **Management/treatment – Stereotactic radiosurgery for multiple brain metastases** | | | | | |
| 24 | SCM1 | Key area for quality improvement 5  Stereotactic Radiosurgery (SRS) for people with >1 Brain Metastasis | Focal treatment of brain metastases can provide lasting local control without further significant neurocognitive impact.  NICE guidance recommends consideration of SRS for those with multiple brain metastases, good performance status and controlled/controllable extra-cranial disease | The number of centres offering SRS is limited, so people with brain metastases often have to be referred outside of their local cancer centre, which is a barrier to treatment. This is particularly an issue for those with >5 brain metastases who may need to be referred to a centre outside the region as only some SRS centres (for example those utilising a Gamma Knife) have the physical ability to treat multiple metastases. This creates a barrier for those people with multiple brain metastases to access these services. | Clinical commissioning policy: stereotactic radiosurgery/stereotactic radiotherapy for cerebral metastases (NHS England 2013)  Schimmel et al Clinical Oncology (RCR) 33(2021) 314-21- cognitive function was preserved or improved after SRS for people with 1-10 brain metastases |
| **Follow-up – Imaging** | | | | | |
| 25 | Brain Tumour Research | Imaging and surveillance: | The clinical management of patient with brain cancer is critically determined by the appearances of their disease on regular MRI brain imaging  1. Currently with Covid regulations and the need for reducing intercurrent throughput of cases in imaging departments, there are now delays in both diagnostic imaging and surveillance imaging of patients with brain tumours.  2. Coupled with this are the very real pressures causing delay in professional/specialist consultant reporting of this imaging. Thus, in addition to delays in accessing imaging patients also have to wait after the event for a report on the imaging result.  3. Added to this is the pressure on outpatient appointments and we have a threefold delay problem that is injurious to the patient both clinically and mentally. | A new standard of Quality is required here  1. Ideally a patient should have their scan, report and consultation with the report on the same day so that decisions can be made quickly and in the interests of the patient.  2. The delivery of the current system of imaging and OPD is subject to the competition existing from the flow of patients from other disease pathways.  3. As such completing imaging reporting and consultation for a patient in one hospital visit would hugely decrease unnecessary footfall of patients through hospital at a time when we are trying extremely hard to achieve this to reduce the risks from Covid.  4. To synchronise imaging reporting and consultation to one visit is thus highly desirable to both the hospital and the patient.  5. As the three events all require a chronological itemisation then it should be possible to rationalise them into one episode with suitable application of IT, management and the will to realise this.  6. At least one centre ‘ the Royal Marsden’ a centre of cancer treatment excellence already does this and on this rationale.  We would therefore propose new Quality standard of ….’the number of patients having their imaging reporting and consultation in one hospital visit’ | [Brain tumours (primary) and brain metastases in adults](https://www.nice.org.uk/guidance/ng99) (2018) NICE guideline NG99 |
| 26 | British Society of Neuroradiologists | Key area for quality improvement 1 – Standardisation of MRI imaging protocols for assessment of brain tumours across regional networks. | Patients with a brain tumour are often scanned at a number of different centres during diagnosis, treatment and surveillance, and at each centre the MRI scan protocol used may differ. A standardised imaging approach across different centres will help to improve accuracy in assessment of brain tumours, the response to treatment, and during surveillance. |  |  |
| 27 | British Society of Neuroradiologists | Key area for quality improvement 2 – Ensuring imaging schedules during the treatment and surveillance of patients with brain tumours are consistent. | Imaging is central to the diagnosis and management of patients with brain tumours, but the frequency with which it is undertaken varies between centres. | Imaging is a limited and expensive resource and therefore needs to be employed to best effect. Inappropriately timed scans may adversely affect patient management decisions. Although there is little evidence to define the most appropriate timepoints for imaging, guidance is required to ensure a consistent approach. |  |
| 28 | British Society of Neuroradiologists | Key area for quality improvement 5 –Appropriate and adequate clinical information should be provided on requests for imaging. | The clinical information provided to on requests for imaging is variable, often limited and unstructured. Lack of important information can result in a lower quality or less useful report of the imaging study, or even misinterpretation. | Clear identification of tumour type, current/prior treatment status and current clinical status along with reason for imaging is variably provided in requests for imaging. Development of a core data set for referral information would improve consistency of communication and diagnosis. This could potentially be embedded in an electronic referral system. |  |
| 29 | SCM3 | Standardisation of imaging protocols for tumour imaging | Patients may be imaged in different sites during their treatment and follow up. Accurate assessment of treatment response is greatly helped by consistent imaging standards regardless of location. | It is of considerable benefit for some patients to be imaged near home, which may be remote from the tertiary centres where treatment is usually based. Networks of imaging centres should ensure consistent quality of brain imaging can be provided across sites in the regional network | Brain tumours (primary) and brain metastases in adults (2018) NICE guideline NG99 – suggested protocol. |
| 30 | SCM3 | Consistent imaging schedules | Treatment and followup imaging is key to response assessment and symptom management. Evidence for optimal imaging timing and schedules is very limited. | Imaging plays a key role in the diagnosis and management of brain tumours. It is an expensive and limited resource, and should be used to best effect. It can also be a cause of anxiety for patients; Imaging delays can result in missed opportunities to intervene, but too-frequent or mis-timed imaging may be unhelpful, and can sometimes lead to inappropriate treatment change. |  |
| 31 | SCM3 | Structured referral information for imaging studies | Clear identification of tumour type, current/prior treatment status and current clinical status along with purpose of imaging is very variable. | The clinical information provided to imaging is variable, and may be limited and unstructured. This can result in lower quality reporting of imaging studies or misinterpretation. Development of a core data set for referral information (potentially embedded in electronic referral systems) would improve consistency of communication and diagnosis. |  |
| **Follow-up – Advanced imaging** | | | | | |
| 32 | British Society of Neuroradiologists | Key area for quality improvement 3 – Consistency in application of ‘advanced’ imaging techniques. | Many imaging techniques are available that may provide additional analysis of brain tumours beyond purely structural/anatomical information. However, their availability and use is inconsistent. | Some ‘advanced’ techniques are widely available, but acquisition and analysis techniques, as well as experience of use by clinicians, vary, and their use may not be routine. Access to some techniques is limited. Stratification of these varied techniques into those which are now standard care and those which are in clinical development or research tools would assist in standardisation of services. | Advancements in Neuroimaging to Unravel Biological and Molecular Features of Brain Tumors. Sanvito F, Castellano A, Falini A. Cancers (2021) 13(3):424. <https://doi.org/10.3390/cancers13030424> |
| 33 | SCM3 | Consistent application of ‘advanced’/physiological imaging | A large number of techniques beyond standard anatomical imaging are in use in brain tumour assessment. Their application is not consistent or guideline-led at present. | MRI can provide extensive information beyond anatomy. These techniques include tumour perfusion, microstructure and chemical make up. Other techniques include CT-PET and MR-PET again with variable access and use. Identification of the status of these varied techniques (standard care, clinical development or research) would help with greater standardisation of care. Of particular interest is MR perfusion imaging which has variation in acquisition and analysis techniques that would merit greater consistency. | Kong L, Chen H, Yang Y, Chen L. A meta-analysis of arterial spin labelling perfusion values for the prediction of glioma grade. Clin Radiol 2017; 72:255-261  Sanvito F, Castellano A, Falini A. Advancements in Neuroimaging to Unravel Biological and Molecular Features of Brain Tumors. Cancers. 2021; 13(3):424. <https://doi.org/10.3390/cancers13030424> |
| **Care needs- Holistic needs assessment** | | | | | |
| 34 | Braintrust |  | Assessment of patient and caregiver quality of life needs after diagnosis to ensure rapid access to the appropriate services in order to optimise quality of life on the brain tumour pathway, including regular holistic needs assessment at transition points so that the patient has a regularly refreshed care plan. This should include ongoing neuropsychology assessments for people at risk of cognitive decline. |  |  |
| 35 | NCRI-ACP-RCP | Key area for quality improvement 5 | Patients should have a completed Health Needs Assessment completed, documented in the discharge letter and sent to the GP on completion of Radiotherapy |  |  |
| 36 | NHS England and NHS Improvement | **(Spec Comm)** 5 Improving the process of consent through shared decision making & support | Updated GMC guidance lists ‘seven principles’ of decision making and consent, including:   * All patients have the right to be involved in decisions about their treatment and care, and to be supported to make informed decisions. * Decision making is an ongoing process focused on meaningful dialogue, based on the exchange of relevant information specific to the patient. * All patients have the right to be listened to, and to be given the information they need to make a decision and the time and support they need to understand it. * Doctors must try to find out what matters to patients so they can share relevant information about the benefits and harms of proposed options and reasonable alternatives. * Doctors must start from the presumption that all adult patients have capacity to make decisions about their treatment and care. A patient can only be judged to lack capacity after assessment in line with legal requirements. |  | NICE NG99 Section 1.9.2  GMC guidelines: <https://www.gmc-uk.org/news/news-archive/shared-decision-making-is-key-to-good-patient-care---gmc-guidance> |
| 37 | Primary care and Community Neurology Society (P-CNS) | Key area for quality improvement 2  Assessment of patient and family quality of life needs after surgery | Assessment of patient and family quality of life needs after surgery or during intervention is a vital step to ensuring timely access to appropriate services, if the NHS is to deliver on optimising life opportunities after surgery or supporting the patient and family to live through chemotherapy or radiotherapy. | Supporting Quality of Life must be at the heart of any healthcare service proporting to care, no matter how long or short that life may be, to ensure that that life can be enjoyed for as long as possible. | Patient‐reported health‐related quality of life outcomes in supportive‐care interventions for adults with brain tumors: A systematic review  Pan‐Weisz et al, Psycho-Oncology 2019  <https://onlinelibrary.wiley.com/doi/abs/10.1002/pon.4906> |
| 38 | Society of British Neurological Surgeons | Key area for quality improvement 4  Holistic needs assessment for 16-25yrs patients with Brain Tumours. | These patients have slow growing tumours and have to live with them. | Long term and regular psychological, cognitive, educational, financial support is very variable which needs to be addressed. | [Brain tumours (primary) and brain metastases in adults](https://www.nice.org.uk/guidance/ng99) (2018) NICE guideline NG99 |
| 39 | The Brain Tumour Charity | Key area for quality improvement 2  A Holistic Needs Assessment and Personalised Care and Support Plan for everyone living with a brain tumour, to be undertaken and provided in the weeks following diagnosis and to be reviewed and updated after first treatment and at every significant change in treatment or condition. | A Holistic Needs Assessment (HNA) and a Personalised Care and Support Plan enables people living with cancer to take an active role in their treatment and care.  These interventions empower people living with cancer to ensure their care is planned and delivered in a tailored manner.  NICE guideline NG99 (1.9.1) recommends an awareness of the unique needs of those living with a brain tumour as ‘in addition to physical disability, the tumour and treatment can have effects on behaviour, cognition and personality. 1.9.4 of NG99 also recommends ‘Health and social care professionals involved in the care of people with brain tumours should address additional complex needs during or at the end of treatment and throughout follow‑up’.  A push for greater personalisation in treatment is also highlighted in the NHS Long Term Plan. | The Brain Tumour Charity’s 2020 Improving Brain Tumour Care Survey found just 39% of respondents reported being offered an HNA, with large variability in how these assessments and plans were delivered and implemented (sample: 586 people diagnosed or in active treatment in the last two years). Further, just 21% said they had an assessment of their needs and a good written care plan in place.  This follows results from the 2019 NCPES, which suggested that just 27.5% of people with a brain or CNS tumour had been offered a care plan. | The personalisation of care is discussed in:   * [Chapter 3 (section 1.9) of the NHS Long Term Plan](https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf) * [NG99 – NICE guidelines on Brain Tumours (primary) and brain metastases in adults](https://www.nice.org.uk/guidance/ng99/chapter/Recommendations#care-needs-of-people-with-brain-tumours)   The importance of the establishment and use of HNA and care plan is also recommended in the [Tessa Jowell Centre of Excellence Designation of Standards](https://www.tessajowellbraincancermission.org/wp-content/uploads/2020/10/TJ-Centre-Designation-Standards-1.pdf), developed in collaboration with the Tessa Jowell Brain Cancer Mission, NHS England, the Department of Health and Social Care, NCRI and partner charities including CRUK and The Brain Tumour Charity.  [The Brainstrust NCPES Summary document](https://brainstrust.org.uk/wp-content/uploads/2020/10/national-cancer-patient-experience-survey-2019.pdf) discusses the availability of a care plan for people living with a brain tumour.  The Brain Tumour Charity’s Improving Brain Tumour Care Survey is currently unpublished, but we would be very happy to share or discuss any of the results if helpful. |
| **Care needs- Named healthcare professional** | | | | | |
| 40 | Braintrust |  | Seamless care (including better and consistent triangulated communications) for people between district general hospitals, the main neuroscience centres and primary care through the provision of a named healthcare professional (for example, a key worker (often a clinical nurse specialist) as defined in NICE guidance) with responsibility for coordinating health and social care support for people with brain tumours and carers.  This is not always happening and it’s very difficult for people to get answers to questions and concerns without one. It seems particularly the case that people, particularly those who have been seen as emergency cases, really have no idea what happened to them and not having a named contact person for subsequent clarity is a challenge. |  |  |
| 41 | Braintrust |  | For people diagnosed with brain metastases better signposting of impactful support and advice that reflects the nuance of what it means to be diagnosed with a brain metastasis, including access to a key person who helps the patient navigate the complexity of the secondary diagnosis. |  |  |
| 42 | NHS England and NHS Improvement | **(CAHPO)**Key area for quality improvement 1  Provide a named healthcare professional with responsibility for coordinating health and social care support for people with brain tumours and their relatives and carers, for example, a key worker as defined in NICE guidance on improving outcomes for people with brain and other central nervous system tumours. | It is recommended that all patients with brain tumours should have an identified key worker (NICE, 2018). Having a clearly identified key worker is important to ensure that care is adequately co-ordinated for patients with brain tumours. |  | The key worker is often identified as a Clinical Nurse specialist, but the role could be managed by several Allied Health Professions including Occupational Therapists and Therapeutic Radiographers within an advanced practice role |
| 43 | SCM1 | Key area for quality improvement 2  All people with a brain tumour should have an allocated healthcare professional to co-ordinate their health and social care support | There are significant cognitive, behavioural, physical, and emotional impacts on the person with a brain tumour that are difficult for both the person and their family/support to manage. The ability to navigate the health and social care system is negatively impacted by the brain tumour itself.  NICE guidance is that all people with a brain tumour should have allocated a healthcare professional to co-ordinate the health and social care. | The access for all people with brain tumours to a healthcare professional is patchy and often varies dependant on hospital and tumour diagnosis. For example, in some hospitals people with a meningioma and other low grade tumours are not offered this. | <https://www.scan.scot.nhs.uk/wp-content/uploads/2020/10/Final_BrainCNS_QPI_Audit_Report_2018_v1_0.pdf>  A 2018 Scottish audit noted that only in one of 4 services was a keyworker identified at first MDT in >95% patients (average 35%) |
| 44 | SCM2 | GP understanding of brain tumours: | Brain tumours are rare. This can make appointments with GPs difficult for the patient.  Referral to secondary services such as pain clinics, ophthalmology etc quite often requires the referral be made by GPs. GP misunderstanding of brain tumours and the ongoing effects, for low grade gliomas can make referral a slow process. In the meantime, the delays can cause distress for the patient. The CNS’ can end up dealing with issues that can be picked up by GPs. Either GPs have to be prepared to learn more about brain tumours or the number of CNS’ needs to be increased. |  |  |
| 45 | SCM4 | Key area for quality improvement 5 | The 2010 Cancer Patient Experience Survey provided  evidence that patients who had access to one to one support through a Clinical Nurse Specialist (CNS) reported more favourably on aspects of their experience, such as access to information and being given a choice of treatment compared to patients who reported not having had access to a CNS. **CNS provision** – still sole working in remote hospitals. Safe staffing levels to be considered. | The distribution of Cancer Specialist Nurses and in particular Clinical Nurse Specialists (CNSs) is not consistent with cancer incidence across the country. In addition, the number of posts is not proportional to cancer incidence across English Cancer Networks. | Excellence in Cancer Care: The Contribution  of the Clinical Nurse Specialist. NCAT 201011  <https://www.england.nhs.uk/improvement-hub/wp-content/uploads/sites/44/2017/11/Clinical-Nurse-Specialists-in-Cancer-Care_Census-of-the-Nurse-Workforce_Eng-2011.pdf>  · Clinical Nurse Specialists in Cancer;  Provision, Proportion and Performance.  NCAT 20103  · Advanced Level Nursing: A Position  Statement DH 201012  · Manual of Cancer Services. Department of  Health. 200413  · NHS Cancer Commissioning Toolkit.  National Cancer Intelligence Network.  Updated 201114  · One to one support for cancer patients.  A report prepared for DH. Frontier  Ecomonics. December 2010.15 |
| 46 | The Brain Tumour Charity | Key area for quality improvement 1  The provision of a named key worker or Clinical Nurse Specialist for all patients living with a brain tumour, including those living with a low-grade or non-malignant brain tumour | There is evidence to support the need for an accessible key worker (often a Clinical Nurse Specialist) for those living with cancer, benefitting the individual by providing information, emotional support and the coordination of patient care.  NICE guideline NG99 (1.9.5) recommends the provision of a ‘named healthcare professional for ensuring the coordination of health and social care support for people with a brain tumour and their relatives and carers, for example a key worker (often a clinical nurse specialist)’.  Further, cancer service guideline CSG10 recommends that ‘all patients should have a clearly defined key worker’. | The Brain Tumour Charity’s 2020 Improving Brain Tumour Care Survey found that 15% of respondents had not been given a named CNS or key worker (sample: 690 people diagnosed or in active treatment in the last two years). In particular, 25% of respondents with a low-grade tumour reported that they had not been given a named CNS or key worker – compared to just 7% of patients with a high-grade brain tumour.  Further data from the 2019 National Cancer Patient Experience survey (NCPES), suggests that 89% of people living with cancer were given a named CNS, however only 46% said they were ‘very easy’ to contact. A further 30% felt their named CNS was ‘quite easy’ to contact.  95% of people with high-grade/malignant brain cancer were given a named CNS, of which 86% felt they were at least ‘quite easy’ to contact. This data is not available for those living with a low-grade/ benign brain tumour.  Our Improving Brain Tumour Care Surveys also found that people who had a CNS or key worker were more likely to be told about basic forms of support than those who did not. | NHS and NICE guidelines recommending the provision of a key worker/CNS:   * [Cancer service guideline [CSG10] – Improving outcomes for people with brain and other central nervous system tumours](https://www.nice.org.uk/guidance/csg10) * [NG99 – NICE guidelines on Brain Tumours (primary) and brain metastases in adults](https://www.nice.org.uk/guidance/ng99/chapter/Recommendations#care-needs-of-people-with-brain-tumours)   The Brain Tumour Charity’s Improving Brain Tumour Care Survey is currently unpublished, but we would be very happy to share or discuss any of the results if helpful. It should be noted that the survey sample was not representative of the whole population affected by a brain tumour, and so these results should be treated as indicative.  2019 NCPES summary document highlights the provision and ease with which people living with cancer were able to contact their CNS:  <https://www.ncpes.co.uk/wp-content/uploads/2020/06/CPES-2019-National-Report_V1.pdf> |
| **Care needs- Specific support** | | | | | |
| 47 | NCRI-ACP-RCP | Key area for quality improvement 1 |  |  |  |
| 48 | NHS England and NHS Improvement | **(Spec Comm)** 3 Neuropsychology and clinical psychology support along the whole patient pathway seamlessly transitioning into palliative care at EoL | Cognitive and functional support for brain tumour patients will support family life, return to work/employment  Good quality palliative care can ensure a dignified death and help families come to terms with loss of loved ones |  | NICE guidance 2018 section 1.9 Care needs of people with brain tumours |
| 49 | NHS England and NHS Improvement | Additional developmental areas of emergent practice | Access to appropriate Allied Health Professions (AHPs) to support patients through survivorship ensuring patients live their best lives post tumour diagnosis and treatment. | This KPI is linked to the notion of “adding life to years’ “. The Allied Health Professions (AHPs) are the third largest workforce in the NHS. AHPs provide system-wide care to assess, treat, diagnose and discharge patients across social care, housing, education, and independent and voluntary sectors. Through adopting a holistic approach to healthcare, AHPs can help manage patients’ care throughout the life course from birth to palliative care. Their focus is on prevention and improvement of health and wellbeing to maximise the potential for individuals to live full and active lives within their family circles, social networks, education/training and the workplace. | We have not been able to identify sufficient evidence, However, more details about the value added by Allied Health Professions within patient pathways can be found here:  <https://www.england.nhs.uk/ahp/about/> |
| 50 | SCM2 | Driving | This is a really important issue for people with brain tumours. There are guidelines regarding people with brain tumours and quite often this means a period not driving or having licenses withheld. However, patients experience inconsistent advice The DVLA as an organisation is difficult to communicate with. Some transparent, clear and consistent advice is required for patients. |  |  |
| 51 | Scottish Adult Neuro-oncology Network | Key area for quality improvement 1  Seizure Management by a Neurologist | Diagnosing epilepsy can be complex and it is crucial that specialists are involved early to avoid misdiagnosis.21 | The diagnosis of epilepsy is more accurate when made by a medical practitioner who specialises in epilepsy, resulting in better patient outcomes. Access to a specialist nurse with expertise in epilepsy management enhances the quality of life for patients and gives a more patient centred approach to care | NICE (2013) Epilepsy in Adults: Quality Standard 26. Available from: https://www.nice.org.uk/guidance/qs26 (accessed 16th February 2018). 22. NICE (2005) Referral guidelines for suspected cancer (accessed 23rd August 2013). 23. SIGN (2003) Diagnosis and Management of Epilepsy in Adults (accessed 23rd August 2013). Update available from: http://www.sign.ac.uk/sign-143-diagnosis-and-managementof-epilepsy-in-adults.html. 24. NHS Quality Improvement Scotland (2008) Management of Core Cancer Services Standards. Available from: http://www.healthcareimprovementscotland.org/our\_work /cancer\_care\_improvement/cancer\_resources/standards\_for\_cancer\_services.aspx (accessed 12th September 2017) 25. Downing A, et al (2016). High Hospital Research Participation and Improved Colorecta |
| 52 | Scottish Adult Neuro-oncology Network | Key area for quality improvement 5  Equity to community and social supportive services | There is a wide variation in the wider community support for patients with Brain tumours. Outreach services and support services such as physiotherapy, inpatient neurorehabilitation, speech and language as well as neuropsychology assessment and services are often lacking. | Long term survivors of brain tumours/metastases often have treatment related cognitive and physical deficits that impact on their quality of social life. Services such as neuropsychology or rehabilitation can help improve physical, social and psychological well being |  |
| 53 | The Brain Tumour Charity | Key area for quality improvement 3  Prompt signposting to available support networks at diagnosis and at key points in the treatment and care pathway. | Signposting to avenues of support and networks to benefit wellbeing as early as possible is beneficial for the complex emotional and psychological needs of those living with a brain tumour.  Cancer service guidelines CSG10 highlights the complex psychological care needs of those living with a brain tumour and discusses the importance of individuals such as neuropsychologists in their care.  The need for a clinical review to assess changes in an individual’s physical, psychological and cognitive wellbeing is recommended in NICE guidelines NG99.  Signposting to support groups, charities and relevant services is a recommendation of the [Tessa Jowell Centre of Excellence Designation of Standards](https://www.tessajowellbraincancermission.org/wp-content/uploads/2020/10/TJ-Centre-Designation-Standards-1.pdf). | The Brain Tumour Charity’s Improving Brain Tumour Care Survey highlighted that just 21% of respondents were told about basic support.  Further, just 44% of people were signposted to counselling or emotional support, which has been highlighted as a key area of unmet need for the brain tumour community.  A 2015 report by The Charity, Finding Myself in Your Hands, showed only 25% of respondents had access to a psychologist.  Further, the 2019 NCPES results showed that 83.2% of those living with a brain or CNS tumour answered ‘Yes’ to the question ‘Did hospital staff give you information about support or self-help groups for people with cancer?’ A further 6.5% said that this support was not necessary. Again, this data does not include the experiences of people living with a low-grade /benign brain tumour. | For more information on the psychological care needs of those living with a brain tumour:   * [Cancer service guideline [CSG10] – Improving outcomes for people with brain and other central nervous system tumours](https://www.nice.org.uk/guidance/csg10) * [NG99 – NICE guidelines on Brain Tumours (primary) and brain metastases in adults](https://www.nice.org.uk/guidance/ng99/chapter/Recommendations#care-needs-of-people-with-brain-tumours)   For the importance on the signposting to information about support networks and support charities, please see:   * [Tessa Jowell Centre of Excellence Designation of Standards](https://www.tessajowellbraincancermission.org/wp-content/uploads/2020/10/TJ-Centre-Designation-Standards-1.pdf)   The Brain Tumour Charity’s report ‘ [Finding Myself in Your Hands’](https://www.thebraintumourcharity.org/about-us/our-publications/finding-myself/#:~:text=Finding%20Myself%20in%20Your%20Hands%20is%20the%20most%20comprehensive%20study,grade%20and%20low%20grade%20tumours.). |
| **Neurorehabilitation – Assessment** | | | | | |
| 54 | SCM1 | Key area for quality improvement 3  Assessment and referral to neuro-rehabilitation | Neurorehabilitation can improve function in those with brain tumours.  NICE guidance recommends that assessment for rehabilitation should be considered at every point, and information should be provided on how to get an assessment, what needs it can address and the neurological rehabilitation options available in the community. | Access to, and assessment for, neurorehabilitation for people with brain tumours is limited and patchy across England. | Regarding issues with access see paper by McCartney et al Palliat Med 2011 Dec 25(8):788-96 |
| 55 | SCM4 | Key area for quality improvement 1 | It is suggest that specific and **specialised neuro rehabilitation for brain tumour patients** is beneficial in allowing maximum improvements in cognition, mobility and neuroplasticity.  NICE recommends assessment should be carried out at every stage of diagnosis and follow‑up to identify which, if any, forms of rehabilitation are suitable for the person. The aim of the recommendations is to ensure that neurological rehabilitation is considered at every stage of treatment and follow‑up. | There is currently variation in practice in assessing whether people with a brain tumour need neurological rehabilitation. Some of this reflects the availability of neurological rehabilitation services. The NICE guideline committee found no evidence to support the neuro-rehabilitation needs of the patient. Neurological rehabilitation is time consuming and patients may not live near a rehabilitation centre. Hence the need to work more closely with community and primary care providers is essential. | <https://www.nice.org.uk/guidance/ng99/chapter/Recommendations#neurorehabilitation-needs-of-people-with-brain-tumours>  “Neurorahabilitation in Neuro-Oncology” Eds M Bartolo; R Soffietti, M Klein (Springer 2019) |
| **Neurorehabilitation- Access to services** | | | | | |
| 56 | Braintrust |  | Access to neurorehabilitation and neuropsychological services locally so that what is in the care plan (see 2) can be delivered. |  |  |
| 57 | NHS England and NHS Improvement | Key area for quality improvement 5  **(Spec Comm)** Access to rehabilitation services including on community rehabilitation | Rehabilitation for long-term survivors including young adults who were treated as children will improve quality of life  Community-based services will reduce pressure on hospital resources and avoid unnecessary hospital admissions and delays in discharge |  | NICE NG99 2018 Section 1.10 Neurorehabilitation needs of people with brain tumours  NHSE national service transformation work 2018-present |
| 58 | Society of British Neurological Surgeons | Key area for quality improvement 1  Rehabilitation for brain cancer patients. | Availability of rehabilitation (with dedicated occupational therapy and physiotherapy input) and post surgery for brain cancer patients. | There is evidence that dedicated and exclusive Rehabilitation pre and post surgical resection, can result in improved outcomes for patients. | * [Brain tumours (primary) and brain metastases in adults](https://www.nice.org.uk/guidance/ng99) (2018) NICE guideline NG99 * Oxford University Hospitals MacMillan funded Pilot study for dedicated and exclusive physiotherapy and occupational therapy input for Brain cancer patients 2019. * Cancer Prehabilitation An Opportunity to Decrease Treatment-Related Morbidity, Increase Cancer Treatment Options, and Improve Physical and Psychological Health Outcome. Am J Phys Med Rehabil 2013;92:715Y727.   [The Role and Scope of Prehabilitation in Cancer Care.](https://www.ncbi.nlm.nih.gov/pubmed/31987643) Semin Oncol Nurs. 2020 Feb;36(1):150976. Doi: 10.1016/j.soncn.2019.150976. Epub 2020 Jan 25. Review |
| **Surveillance for late-onset side effects of treatment** | | | | | |
| 59 | SCM1 | Key area for quality improvement 4  Management of late effects of treatment in people with brain tumours | Treatment of a brain tumour can result in significant late effects that can manifest years after treatment.  NICE guidance recommends assessing the individual person’s risk of late effects, recording this in a summary and explaining this to the person, and then managing those risks appropriately. | The generation of individualised summaries that are explained to the person is variable and the active management of these risks (stroke, hypopituitarism, visual and hearing loss, neurocognitive effects) is low. Prospective holistic management of these effects will improve the quality of care provided to people with brain tumours. | Stroke risk: Circulation 2017 135 1194-1210 |
| 60 | NHS England and NHS Improvement | **(Spec Comm)** 2 Late effects clinics: to help patients cope with the endocrine, neurological, and psychological sequelae with emphasis on management through OPD & community | People with brain tumours can develop side effects of treatment months or years after treatment, which can include: Cataracts, cavernoma, cognitive decline, epilepsy, hearing loss, hypopituitarism, infertility, neuropathy (for example, nerve damage causing visual loss, numbness, pain or weakness), radionecrosis, secondary tumours, SMART (stroke-like migraine attacks after radiotherapy), stroke. |  | NICE guidance 2018 Section 1.11 Surveillance for the late-onset side effects of treatment  NHS Integrated Care Systems (ICS) guidelines: <https://www.england.nhs.uk/integratedcare/what-is-integrated-care/> |
| 61 | SCM2 | Living with a brain tumour: | Low grade gliomas can mean the patient can look forward to a survival that surpasses expectations. In this time deterioration will continue there is no cure. In addition, new impairments and disabilities will be collected. Support and assessment is required to manage this. For example Late effects of radiotherapy clinics are helpful in picking up long term effects of the radiotherapy such as cognition, sight, weaknesses. From this referrals can be made. I guess this is palliation but professionals such as GPs need help in understanding this, rather than the common myth that ‘all’ brain tumours mean a quick demise. |  |  |
| 62 | SCM5 | Neurological surveillance of those with/ at risk of tumour related epilepsy | Tumour related epilepsy is recognised within NG99 as an area which impacts on patients’ well-being and can develop as a late effect following treatment. | Regional networks differ widely in their access to neurological input and thus scope for seizure surveillance. | NG CG137- the epilepsies- recognises the importance of early specialist at diagnosis/ following a first seizure and ongoing access to the epilepsy specialist team. |
| 63 | SCM5 | Access to neuropsychology for those with/ at risk of psychological symptoms during their disease course | Changes in cognition and psychological symptoms are recognised within NG99 as potential late effects requiring neurorehabilitation. | Regional services are not required to provide dedicated neuropsychology input within the neuro-oncology MDT. Access to neuropsychology differs within areas. | NG CG137- the epilepsies – organisation of tertiary epilepsy services states that the management of complex epilepsies should involve an MDT approach including psychology input. |
| **Additional areas- participation in clinical trials/research** | | | | | |
| 64 | British Society of Neuroradiologists | Additional developmental areas of emergent practice – Sharing of anonymised imaging datasets with proven formal diagnosis. | Standardisation of protocols for and scheduling of imaging during diagnosis, treatment and follow up, could result in a large homogenous dataset, which may improve our understanding of predictors for and the natural history of brain tumours. | Imaging can be readily shared across the UK via the Image Exchange Portal (IEP). Collection and transfer of clinical imaging data in an anonymised format could provide large datasets for research at relatively low cost. This has the potential to vastly improve our understanding of brain tumours, ultimately leading to patient benefit. |  |
| 65 | NCRI-ACP-RCP | Key area for quality improvement 4 |  |  |  |
| 66 | NHS England and NHS Improvement | **(CAHPO)**Key area for quality improvement 3   * All patients should be considered for participation in available clinical trials / research studies, wherever eligible | Clinical trials are necessary to demonstrate the efficacy of new therapies and other interventions. Evidence suggests improved patient outcomes when hospitals actively recruit patients into clinical trials. | Generally, for people with a cancerous (malignant) brain tumour in England:  •40 out of 100 people (40%) survive their cancer for 1 year or more  •more than 10 out of 100 people (more than 10%) survive their cancer for 5 years or more  These represent lower rates than other cancer types although it is noted this will vary dependent on the specific brain tumour | <https://www.cancerresearchuk.org/about-cancer/brain-tumours/survival> |
| 67 | Scottish Adult Neuro-oncology Network | Key area for quality improvement 3  Clinical Trials and Research Study Access | Clinical trials are necessary to demonstrate the efficacy of new therapies and other interventions24 . Evidence suggests improved patient outcomes when hospitals are actively recruiting patients into clinical trials25 . | Clinicians are therefore encouraged to enter patients into welldesigned trials and to collect longer-term follow-up data. High accrual activity into clinical trials is used as a goal of an exemplary clinical research site. The measurement of this QPI focuses on those patients who have consented in order to reflect the intent to join a clinical trial and demonstrate the commitment to recruit patients. Often patients can be prevented from enrolling within a trial due to stratification of studies and precise inclusion criteria identified during the screening process | NHS Quality Improvement Scotland (2008) Management of Core Cancer Services Standards. Available from: http://www.healthcareimprovementscotland.org/our\_work /cancer\_care\_improvement/cancer\_resources/standards\_for\_cancer\_services.aspx (accessed 12th September 2017) 25. Downing A, et al (2016). High Hospital Research Participation and Improved Colorectal Cancer Survival Outcomes: A Population Based Study. Gut 0:1–8. Doi:10.1136/gutjnl2015-311308. Available from: http://gut.bmj.com/content/66/1/89 (accessed 25th Octobe |
| 68 | The Brain Tumour Charity | Key area for quality improvement 5  Research participation through tumour biobanking and whole brain donation. | Where appropriate, providing people living with a brain tumour the opportunity to become involved in research is key to progressing patient treatment and care. Banking tissue samples for the purpose of research (biobanking), including whole brain donation, is an important area of this.  Currently, the lack of biobanking reduces the availability of samples for research and genetic testing, especially for rarer tumour types. Further, the lack of longitudinal tumour sampling means we have a limited understanding of how tumours change over time and how we can best manage this. | Despite the benefits for research in tissue collection, we know that it is still not undertaken routinely. Currently, a limited number of adult tissue samples are stored in local tissue banks across the UK, resulting in small, fragmented collections. | Initiatives for whole brain donation have shown to be effective for other disease areas, such as for dementia research, which through [Brains for Dementia Research](https://www.brainsfordementiaresearch.org.uk/), now has over 3300 promised donations for research.  Building an understanding of the availability of tissue and whole brain donation in England and Wales could be extremely beneficial for the future of patient treatment, care and research.  People affected by a brain tumour should be empowered and told that their tissue sample may be used for purposes beyond direct care if appropriate. Where tissue banking is available, patients should be made aware of how their tissue is banked and what it means. |
| **Additional areas – end of life care** | | | | | |
| 69 | Braintrust |  | For people transitioning to end of life care appropriate community care that recognises and understands that the needs of people dying with a brain tumour may be different through progressive neurological and neurocognitive decline. |  |  |
| 70 | Compassion in dying | Advance Care Planning (ACP) | There is clear evidence that advance care planning (ACP) results in significant benefits for individuals and care providers: in addition to increased satisfaction with overall care, people receive fewer aggressive medical interventions, have fewer hospital admissions and benefit from increased use of palliative care services, and communication between patients, their doctors and families is enhanced *(Literature review on the impact of advance care planning, produced by the International Longevity Centre on behalf of Compassion in Dying, 2016)*.  Not only is there clear evidence of the benefits of ACP, people place great value on choice and control over decision-making and as we have learned from our service users, planning ahead gives people peace of mind and allows them to live well now. (Compassion in Dying, [*I wish I had known*](https://compassionindying.org.uk/library/i-wish-i-had-known/)*…*2018).  **Early and ongoing conversations about ACP for people with brain tumours and brain metastases, and taking steps to ensure recorded wishes are updated, communicated and respected should therefore form a key part of the Quality Standard.**  Brain tumours may cause a person’s capacity to fluctuate and some may lose all capacity to make decisions about their treatment and care. If people haven’t documented their wishes for future decisions or appointed someone they trust to make decisions on their behalf then they are left to healthcare professionals. Therefore people with brain tumours and metastases must be given opportunities to discuss advance care planning in a timely manner to ensure their future care and treatment is aligned with their preferences and values.  Research shows that a reduction in emergency hospital admissions for those who have an advance care plan in place leads to fewer days in hospital in the last year of life and reduced hospital costs incurred as a result of emergency admissions – a mean reduction of 28% and 8% respectively (Abel *et al.* 2013).  Best practice guidance for other conditions that may or certainly will involve of loss of capacity to make treatment decisions recognise the importance of advance care planning:  The NICE Quality Standard for Dementia (2019) recognises the importance of people being able to “make decisions about their future care early on, before they find it difficult to communicate or they lack the capacity to do so.”  The Royal College of Physicians, in their recently published guidelines for the treatment of people with prolonged disorders of consciousness *(Prolonged disorders of consciousness following sudden onset brain injury: National clinical guidelines, 2020)*, affirmed that what the patient would want is the most important factor when making treatment decisions for a person in a prolonged disorder of consciousness such as vegetative state (VS) and minimally conscious state (MCS). The guidance also clearly explains the legal position that where a patient has made a valid and applicable Advance Decision to Refuse Treatment this *“…is legally binding on clinicians to follow. In this situation there is no need for a best interests discussion as the patient has already made their decision...”* The RCP’s guidance will also soon include a template Advance Decision (annex 4c), suggesting the importance of ensuring more people are aware of the possibility of making these documents in order that their wishes are known should they lose capacity to make decisions due to a prolonged disorder of consciousness. | Whilst research shows that ACP results in significant benefits for individuals and healthcare providers, awareness and uptake is low. In 2018, only 4% of people had made an Advance Decision to Refuse Treatment and just 7% had appointed a Lasting Power of Attorney for Health and Welfare (YouGov, 2018).  A [report](https://www.dignityindying.org.uk/wp-content/uploads/What-matters-to-me-Dignity-in-Dying-Nov-2019.pdf) commissioned by Dignity in Dying, *‘What matters to me’*, asked people with terminal and advanced illness about end of life choices. They found that:   * Only 16% of terminally ill people surveyed have had a discussion with their doctor about what might happen as their condition progresses, particularly at the end of life. * A third (34%) of respondents say they would like to discuss refusing life-sustaining treatment with a healthcare professional but do not feel able to, suggesting there is a need to make people more comfortable about having these conversations. * Despite this, only 12% of respondents say that they have completed an Advance Decision to Refuse Treatment even though 43% know of treatments, such as CPR or assisted nutrition and hydration that they would like to refuse at the end of life.   This is worrying given the significant evidenced benefits of advance care planning, for example that it improves communication and results in people having care and treatment aligned to their preferences.  [The Government’s response](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/318730/cm8884-valuing-every-voice.pdf) in 2014 to a House of Lords Select Committee Report on the Mental Capacity Act stressed the urgency to: *“promote better understanding among health care staff of Advance Decisions”.*  In 2015, the [House of Commons Health Select Committee](https://publications.parliament.uk/pa/cm201415/cmselect/cmhealth/805/805.pdf) reported that care staff often feel that they lack understanding of the mechanisms available to patients and carers under the Mental Capacity Act which allow people to make their wishes clear. The Committee recommended that all staff who provide palliative and end of life care to people with life-limiting conditions should receive training in advance care planning.  Despite these warnings, our own research has found that people who want to plan ahead still face unnecessary barriers, both from individual healthcare professionals and from wider system failures.  A recent Freedom of Information Request to Ambulance Trusts by Compassion in Dying highlighted a lack of a unified system for recording and implementing advance care plans, and a widespread absence of systems for monitoring and analysing adherence to advance care plans. For example, 23% of Trusts have no systems at all for holding advance care plans for patients in their areas, while 31% of Trusts will only accept advance care planning forms from healthcare professionals.  “As a paramedic it is immensely frustrating and upsetting when things aren’t put in place allowing us to leave someone at home where they wish to be. I was not prepared for the heartache of having to take a dying patient away from their home and into general hospital.” ([*The role of Ambulance Trusts in respecting people’s end of life wishes*](https://compassionindying.org.uk/library/the-role-of-ambulance-trusts-in-respecting-peoples-end-of-life-wishes/), 2018)  A further FOI to all Clinical Commissioning Groups (CCGs) in England found that while 87% of CCGs provide information to GP practices on advance care planning, not all CCGs consistently and explicitly covered the topics of Advance Decisions, Lasting Powers of Attorney and Do Not Attempt Resuscitation orders. Templates used for Advance Decisions did not have accompanying guidance notes, resulting in inadequate support, not only for individuals but also for healthcare professionals. ([*Advance care planning in general practice – does policy match reality?*](https://compassionindying.org.uk/library/advance-care-planning-in-general-practice-does-policy-match-reality/)2018) |  |
| **Additional areas- Employment support** | | | | | |
| 71 | SCM2 | Returning to work after treatment and with new disabilities: | A new disability/impairment might lead to the diagnosis of a brain tumour. Through time and treatment these disabilities can deteriorate, and new disabilities acquired. Return to work is an important goal but the patients understanding of how these disabilities will impact on their work can be confusing and difficult for the patient. The effect fatigue has for both the patient and employer can result in fear and confusion. Support is required tor both patient and employer. For smaller employers this may be needed more. |  |  |
| **Additional areas – Quality of Life questionnaires** | | | | | |
| 72 | SCM4 | Key area for quality improvement 2 | According to Macmillan, there are no standardised national metrics looking at the quality of life of people diagnosed and treated for cancer.  **Specific Quality of Life questionnaires for brain tumour patients** is required to enable accurate data collection as a lot of the other tools available are generic and not CNS specific. Brain tumours affect people’s cognition, memory, personality amongst others and we need more research into how to support this patient cohort and their carers | Collecting information that reflects patients’ quality of life is a valuable resource that can then be used to make changes in care that focus on improving outcomes for patients.  (Copied from Brainstrust website): “We know too that an improved quality of life for the brain tumour community means:  •Understanding your illness.  •Exploring options for treatment and for living with the illness – to the best of your ability.  •Sourcing information, knowledge, help and advice.” | <https://www.macmillan.org.uk/_images/quality-of-life_tcm9-355687.pdf>  <https://brainstrust.org.uk/brain-tumour-support/our-campaigns/quality-of-life/>  <https://www.thebraintumourcharity.org/living-with-a-brain-tumour/brian/> |
| **General** | | | | | |
| 73 | NCRI-ACP-RCP | General | General | General | The NCRI-ACP-RCP is grateful for the opportunity to respond to the above consultation. We have liaised with our experts who have suggested we emulate the four Scottish QPIs which I have pasted below for ease of reference. We have also included one original key area for quality improvement. |
| 74 | The Society and College of Radiographers | Key area for quality improvement 2 |  |  | The SCoR would also comment around age, the key development sources and a related quality standard all vary a bit:  NG 127 Suspected neurological conditions: recognition and referral is over 16 NG 99 Existing Brain tumours (primary) and brain metastases in adults is over 16 NG 12 Suspected cancer: recognition and referral covers children, young people and adults QS 42 Headaches in over 12s |
| 75 | The Society and College of Radiographers | Key area for quality improvement 3 |  |  | The NICE clinical knowledge summary  <https://cks.nice.org.uk/childhood-cancers-recognition-and-referral#!diagnosisSub> recognises that in practice young people (aged 16-24) may be referred using either an adult or children's pathway depending on their age and local arrangements. |

1. [Brain tumours (primary) and brain metastases in adults](https://www.nice.org.uk/guidance/ng99) (2018) NICE guideline NG99 [↑](#endnote-ref-1)
2. British Journal of General Practice (2018) [Diagnosing cancer in primary care: results from the National Cancer Diagnosis Audit](https://bjgp.org/content/68/666/e63) [↑](#endnote-ref-2)
3. [Suspected cancer: recognition and referral](https://www.nice.org.uk/guidance/ng12) (2015, updated 2017) NICE guideline NG12 [↑](#endnote-ref-3)
4. [Suspected neurological conditions](https://www.nice.org.uk/guidance/indevelopment/gid-qs10082) (2021) NICE quality standard 198 [↑](#endnote-ref-4)