

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

Quality standard

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This standard is based on NG99 and NG12.

Quality statements

Statement 1 GPs have direct access to MRI for adults with suspected brain tumour.

Statement 2 Adults with brain tumours have a named healthcare professional who coordinates their health and social care support.

Statement 3 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 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 5 Adults with brain tumours have access to neurological rehabilitation in the community and as an outpatient or inpatient.

Quality statement 1: GP direct access to MRI

Quality statement

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

Rationale

Enabling GPs to use direct access for MRI will speed up the diagnosis process for adults with suspected brain tumour and may reduce the number of outpatient appointments needed. If MRI is contraindicated, GPs should use a CT scan.

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 MRI for adults with suspected brain tumour.

Data source: Data can be collected from information recorded locally by provider organisations, for example, service protocols that may be developed to support NHS England's Neurosurgery Transformation Programme.

Process

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

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

Denominator – the number of referrals for brain MRI.

Data source: NHS England's 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 MRI. These may be developed to support NHS England's Neurosurgery Transformation Programme. Providers ensure imaging results are clear to inform GP decision making.

Healthcare professionals (GPs) can refer adults with suspected brain tumour directly for MRI.

Commissioners (such as integrated care systems, clinical commissioning groups and NHS England) ensure GP services can use direct access pathways to refer adults with suspected brain tumour directly for MRI. These may be developed to support NHS England's Neurosurgery Transformation Programme.

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

Suspected cancer: recognition and referral. NICE guideline NG12 (2015, updated 2021),

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](#), terms used in this guideline]

Adults with suspected brain tumour

Adults with progressive, sub-acute loss of central neurological function. [[NICE's guideline on suspected cancer](#), 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 any type of brain tumour may have complex needs, and support is provided by different health and social care services. Having a named healthcare professional to coordinate support will provide continuity of care, including making sure individual needs are assessed and care plans are in place. It will 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 non-malignant tumour or those diagnosed following an emergency presentation. [NHS England's National Cancer Patient Experience Survey](#) 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 coordination of their health and social care support by their named healthcare professional.

Numerator – the number in the denominator who are satisfied with the coordination of their health and social care support 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](#) 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 services) ensure that healthcare professionals with the necessary skills are available to support adults with any type of brain tumour. 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 any type of brain tumour during all stages of their care.

Healthcare professionals (such as members of the multidisciplinary team) ensure that adults with any type of brain tumour 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 integrated care systems, 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 any type of brain tumour throughout all stages of care.

Adults with any type of brain tumour 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 (2018, updated 2021), 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 also includes ensuring people are referred to the appropriate multidisciplinary services at any time. The named healthcare professional ensures that adults with any type of brain tumour, their family and carers know who to contact when help and advice is needed.

The named healthcare professional could be a key worker and will have expertise in the care of adults with brain tumours. The named healthcare professional is likely to be the clinical nurse specialist or allied healthcare professional most closely involved with a person's care. The role should be transferred to the most appropriate healthcare professional as the person's needs change or at transitional points in the care pathway. [Adapted from [NICE's cancer service guideline on improving outcomes for people with brain and other central nervous system tumours](#), section 2 recommendations]

Equality and diversity considerations

Named healthcare professionals should ensure that adults with any type of brain tumour 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 support and 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 (including British Sign Language) or advocate if needed. For people with additional needs related to a disability, impairment or sensory loss (including any disability that develops because of the tumour and the treatment received), information should be provided as set out in [NHS England's Accessible Information Standard](#).

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 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 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 that are 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 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.

b) Progression-free survival in adults with radiologically enhancing high-grade gliomas that are 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 from a specialist.

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 (2018, updated 2021), 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

The risk of late effects of treatment will be discussed with adults with brain tumours as part of the consent process before treatment. This discussion should be revisited when treatment is finished (at the first follow-up appointment after finishing treatment) so that the person's individual risk can be assessed based on the treatment they received. 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 through ongoing monitoring 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 protocol 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 care 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). Providers ensure that referral pathways are in place for ongoing monitoring for late effects of treatment.

Healthcare professionals (such as clinical oncologists and therapeutic 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). Healthcare professionals refer adults who finish treatment for brain tumours for monitoring of potential late effects of treatment if needed.

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). Commissioners work with providers to ensure referral pathways are in place for ongoing monitoring for late effects of treatment.

Adults who finish treatment for brain tumours have an assessment at their first follow-up appointment to find out if they might develop side effects 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](#) (2018, updated 2021), recommendation 1.11.2
- The first follow-up appointment timescale is based on expert consensus. The timeframe is not derived from the NICE guideline on brain tumours. It is considered a practical timeframe to enable stakeholders to measure performance.

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)
- speech, language and communication difficulties
- stroke.

[NICE's guideline on brain tumours (primary) and brain metastases in adults, recommendations 1.11.1, and expert opinion]

Equality and diversity considerations

It is important for providers to make reasonable adjustments to ensure that adults with additional needs, such as physical, sensory and learning disabilities or cognitive

impairment, and people who do not speak or read English, or who have communication difficulties, can have an assessment and discussion about potential late effects of treatment that is accessible and takes account of their needs. Healthcare professionals should be aware that adults with brain tumours can develop a disability because of their tumour, the treatment they receive and potential late effects of their treatment. People should have access to an interpreter (including British Sign Language) or advocate if needed. Adults with cognitive impairment may need support and more time to process information.

Quality statement 5: Neurological rehabilitation

Quality statement

Adults with brain tumours have access to neurological rehabilitation in the community and as an outpatient or inpatient.

Rationale

Adults with any type of brain tumour often have complex physical, cognitive and psychological needs. Providing access to neurological rehabilitation locally in the community and in hospital, in a setting that can meet their individual needs, will give people the support they might need to have the best quality of life. Access to neurological rehabilitation should be available at every stage of treatment and follow up.

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 in the community and as an outpatient or inpatient, 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 services.

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 are recognised referral pathways for adults with brain tumours to neurological rehabilitation in the community and as an outpatient or inpatient, at all stages of their care.

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

Commissioners (such as integrated care systems and clinical commissioning groups) commission services with sufficient capacity to provide neurological rehabilitation in the community and as an outpatient or inpatient, for adults with brain tumours at all stages of their care.

Adults with brain tumours can get support from neurological rehabilitation services in the community or in hospital 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](#) (2018, updated 2021), recommendations 1.10.1 to 1.10.3
- [Improving outcomes for people with brain and other central nervous system tumours. NICE cancer service guideline CSG10](#) (2006), section 8 rehabilitation services, recommendation 2 (page 112)

Definitions of terms used in this quality statement

Neurological rehabilitation

Rehabilitation is defined by the World Health Organization as 'a set of interventions designed to optimise functioning and reduce disability in individuals with health conditions in interaction with their environment'. Functioning and disability are broad terms which are further conceptualised in the International Classification of Functioning, Disability and Health. This framework highlights the relationships and interplay between the following domains:

- health condition
- body structure and function
- activity
- participation
- environmental factors
- personal factors.

Rehabilitation is an overall process composed of individual interventions. These interventions range from the relatively simple, acting at one or a few domains, to complex interventions that may act across several domains. Rehabilitation is not a 'one size fits all' process and aims and goals should be identified and agreed with each person to fully inform personalised treatment and therapy programmes.

Inpatient rehabilitation is delivered through a range of services based within the NHS, the private sector and the voluntary sector. Referral criteria for these services are often specific for disease or condition, symptoms, locality or age group.

In the longer term, rehabilitation may be delivered through hospital or community services, including education-based services. It may also be provided by the private or voluntary sectors. Rehabilitation can involve impairment-focused approaches, for example, to improve mobility, or a less impairment-specific focus towards functional goals (such as managing personal care or preparing a meal). Referral criteria may include diagnosis, age, or time since injury, or may depend on the purpose or setting of the intervention (for example, vocational rehabilitation). [[NICE's guideline on rehabilitation for chronic](#)

Equality and diversity considerations

Neurological rehabilitation should be available for all adults with brain tumours, including those who may be house-bound or in a nursing home. To ensure equality of access to rehabilitation, measures such as providing transport for people to attend sessions and holding the sessions in different locations should be considered. Rehabilitation should be provided in centres that have access for disabled people.

It is important for providers to make reasonable adjustments to ensure that adults with additional needs, such as physical, sensory and learning disabilities or cognitive impairment, and people who do not speak or read English, or who have communication difficulties, can access neurological rehabilitation services. Healthcare professionals should be aware that adults with brain tumours can develop a disability because of their tumour, the treatment they receive and potential late effects of their treatment. People should have access to an interpreter (including British Sign Language) or advocate if needed. Adults with cognitive impairment may need support and more time to process information.

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](#) is available from the NICE website.

See our [webpage on quality standard advisory committees](#) 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](#).

This quality standard has been included in the [NICE Pathways on brain tumours and metastases](#) and [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](#) 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 NICE guideline on brain tumours \(primary\) and brain metastases in adults](#) to help estimate local costs.

Diversity, equality and language

Equality issues were considered during development and [equality assessments for this quality standard](#) 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.

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Endorsing organisation

This quality standard has been endorsed by NHS England, as required by the Health and Social Care Act (2012)

Supporting organisations

Many organisations share NICE's commitment to quality improvement using evidence-based guidance. The following supporting organisations have recognised the benefit of the quality standard in improving care for patients, carers, service users and members of the public. They have agreed to work with NICE to ensure that those commissioning or providing services are made aware of and encouraged to use the quality standard.

- [The Brain Tumour Charity](#)
- [Brainstrust](#)

- Royal College of General Practitioners (RCGP)
- Royal College of Nursing (RCN)
- Brain Tumour Research
- Primary care and Community Neurology Society (P-CNS)
- British Neuro-Oncology Society
- Royal College of Physicians (RCP)