

**NATIONAL INSTITUTE FOR HEALTH AND CARE  
EXCELLENCE**

**Guideline scope**

**Brain tumours (primary) and brain metastases  
in over 16s**

**Update information**

**January 2022:** During guideline development, the population group covered was extended from adults to people aged 16 and over for consistency with the pre-existing quality standard on this topic. The treatments for 16- and 17-year-olds are the same as those for people aged 18.

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**Guideline scope**

**Brain tumours (primary) and brain  
metastases in adults**

***Topic***

The Department of Health in England has asked NICE to develop a clinical guideline on primary brain tumours and brain metastases.

This guideline will also be used to develop the NICE quality standard for brain metastases.

The guideline will be developed using the methods and processes outlined in [Developing NICE guidelines: the manual](#).

For more information about why this guideline is being developed, and how the guideline will fit into current practice, see the [context](#) section.

***Who the guideline is for***

- People using services for the diagnosis, management and care of a primary brain tumour or brain metastases.
- Professionals or practitioners involved in the multidisciplinary care of people with primary brain tumours or brain metastases.
- Commissioners of brain tumour services (including clinical commissioning groups and NHS England specialised commissioning).

NICE guidelines cover health and care in England. Decisions on how they apply in other UK countries are made by ministers in the [Welsh Government](#), [Scottish Government](#) and [Northern Ireland Executive](#).

## ***Equality considerations***

NICE has carried out [an equality impact assessment](#) during scoping. The assessment:

- lists equality issues identified, and how they have been addressed
- explains why any groups are excluded from the scope.

The guideline will look at inequalities relating to age.

# **1 What the guideline is about**

## ***1.1 Who is the focus?***

### **Groups that will be covered**

- Adults (18 and over) with radiologically identified glioma, meningioma, or 1 or more brain metastases.
- Adults with any type of primary brain tumour or brain metastases who might need assessment for neurological rehabilitation.

## ***1.2 Settings***

### **Settings that will be covered**

- All settings in which NHS care is provided.
- Shared care, including social services.

## ***1.3 Activities, services or aspects of care***

We will look at evidence on the areas listed below when developing the guideline, but it may not be possible to make recommendations on all the areas.

### **Key areas that will be covered**

- 1 Diagnosing radiologically identified glioma, meningioma and brain metastases.
- 2 Managing glioma.
- 3 Managing meningioma.

- 4 Managing brain metastases.
- 5 Follow-up care after treatment for glioma, meningioma or brain metastases.
- 6 Referring adults with primary brain tumours or brain metastases for neurological rehabilitation assessment.

#### **Areas that will not be covered**

- 7 Identifying people in primary care with suspected primary brain tumours or cerebral metastases and referring them to secondary care. This is already covered in NICE's guideline on [suspected cancer: recognition and referral](#).
- 8 The following (non-exhaustive) list of tumour types:
  - neuronal and mixed neuronal-glial tumours
  - tumours of the pineal region
  - embryonal tumours
  - tumours of the cranial and paraspinal nerves
  - melanocytic tumours
  - lymphomas
  - mesenchymal, histiocytic, germ cell, sellar originating and choroid plexus tumours.

### **1.4 Economic aspects**

We will take economic aspects into account when making recommendations. We will develop an economic plan that states for each review question (or key area in the scope) whether economic considerations are relevant, and if so whether this is an area that should be prioritised for economic modelling and analysis. We will review the economic evidence and carry out economic analyses, using an NHS and personal social services (PSS) perspective, as appropriate.

### **1.5 Key issues and questions**

While writing this scope, we have identified the following key issues, and draft review questions related to them:

- 1 Diagnosing radiologically identified glioma, meningioma and brain metastases.
  - 1.1 What is the most effective diagnostic imaging in newly diagnosed glioma?
  - 1.2 What is the most effective diagnostic imaging in newly diagnosed meningioma?
  - 1.3 What is the most effective diagnostic imaging in newly diagnosed brain metastases?
  - 1.4 What are the most useful molecular markers to guide treatment for gliomas?
  - 1.5 What are the most useful molecular markers to estimate prognosis for gliomas?
- 2 Managing glioma.
  - 2.1 What is the optimal initial treatment (surgery [including extent of resection], radiotherapy, observation, chemotherapy or combinations of these) for low-grade glioma?
  - 2.2 What is the most effective method of resecting high-grade glioma (for example with 5ALA, awake craniotomy, intraoperative ultrasound, intraoperative MRI)?
  - 2.3 What is the optimal management (surgery, radiotherapy, chemotherapy, combinations of these, or other therapies such as metformin or tumour-treating fields) of recurrent high-grade glioma?
- 3 Managing meningioma.
  - 3.1 Which adults with previously untreated meningioma should have radiotherapy?
  - 3.2 Which adults with recurrent meningioma should have radiotherapy?
- 4 Managing brain metastases.
  - 4.1 What is the most effective intracranial treatment (surgery, stereotactic radiotherapy, whole-brain radiotherapy or combinations of these) for a single brain metastasis?
  - 4.2 What is the most effective intracranial treatment (surgery, stereotactic radiotherapy, whole-brain radiotherapy, combinations of these, or no treatment) for multiple brain metastases?

- 5 Follow-up care after treatment for glioma, meningioma or brain metastases.
  - 5.1 What is the most effective follow-up protocol (including duration, frequency and tests) to detect recurrence after treatment for glioma?
  - 5.2 What is the most effective follow-up protocol (including duration, frequency and tests) to detect recurrence after treatment for meningioma?
  - 5.3 What is the most effective follow-up protocol (including duration, frequency and tests) to detect intracranial recurrence after treatment for brain metastases?
  - 5.4 What is the most effective surveillance protocol (including no surveillance) for detecting late effects of treatment for glioma, meningioma or brain metastases?
  - 5.5 What are the health and social care support needs of people with brain tumours (primary) and brain metastases and their families and carers?
- 6 Referring adults with primary brain tumours or brain metastases for neurological rehabilitation assessment.
  - 6.1 Which adults with primary brain tumours or brain metastases should be referred for neurological rehabilitation assessment and when is the optimal time to refer?

## **1.6 Main outcomes**

The main outcomes that will be considered when searching for and assessing the evidence are:

- 1 Overall survival.
- 2 Progression-free survival (at tumour site and within the head).
- 3 Cognitive function.
- 4 Treatment-related mortality and morbidity.
- 5 Health-related quality of life.
- 6 Patient and carer experience.

## 2 Links with other NICE guidance, NICE quality standards and NICE Pathways

### 2.1 *NICE guidance*

#### **NICE guidance that may be updated by this guideline**

The following guidance contains recommendations on brain metastases and may be affected depending on the final choice of review questions:

- [Melanoma: assessment and management](#) (2015) NICE guideline NG14
- [Colorectal cancer: diagnosis and management](#) (2011) NICE guideline CG131
- [Lung cancer: diagnosis and management](#) (2011) NICE guideline CG121
- [Metastatic malignant disease of unknown primary origin in adults: diagnosis and management](#) (2010) NICE guideline CG104
- [Advanced breast cancer: diagnosis and treatment](#) (2009) NICE guideline CG81
- [Improving outcomes for people with brain and other central nervous system tumours](#) (2006) NICE cancer service guidance 10

#### **NICE guidance that will be incorporated unchanged in this guideline**

- [Carmustine implants and temozolomide for the treatment of newly diagnosed high-grade glioma](#) (2007) NICE technology appraisal guidance 121
- [Guidance on the use of temozolomide for the treatment of recurrent malignant glioma](#) (2001) NICE technology appraisal guidance 23

#### **NICE guidance about the experience of people using NHS services**

NICE has produced the following guidance on the experience of people using the NHS. This guideline will not include additional recommendations on these topics unless there are specific issues related to the diagnosis and management of primary brain tumours or brain metastases:

- [Patient experience in adult NHS services](#) (2012) NICE guideline CG138

- [Medicines adherence](#) (2009) NICE guideline CG76

### **NICE guidance that is closely related to this guideline**

NICE has published the following guidance that is closely related to this guideline:

- [Palliative care for adults: strong opioids for pain relief](#) (2012) NICE guideline CG140
- [Photodynamic therapy for brain tumours](#) (2009) NICE interventional procedure guidance 290
- [Improving supportive and palliative care for adults with cancer](#) (2004) NICE cancer service guidance 4
- [End of life care for adults](#) (2011) NICE quality standard 13

## **2.2 NICE quality standards**

### **NICE quality standards that may need to be revised or updated when this guideline is published**

- [Breast cancer](#) (2011) NICE quality standard 12

### **NICE quality standards that may use this guideline as an evidence source when they are being developed**

- Brain metastases. NICE quality standard (publication date to be confirmed)

## **2.3 NICE Pathways**

When this guideline is published, the recommendations will be added to [NICE Pathways](#). NICE Pathways bring together all related NICE guidance and associated products on a topic in an interactive topic-based flow chart.

A draft pathway outline on brain cancer, based on the draft scope, is included below. It will be adapted and more detail added as the recommendations are written during guideline development.

Other relevant NICE guidance will also be added to the NICE Pathway, including:



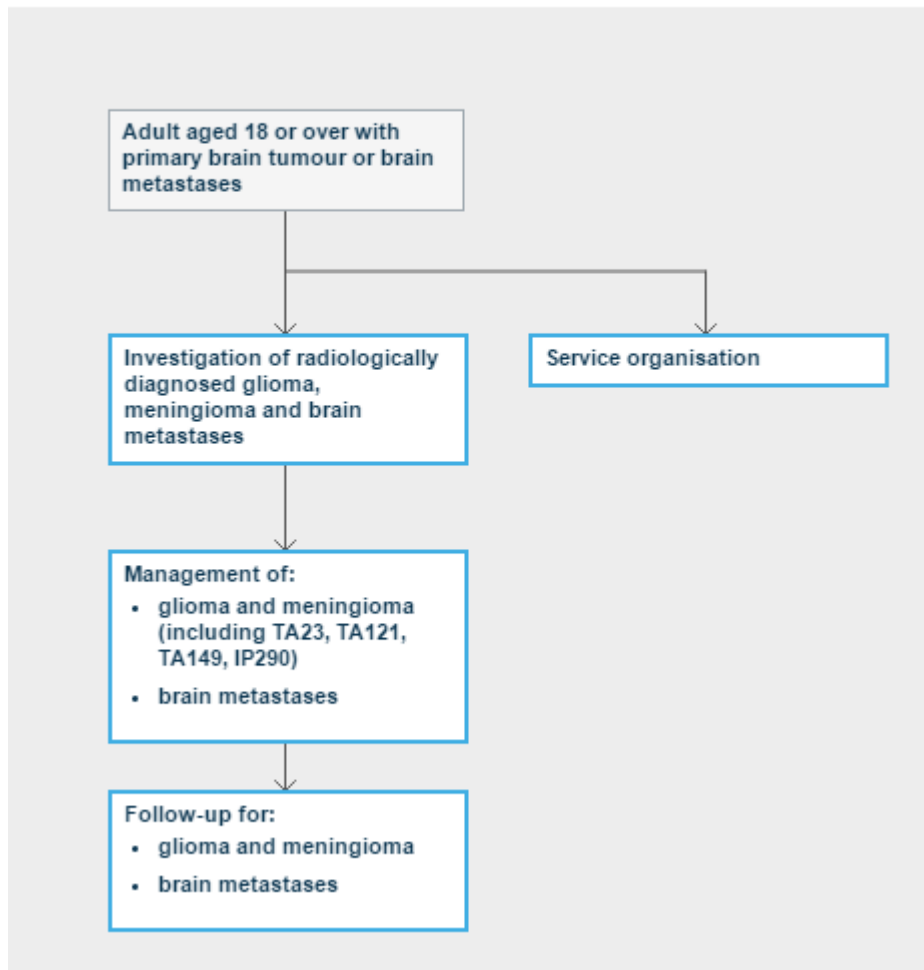
- [Carmustine implants for the treatment of recurrent glioblastoma multiforme](#) (terminated appraisal) (2008) NICE technology appraisal 149
- [Carmustine implants and temozolomide for the treatment of newly diagnosed high-grade glioma](#) (2007) NICE technology appraisal guidance 121
- [Guidance on the use of temozolomide for the treatment of recurrent malignant glioma](#) (2001) NICE technology appraisal guidance 23
- [Photodynamic therapy for brain tumours](#) (2009) NICE interventional procedure guidance 290

The pathway will also link to the NICE pathway on [opioids for pain relief in palliative care](#), and to the following NICE guidance:

- [Improving outcomes for people with brain and other central nervous system tumours](#) (2006) NICE cancer service guidance 10
- [Improving supportive and palliative care for adults with cancer](#) (2004) NICE cancer service guidance 4

This pathway will replace the existing NICE pathway on [brain cancers](#).

## Brain cancer overview



### 3 Context

#### 3.1 Key facts and figures

It is estimated there are around 10,000 new cases of primary brain tumours per year. These 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.

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.

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.

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. 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.

### **3.2 Current practice**

The specialist nature of neuroimaging and the need for complex diagnostic and reductive surgery emphasises the importance of well-organised service delivery by dedicated units. 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. The peak age of presentation of brain cancer is between 65 and 69, and there are concerns that delivery of all services to these older people is suboptimal. There are also concerns that the transition from paediatric to adult units could create a care gap. This would most specifically affect patients who are between 18 and 30 years old.

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.

### **3.3 Policy, legislation, regulation and commissioning**

#### **Policy**

This guideline will address at least 1 of the aims in [Achieving world-class cancer outcomes - a strategy for England 2015-2020](#) (NHS England 2015) by helping to deliver a 'modern high quality service'. It will also look at care after treatment to improve outcomes as set out in [Commissioning cancer services](#) (Department of Health 2011).

#### **Legislation, regulation and guidance**

This guideline will contribute to the evidence base for the commissioning of services for people with primary brain tumours and brain metastases as set out in [Implementing the Cancer Taskforce recommendations: commissioning person-centred care for people affected by cancer](#) (NHS England 2016) and the [2013/14 NHS standard contract for cancer: brain/central nervous system \(adult\)](#) (NHS England 2013).

## **4 Further information**

This is the final scope, incorporating comments from registered stakeholders during consultation.

The guideline is expected to be published in July 2018.

You can follow progress of the [guideline](#).

Our website has information about how [NICE guidelines](#) are developed.