NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Brain tumours (primary) and brain metastases in adults

NICE quality standard

Draft for consultation

2 August 2021

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| **This quality standard covers** diagnosing, monitoring and managing any type of primary brain tumour or brain metastases in people aged 16 or over. It describes high-quality care in priority areas for improvement.  This is the draft quality standard for consultation (from 2 August to 6 September 2021). The final quality standard is expected to publish in December 2021. |

# Quality statements

[Statement 1](#_Quality_statement_1:) GPs have direct access to standard structural MRI for adults with suspected brain tumour.

[Statement 2](#_Quality_statement_2:) Adults with brain tumours have a named healthcare professional who coordinates their health and social care support.

[Statement 3](#_Quality_statement_X) Adults with radiologically enhancing suspected high-grade gliomas that are suitable for resection of all enhancing tumour have 5‑aminolevulinic acid (5‑ALA)-guided resection.

[Statement 4](#_Quality_statement_[X]) Adults who finish treatment for brain tumours have an assessment and discussion about their risk of late effects of treatment at their first follow-up appointment.

[Statement](#_Quality_statement_1:) 5 Adults with brain tumours can access neurological rehabilitation assessment in the community.

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| Questions for consultationQuestions about the quality standard **Question 1** Does this draft quality standard accurately reflect the key areas for quality improvement?  **Question 2** Are local systems and structures in place to collect data for the proposed quality measures? If not, how feasible would it be for these to be put in place?  **Question 3** Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed to deliver them? Please describe any resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment. Questions about the individual quality statements **Question 4** For draft quality statement 4: Is it feasible to carry out an assessment and discussion about the risk of late effects of treatment at the first follow-up appointment after treatment? If not, please say why and if possible, suggest an alternative timescale.  **Question 5** For draft quality statement 5: Stakeholders have highlighted the need to improve access to neurological rehabilitation for adults with brain tumours. Do we have the right focus for this statement? If not, please identify the key action needed for improvement. Local practice case studies **Question 6** Do you have an example from practice of implementing the NICE guideline that underpins this quality standard? If so, please provide details on the comments form. |

# Quality statement 1: GP direct access to MRI

## Quality statement

GPs have direct access to standard structural MRI for adults with suspected brain tumour.

## Rationale

Enabling GPs to use direct access for standard structural MRI will speed up diagnosis for adults with suspected brain tumour. Unless MRI is contraindicated, adults referred to the multidisciplinary team will have the imaging needed to inform decision making, and delays and repeat imaging will be avoided.

## Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured and can be adapted and used flexibly.

### Structure

Evidence of local arrangements to give GPs direct access to standard structural MRI for adults with suspected brain tumour.

**Data source:** Data can be collected from information recorded locally by provider organisations, for example, service protocols.

### Process

Proportion of referrals for brain standard structural MRI that are GP direct referrals.

Numerator – the number in the denominator that are GP direct referrals.

Denominator – the number of referrals for brain standard structural MRI.

**Data source:** [NHS England’s Diagnostic imaging dataset](https://www.england.nhs.uk/statistics/statistical-work-areas/diagnostic-imaging-dataset/) includes details of GP direct referrals for brain MRI.

### Outcome

Time from presentation at GP to brain tumour diagnosis.

**Data source:**No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records.

## What the quality statement means for different audiences

**Service providers** (primary care, secondary care and community imaging services) ensure that direct access referral pathways are in place for GPs to refer adults with suspected brain tumour for standard structural MRI.

**Healthcare professionals** (GPs) can refer adults with suspected brain tumour directly for standard structural MRI unless contraindicated.

**Commissioners** (such as clinical commissioning groups and NHS England) ensure GP services can use direct access pathways to refer adults with suspected brain tumour directly for standard structural MRI.

**Adults with symptoms that may suggest brain tumour** can be referred directly by their GP for an MRI scan to find out if their symptoms are caused by brain tumour. This will ensure that brain tumours can be diagnosed as quickly as possible.

## Source guidance

* [Brain tumours (primary) and brain metastases in adults. NICE guideline NG99](https://www.nice.org.uk/guidance/ng99) (2018), recommendations 1.1.1, 1.4.1 and 1.6.1
* [Suspected cancer: recognition and referral. NICE guideline NG12](https://www.nice.org.uk/guidance/ng12) (2015), recommendation 1.9.1

## Definitions of terms used in this quality statement

### Direct access

When a person is referred directly by their GP for a test in a specialist service and the GP retains responsibility for the person's care, including following up and acting on the results. [Adapted from [NICE's guideline on suspected cancer](https://www.nice.org.uk/guidance/ng12), terms used in this guideline]

### Standard structural MRI

Imaging protocol should be T2 weighted, FLAIR, DWI series and T1 pre- and post-contrast volume. [[NICE’s guideline on brain tumours (primary) and brain metastases in adults](https://www.nice.org.uk/guidance/ng99) recommendations 1.1.1, 1.4.1 and 1.6.1]

### Adults with suspected brain tumour

Adults with progressive, sub-acute loss of central neurological function. [[NICE's guideline on suspected cancer](https://www.nice.org.uk/guidance/ng12) recommendation 1.9.1]

# Quality statement 2: Named healthcare professional

## Quality statement

Adults with brain tumours have a named healthcare professional who coordinates their health and social care support.

## Rationale

Adults with brain tumours have complex needs and support is provided by different health and social care services. Having a named healthcare professional will provide continuity of care and enable adults with brain tumours and their family and carers to access advice and support when they need it. This will improve their experience and quality of life throughout the whole care pathway.

## Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured and can be adapted and used flexibly.

### Structure

Evidence of local processes to ensure that adults with brain tumours are assigned a named healthcare professional who coordinates their health and social care support at all stages of the care pathway.

**Data source:** Data can be collected from information recorded locally by provider organisations, for example from service protocols.

### Process

Proportion of adults with brain tumours who have the name and contact details of a healthcare professional who coordinates their health and social care support.

Numerator – the number in the denominator who have the name and contact details of a healthcare professional who coordinates their health and social care support.

Denominator – the number of adults with brain tumours.

**Data source:** No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example audit of patient records. Providers may wish to check if some groups are less likely to have a named healthcare professional such as those with a low-grade or benign tumour or those diagnosed following an emergency presentation. [NHS England’s National Cancer Patient Experience Survey](https://www.ncpes.co.uk/) includes data for part of the pathway for adults with brain tumours admitted to hospital for treatment who were given the name of a clinical nurse specialist who would support them during treatment.

### Outcome

Proportion of adults with brain tumours who are satisfied with the support provided by their named healthcare professional.

Numerator – the number in the denominator who are satisfied with the support provided by their named healthcare professional.

Denominator – the number of adults with brain tumours.

**Data source:**No routinely collected national data for this measure has been identified. Data could be collected from a local survey of adults with brain tumours and their family and carers. [NHS England’s National Cancer Patient Experience Survey](https://www.ncpes.co.uk/) includes data on ease of contacting a clinical nurse specialist for adults with brain tumours receiving hospital treatment.

## What the quality statement means for different audiences

**Service providers** (such as primary, secondary and tertiary care) ensure that healthcare professionals with the necessary skills are available to support adults with brain tumours. Providers ensure that protocols are in place with local partners for a named healthcare professional to coordinate health and social care support for adults with brain tumours during all stages of their care.

**Healthcare professionals** (such as members of the multidisciplinary team) ensure that adults with brain tumours and their family and carers know how to contact the healthcare professional who coordinates their health and social care support. Healthcare professionals share information with the named healthcare professional to allow them to coordinate care for adults with brain tumours. Named healthcare professionals provide support and information to adults with brain tumours and their family and carers, carry out assessments at key points of care and make referrals when needed.

**Commissioners** (such as clinical commissioning groups and NHS England) ensure that the services they commission have enough capacity to provide named healthcare professionals who coordinate health and social care support for adults with brain tumours throughout all stages of care.

**Adults with brain tumours** can contact a healthcare professional who coordinates their health and social care support for information, advice and support throughout their care.

## Source guidance

[Brain tumours (primary) and brain metastases in adults. NICE guideline NG99](https://www.nice.org.uk/guidance/ng99) (2018), recommendation 1.9.5

## Definitions of terms used in this quality statement

### Named healthcare professional who coordinates health and social care support

The named healthcare professional should promote continuity of care and manage transitions of care. This is done by assessing the person’s needs, ensuring care plans have been agreed with the person receiving care and that findings from assessments and care plans are communicated to others involved in the person’s care. Coordination of care across the patient pathway should also include ensuring people are referred to the appropriate multidisciplinary services at any time. The named healthcare professional should ensure that adults with brain tumours, their family and carers know who to contact when help and advice is needed.

The named healthcare professional could be a key worker and is likely to be the clinical nurse specialist or allied healthcare professional most closely involved with a person’s care. [Adapted from [NICE’s cancer service guideline on improving outcomes for people with brain and other CNS tumours](https://www.nice.org.uk/guidance/csg10), section 2 recommendations]

## Equality and diversity considerations

Named healthcare professionals should ensure that adults are provided with information that they can easily read and understand themselves, or with support, so that they can communicate effectively with health and care services. Information should be in a format that suits their needs and preferences. Adults with cognitive impairment may need more time to process information. Information should be accessible to people who do not speak or read English, and it should be culturally appropriate. People should have access to an interpreter or advocate if needed. For people with additional needs related to a disability, impairment or sensory loss, information should be provided as set out in [NHS England's Accessible Information Standard](https://www.england.nhs.uk/ourwork/accessibleinfo/).

# Quality statement 3: 5-aminolevulinic acid-guided- resection

## Quality statement

Adults with radiologically enhancing suspected high-grade gliomas that are suitable for resection of all enhancing tumour have 5‑aminolevulinic acid (5‑ALA)-guided resection.

## Rationale

Neurological resection is the first treatment for many gliomas (a type of brain tumour). But it can be very difficult to remove all the tumour. Although it is not possible to cure high-grade gliomas, 5-ALA-guided resection is more likely to result in complete or near-complete removal of the tumour and improves progression-free survival.

## Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured and can be adapted and used flexibly.

### Structure

Evidence of local arrangements to ensure that 5-ALA-guided resection is available for adults with radiologically enhancing suspected high-grade gliomas that are suitable for resection of all enhancing tumour.

**Data source:** Data can be collected from implementation plans recorded locally including access to a fluorescence-detecting microscope and specialist skills to undertake 5-ALA-guided resection.

### Process

Proportion of adults with radiologically enhancing suspected high-grade gliomas that are suitable for resection of all enhancing tumour who received 5‑ALA-guided resection.

Numerator – the number in the denominator who received 5‑ALA-guided resection.

Denominator – the number of adults with radiologically enhancing suspected high-grade gliomas that are suitable for resection of all enhancing tumour.

**Data source:** No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records.

### Outcome

a) Proportion of adults with radiologically enhancing high-grade gliomas suitable for resection of all enhancing tumour who underwent resection where a 95% or greater reduction in tumour volume was achieved.

Numerator – the number in the denominator who underwent resection where a 95% or greater reduction in tumour volume was achieved.

Denominator – the number of adults with radiologically enhancing high-grade gliomas suitable for resection of all enhancing tumour.

**Data source:**No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records.

b) Progression-free survival in adults with radiologically enhancing high-grade gliomas suitable for resection of all enhancing tumour who had 5‑ALA-guided resection.

**Data source:**No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records.

## What the quality statement means for different audiences

**Service providers** (such as specialist regional centres) ensure that specialist resources, processes and pathways are in place for adults with radiologically enhancing suspected high-grade gliomas that are suitable for resection of all enhancing tumour to have 5‑ALA-guided resection.

**Healthcare professionals** (such as neurosurgeons) are aware of the local pathways for adults with radiologically enhancing suspected high-grade gliomas that are suitable for resection of all enhancing tumour and ensure that they receive 5‑ALA-guided resection.

**Commissioners** (NHS England) commission services that have the capacity and expertise to provide 5‑ALA-guided resection to adults with radiologically enhancing suspected high-grade gliomas that are suitable for resection of all enhancing tumour.

**Adults with a suspected high-grade glioma (a type of brain tumour) that is suitable for surgery to remove the tumour** have an operation that ensures as much of the tumour as possible is removed.

## Source guidance

[Brain tumours (primary) and brain metastases in adults. NICE guideline NG99](https://www.nice.org.uk/guidance/ng99) (2018), recommendation 1.2.36

# Quality statement 4: Risk of late effects of treatment

## Quality statement

Adults who finish treatment for brain tumours have an assessment and discussion about their risk of late effects of treatment at their first follow-up appointment.

## Rationale

Early identification of a person’s potential late effects of treatment for a brain tumour, which can occur months or years later, may allow the risk to be modified and the effect to be quickly identified and treated. This can increase the length and quality of life for people who finish treatment.

## Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured and can be adapted and used flexibly.

### Structure

Evidence of local processes to assess and discuss the risk of late effects of treatment with adults who finish treatment for brain tumours at their first follow-up appointment.

**Data source:** Data could be collected from information recorded locally by healthcare professionals and provider organisations, for example from service protocol and written treatment summaries.

### Process

a) Proportion of adults who finish treatment for brain tumours who have an assessment for their risk of late effects of treatment at their first follow-up appointment.

Numerator – the number in the denominator who have an assessment for their risk of late effects of treatment at their first follow-up appointment.

Denominator – the number of adults who finish treatment for brain tumours.

**Data source:** Data could be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records.

b) Proportion of adults who finish treatment for brain tumours who have a documented discussion about their risk of late effects of treatment at their first follow-up appointment.

Numerator – the number in the denominator who have a documented discussion about their risk of late effects of treatment at their first follow-up appointment.

Denominator – the number of adults who finish treatment for brain tumours.

**Data source:** Data could be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records.

### Outcome

Adults who finish treatment for brain tumours feel informed about their risk of late effects of treatment.

**Data source:** Data could be collected from a local survey of adults who finish treatment for brain tumours and their family and carers.

## What the quality statement means for different audiences

**Service providers** (such as secondary and tertiary services and specialist regional centres) ensure that processes are in place to assess adults who finish treatment for brain tumours for the risk of late effects of treatment at their first follow-up appointment and to record any risks in their written treatment summary. Providers ensure that staff can explain and discuss any risk of late effects of treatment with the person and their family and carers (if appropriate).

**Healthcare professionals** (such as clinical oncologists and radiographers) assess adults who finish treatment for brain tumours for the risk of late effects of treatment at their first follow-up appointment and record any risks in their written treatment summary. Healthcare professionals explain and discuss any risk of late effects of treatment with the person and their family and carers (if appropriate)

**Commissioners** (NHS England) commission services that carry out assessments for adults who finish treatment for brain tumours for the risk of late effects of treatment at their first follow-up appointment and discuss any risks with the person and their family and carers (if appropriate).

**Adults who finish treatment for brain tumours** have an assessment at their first follow-up appointment to find out if they might develop additional health conditions after their treatment. Their healthcare professional will explain any risks to them and their family and carers (if appropriate) and discuss how the risks will be managed.

## Source guidance

[Brain tumours (primary) and brain metastases in adults. NICE guideline NG99](https://www.nice.org.uk/guidance/ng99) (2018), recommendation 1.11.2

## Definitions of terms used in this quality statement

### Late effects of treatment

People with brain tumours can develop side effects of treatment months or years after treatment. The side effects 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’s guideline on brain tumours (primary) and brain metastases in adults](https://www.nice.org.uk/guidance/ng99), recommendations 1.11.1]

## Equality and diversity considerations

It is important for providers to make reasonable adjustments to ensure that adults with additional needs, such as physical, sensory, learning disabilities or cognitive impairment and people who do not speak or read English, or who have reduced communication skills, can have an assessment and discussion about potential late effects of treatment that is accessible and takes account of their needs. People should have access to an interpreter (including British Sign Language) or advocate if needed. Adults with cognitive impairment may need more time to process information.

## Question for consultation

Is it feasible to carry out an assessment and discussion about the risk of late effects of treatment at the first follow-up appointment after treatment? If not, please say why and if possible, suggest an alternative timescale.

# Quality statement 5: Neurological rehabilitation assessment

## Quality statement

Adults with brain tumours can access neurological rehabilitation assessment in the community.

## Rationale

People with brain tumours often have complex physical, cognitive, and psychological needs. Providing access to neurological rehabilitation assessment in the community will give people the support they might need to have the best quality of life, without the need to travel long distances to specialist centres. Assessment should be available at every stage of treatment and follow up to identify if any forms of rehabilitation are suitable for the person.

## Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured and can be adapted and used flexibly.

### Structure

Evidence of local arrangements to provide neurological rehabilitation assessment in the community for adults with brain tumours.

**Data source:** Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from referral criteria and pathways to neurological rehabilitation assessment.

### Process

Proportion of adults with brain tumours who access neurological rehabilitation in the community.

Numerator – the number in the denominator who access neurological rehabilitation in the community.

Denominator – the number of adults with brain tumours.

**Data source:** Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from referrals and patient records.

### Outcome

Health-related quality of life for adults with brain tumours.

**Data source:**No routinely collected national data for this measure has been identified. Data could be collected from a local quality-of-life survey of adults with brain tumours and their family and carers including patient-reported outcome measures.

## What the quality statement means for different audiences

**Service providers** (such as primary and secondary care services) ensure that there is a recognised referral pathway for adults with brain tumours to have a neurological rehabilitation assessment in the community at all stages of their care.

**Healthcare professionals** (such as oncologists, neurosurgeons and keyworkers) are aware of referral pathways for neurological rehabilitation assessment in the community for adults with brain tumours and support them to access an assessment if they need to.

**Healthcare professionals** (such as physiotherapists, occupational therapists, neuropsychologists and speech and language therapists) carry out assessments for neurological rehabilitation in the community for adults with brain tumours at all stages of their care.

**Commissioners** (such as clinical commissioning groups) commission services that provide neurological rehabilitation assessment in the community for adults with brain tumours at all stages of their care.

**Adults with brain tumours** can have an assessment in the community to identify what might help to improve any physical, emotional or psychological problems they experience at any stage of their care.

## Source guidance

* [Brain tumours (primary) and brain metastases in adults. NICE guideline NG99](https://www.nice.org.uk/guidance/ng99) (2018), recommendation 1.10.1, 1.10.2 and 1.10.3
* [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), section 8 rehabilitation services recommendation 2

## Equality and diversity considerations

It is important for providers to make reasonable adjustments to ensure that adults with additional needs, such as physical, sensory, learning disabilities or cognitive impairment and people who do not speak or read English, or who have reduced communication skills, can have a neurological rehabilitation assessment that is accessible and takes account of their needs. People should have access to an interpreter (including British Sign Language) or advocate if needed. Adults with cognitive impairment may need more time to process information.

## Question for consultation

Stakeholders have highlighted the need to improve access to neurological rehabilitation for adults with brain tumours. Do we have the right focus for this statement? If not, please identify the key action needed for improvement.

# About this quality standard

NICE quality standards describe high-priority areas for quality improvement in a defined care or service area. Each standard consists of a prioritised set of specific, concise and measurable statements. NICE quality standards draw on existing NICE or NICE-accredited guidance that provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement.

Expected levels of achievement for quality measures are not specified. Quality standards are intended to drive up the quality of care, and so achievement levels of 100% should be aspired to (or 0% if the quality statement states that something should not be done). However, this may not always be appropriate in practice. Taking account of safety, shared decision-making, choice and professional judgement, desired levels of achievement should be defined locally.

Information about [how NICE quality standards are developed](https://www.nice.org.uk/standards-and-indicators/timeline-developing-quality-standards) is available from the NICE website.

See our [webpage on quality standard advisory committees](http://www.nice.org.uk/Get-Involved/Meetings-in-public/Quality-Standards-Advisory-Committee) for details of standing committee 3 members who advised on this quality standard. Information about the topic experts invited to join the standing members is available from the [webpage for this quality standard](https://www.nice.org.uk/guidance/indevelopment/gid-qs10092/documents).

This quality standard has been included in the [NICE Pathway on brain](https://pathways.nice.org.uk/pathways/brain-tumours-and-metastases) tumours and metastases and the [NICE Pathway on suspected cancer recognition and referral](https://pathways.nice.org.uk/pathways/suspected-cancer-recognition-and-referral), which bring together everything we have said on a topic in an interactive flowchart.

NICE has produced a [quality standard service improvement template](https://www.nice.org.uk/about/what-we-do/into-practice/measuring-the-uptake-of-nice-guidance) to help providers make an initial assessment of their service compared with a selection of quality statements. This tool is updated monthly to include new quality standards.

NICE guidance and quality standards apply in England and Wales. Decisions on how they apply in Scotland and Northern Ireland are made by the Scottish government and Northern Ireland Executive. NICE quality standards may include references to organisations or people responsible for commissioning or providing care that may be relevant only to England.

## Resource impact

NICE quality standards should be achievable by local services. The potential resource impact is considered by the quality standards advisory committee, drawing on resource impact work for the source guidance. Organisations are encouraged to use the resource impact report and template for the for the [NICE guideline on brain tumours (primary) and brain metastases in adults](https://www.nice.org.uk/guidance/ng99/resources) to help estimate local costs.

## Diversity, equality and language

Equality issues were considered during development and [equality assessments for this quality standard](https://www.nice.org.uk/guidance/indevelopment/gid-qs10092/documents) are available. Any specific issues identified during development of the quality statements are highlighted in each statement.

Commissioners and providers should aim to achieve the quality standard in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relations. Nothing in this quality standard should be interpreted in a way that would be inconsistent with compliance with those duties.

ISBN:

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