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Quality standards

Consultation summary report: Brain tumours (primary) and brain metastases in adults

Quality Standards Advisory Committee post-consultation meeting: 29th September 2021

1. Introduction

The draft quality standard for brain tumours (primary) and brain metastases in adults was made available on the NICE website for a public consultation period between 2nd August and 6th September 2021. Registered stakeholders were notified by email and invited to submit consultation comments on the draft quality standard. General feedback on the quality standard and comments on individual quality statements were accepted.

Comments were received from 16 organisations, which included service providers, national organisations, professional bodies and others.

This report provides the quality standards advisory committee with a high-level summary of the consultation comments, prepared by the NICE quality standards team. It provides a basis for discussion by the committee as part of the final meeting where the committee will consider consultation comments. Where appropriate the quality standard will be refined with input from the committee.

Consultation comments that may result in changes to the quality standard have been highlighted within this report. Comments suggesting changes that are outside of the process have not been included in this summary. The types of comments typically not included are those relating to source guidance recommendations and suggestions for non-accredited source guidance, requests to broaden statements out of scope, requests to include thresholds, targets, large volumes of supporting information, general comments on the role and purpose of quality standards and requests to change NICE templates. However, the committee should read this summary alongside the full set of consultation comments, which are provided in appendix 1.

1. Questions for consultation

Stakeholders were invited to respond to the following general questions:

1. Does this draft quality standard accurately reflect the key areas for quality improvement?

2. Are local systems and structures in place to collect data for the proposed quality measures? If not, how feasible would it be to be for these to be put in place?

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.

Stakeholders were also invited to respond to the following statement-specific questions:

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.

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.

1. General comments

The following is a summary of general (non-statement-specific) comments on the quality standard.

* General support for the areas covered by the quality standard.
* Some additional areas also highlighted as a priority.

### Consultation comments on data collection

* Some local systems are in place to collect data.
* Data could be provided by Trusts as part of the quality delivery element of Specialised Commissioning.
* CCG’s and GPs may need financial incentives to provide data.
* Surveys should be carried out by an independent organisation.
* A care plan that travels with the person receiving care could help with data collection.

### Consultation comments on resource impact

* Statements 2,3 and 4 should be achievable by local services.
* Statement 1 will require investment in MRI scanners and neuro-radiologists given current waiting times.
* Statement 5 will require significant investment in community neuro-rehabilitation services but may reduce hospital admissions and GP visits.

1. Summary of consultation feedback by draft statement
   1. Draft statement 1

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

### Consultation comments

Stakeholders made the following comments in relation to draft statement 1:

* General
  + Some support for the statement and agreement it could cut down waiting times, reduce the burden on the 2 week wait pathway and speed up diagnosis. Others suggested that it will not significantly speed up diagnosis and may not be an improvement on the 2 week wait pathway.
  + Will require significant investment in MRI systems. Concern that radiology departments could be overwhelmed given that there are long delays for MRI post-COVID.
  + Concern that it can be difficult to access the MRI scan and that it may be reviewed/reported on by clinicians who have never met the person and/or non-specialists. This could delay diagnosis of primary brain tumour and referral to a neuroscience centre.
  + Concern that direct access MRI may cause unnecessary worry for some groups of patients where the pathway following MRI may not be clear and they may have to see multiple doctors e.g., people who do not have brain cancer but have a non-specific lesion or an incidental meningioma and those who have had a seizure and may have a brain tumour.
* Statement
  + Should also include CT head scan with or without contrast given long wait times for MRI.
  + Revise statement to ‘GPs and healthcare professionals’ in line with NG12 to reflect that people may present in other settings e.g., opticians.
* Rationale
  + Emphasise reduction in unnecessary outpatient appointments for neurology in line with NHSE rationale for new pathway (neurosurgery transformation programme).
* Measures
  + The process measure is unlikely to give meaningful insight into the efficacy, yield and value of direct GP referral.
  + Process measure should focus on ‘urgent’ referral.
  + Additional measure suggested: Proportion of patients diagnosed with a brain tumour who had GP direct referral MRI.
* Audience descriptors
  + Emphasise the need for training and awareness raising for GPs about the signs and symptoms of brain tumours.
  + Emphasise GP responsibility for managing patient pathway until care can be taken over by another clinician/MDT. Scan reports need to be clear and ideally include referral recommendations including urgency. Alternatively, direct access could include discussion of findings with local neurologists.
* Definitions
  + The definition of adults with suspected brain tumour should include more detail on red flags and clearer referral criteria.
  + NHSE have recommended GP direct access MRI as part of a 2 week wait pathway for very clearly defined clinical scenarios (neurosurgery transformation programme) - NICE should align with this.
  + Helpful and important to include the sequences for a ‘standard MRI’ as most initial screening MRI scans would not meet those requirements and a repeat scan would be needed.

### Issues for consideration

* Should we progress this statement to the final quality standard?
* CT scan is not supported by a recommendation.
* Should the focus be on GPs?
* Can/should we align with the new NHSE pathway (neurosurgery transformation programme)?
* Is the statement achievable given the net resources available?
  1. Draft statement 2

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

### Consultation comments

Stakeholders made the following comments in relation to draft statement 2:

* General
  + Some support for this statement as it represents best practice.
  + There may be limited resources to implement this locally and staff movement could make it difficult to coordinate.
  + Potential role for person themselves to take ownership of their care plan so that it travels with them.
  + Should be clear when the person can be discharged from the caseload of the named healthcare professional.
* Statement
  + Clarify that adults with a high-grade or low-grade brain tumour should have a named healthcare professional.
  + Should the statement apply to all adults with brain tumours including those with low grade glioma? - some people may not have any health or social care needs and others may not have complex needs.
  + Include ‘family and carers’ in the statement.
  + Include ‘ease of access’ to named healthcare professional.
* Rationale
  + Include needs assessments and care and support plans to highlight their importance.
* Measures
  + Concern about using NHS England’s National Cancer Patient Experience Survey as a data source due to low sample size and exclusion of people with a low-grade brain tumour.
  + The outcome should be more specific and include coordination of health and social care support.
* Definition
  + The term ‘key worker’ is confusing.
  + Needs to be clearer that people with asymptomatic incidental benign brain tumours do not need to be managed by the neuro oncology team but can be managed by their local physician instead.
  + Clarify if the named healthcare professional should be a member of the MDT.
  + Include signposting skills to non-medical services including charities and not for profit services.
  + Include advanced care planning.
* Equality and diversity considerations
  + Cognitive impairment should be expanded to include people with communication difficulties.

### Issues for consideration

* Should we progress this statement to the final quality standard?
* How should we describe the population?
* What are the differences/similarities between a key worker and a named healthcare professional?
* Do we need to say any more about which professionals could take on this role?
  1. Draft 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.

### Consultation comments

Stakeholders made the following comments in relation to draft statement 3:

* General
  + General support for this statement.
  + Increased funding and resources may be needed to train enough clinicians to ensure 5-ALA guided resection is available in all centres.
  + Complete radiological tumour resection is only the aim preoperatively for a minority of people with suspected high grade glioma. MDT may assess that person is suitable for complete radiological resection but this may require further imaging and it will always be the surgeon’s choice.
  + 5-ALA should be considered together with other surgical strategies such as Interventional MRI and Awake Surgery with brain mapping to decide which strategy or combination of strategies is most likely to achieve the goal of maximal resection.
  + There should be consideration of the risks, expense and benefit of 5-ALA for each individual person.
* Statement
  + The advantages of 5-ALA are only present if an attempt is being made to remove all the tumour rather than all the enhancing tumour.
* Measures
  + Support for outcome measure a).
  + The extent of resection achieved can be assessed with pre and postoperative imaging.
* Equality and diversity considerations
  + To avoid health inequality there should be minimum objective standards for discussion of risks.

### Issues for consideration

* Should we progress this statement to the final quality standard?
* If this only applies to a minority of adults with brain tumours is it still a priority for quality improvement?
* Clarify the focus on resection of ‘all enhancing tumour’.
  1. Draft 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.

### Consultation comments

Stakeholders made the following comments in relation to draft statement 4:

* General
  + Discussion of risk of late effects is part of informed consent before any surgery, radiotherapy or chemotherapy. Following treatment people are referred for ongoing surveillance for development of specific late effects.
  + Some support for this statement as people will find it helpful to re-visit the discussion about risk of late effects after treatment.
* Statement
  + Focus should be on assessment and discussion of risk of late effects before starting treatment.
* Audience descriptors
  + Risk of late effects and how they should be managed should be documented in the person’s written treatment summary and the person’s survivorship plan.
  + Amend ‘radiographers’ to ‘therapeutic radiographers’
* Definition
  + Expand ‘cognitive decline’ to include ‘speech, language and communication difficulties’.
* Equality and diversity considerations
  + Change ‘reduced communication skills’ to ‘communication difficulties’.

### Consultation question 4

Stakeholders made the following comments in relation to consultation question 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.*

* Concern that it will not be possible to capture all potential issues in one visit – a late effects follow-up programme may be more helpful.
* Some agreement that this timescale is feasible but there may be local variation in being able to deliver on it.

### Issues for consideration

* What is the focus – consideration of late effects before or after treatment?
* Should we progress this statement to the final quality standard?
* Is the ‘first follow-up appointment after treatment’ appropriate?
  1. Draft statement 5

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

### Consultation comments

Stakeholders made the following comments in relation to draft statement 5:

* General
  + Some support for this statement and agreement that more neurorehabilitation should be available close to or in the home. There should be parity with stroke services.
  + Adults with brain tumours should be able to access neurological rehabilitation assessment easily, flexibly and promptly based on their needs at any stage of their condition.
  + Recognition that not everyone with a brain tumour needs rehabilitation.
  + Needs to be clear how this relates to the named healthcare professional in statement 2.
  + Should include vocational rehabilitation services.
* Statement
  + Amend to ‘Adults with any type and grade of brain tumour can access neurological rehabilitation assessment and supportive services in the community for their complex physical, cognitive and psychological needs’.
  + Suggestion to change ‘community’ to ‘local services’.
  + ‘Can’ is not strong enough- suggest amend statement to ‘Adults with brain tumours must be considered for referral to person-centred neurological rehabilitation in the community’.
  + Statement should include ‘optimise their recovery and functional independence’.
  + Include inpatient rehabilitation.
* Rationale
  + Include communication impairment.
* Measures
  + The denominator for the process measure should be ‘the number of adults with a brain tumour who require neurological rehabilitation’.
  + Measure the number referred from MDT or specialised services for neurological rehabilitation who receive the service within an appropriate time period.
* Definitions
  + Include a definition of ‘neurological rehabilitation assessment’.

### Consultation question 5

Stakeholders made the following comments in relation to consultation question 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*.

* Agreement that the focus is right as there is a need for greater provision in the community.

### Issues for consideration

* What is the focus- accessing an assessment or neurorehabilitation services?
* Should we progress this statement to the final quality standard?
* Given the recommendations available can we improve the statement?
* Can we define a ‘neurological rehabilitation assessment’?
* What should we measure?
* Is the statement achievable given the net resources available?

1. Suggestions for additional statements

The following is a summary of stakeholder suggestions for additional statements.

* Advance care planning
  + End of life care including advance care planning was discussed at the QSAC prioritisation meeting but not progressed as there is an existing quality standard on end of life care that has recently been updated.
* Nutrition & dietetics
  + The committee discussed relevant areas including multidisciplinary team, holistic needs assessment and specific support at the QSAC prioritisation meeting but these areas were not progressed.
* Signposting to support
  + The committee discussed signposting and referral to specific support at the QSAC prioritisation meeting, but this area was not progressed.
* Molecular marker testing
  + The committee discussed molecular marker testing at the QSAC prioritisation meeting, but this area was not progressed.
* Clinical studies on triaging people presenting with neurological problems from primary care
  + This area is beyond the scope of the quality standard. Quality statements focus on actions that demonstrate high quality care or support rather than areas where additional research may be required.

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# Appendix 1: Quality standard consultation comments table – registered stakeholders

| ID | Stakeholder | Section | Comments |
| --- | --- | --- | --- |
| 1 | Brain Tumour Northwest (BTNW) | General | I am writing in support of wider availability of Tumour Treating Fields (Novocure) in treating patients with malignant glioma in the UK. I am a founding member of Brain Tumour North West (BTNW) and would advocate for regionally based organisations as a potential pipeline for testing the deployment of novel therapies for brain tumours in a timely and efficient manner within the NHS. My views have formed over my long career as a neurosurgeon initially in London but for the last 25 years in Preston, Lancashire and more widely across the north west of England. The regions can lack access to new therapies for rarer tumours, but I am convinced that through collaborative working under-served areas of the UK can play an important role in evaluating the delivery of new therapies within the cash-limited NHS.  BTNW was formed in 2007 as a collaborative research consortium initially between the Universities of Central Lancashire, Keele, Liverpool and Wolverhampton and the Lancashire Teaching Hospitals NHS Trust, the Clatterbridge Cancer Centre and the Walton Centre NHS Foundation Trust as well as local brain tumour charities and other advocacy groups across the north-west of England. More recently, there has been involvement with the University of Manchester and the Salford Royal NHS Foundation Trust, the University of Leeds, the Leeds Teaching Hospitals NHS Trust and Lancaster University making it probably the largest regional neuro-oncology consortium in the UK.  BTNW brings together neurosurgeons, neurologists, neuropathologists, neuro-radiologists, and basic scientists working together across a large geographical region of the UK running from the northwest Midlands encompassing the Black Country and Staffordshire through Cheshire, Merseyside, Greater Manchester, Yorkshire, and Lancashire as far as the Scottish border with a population of nearly 16 million people comprising around 25% of the population of England. All the centres involved lie close to the M6/M62 motorway network and are around two hours travel time from each other by road or public transport.  Members are committed to cooperation and pooling scarce resources, material and clinical, to address important questions in biological and clinical neuro-oncology and to rapidly evaluate and deploy the latest experimental therapies in these poor-outcome and neglected neoplasms across north-west England and Yorkshire. BTNW has worked to establish strong collaboration with integrated access arrangements across the regional brain tumour tissue banks in Preston, Liverpool, Manchester, and Leeds that provide unrivalled access to NHS ethically approved tumour samples and other material together with appropriate clinical information that allow correlative clinico-biological studies to be rapidly carried out. It is likely that further collaborations will develop with Hull and east Yorkshire through their recent involvement in BTNW.  Further important initiatives under development include a wide-ranging regional biomedical project (GLIOMODEL) to evaluate novel in vitro/in vivo glioblastoma model systems with greater clinical relevance than those presently available and the development of a clinical trial in the northwest of England and Yorkshire of the Novocure TTF technology in the context of the NHS. Further early-stage discussions are underway with other developers of novel therapeutics for brain tumours. BTNW is developing virtual teaching sessions for both clinical and scientific trainees across the region covering both generic research skills and specific neuro-oncology training. BTNW has delivered an annual research conference (delivered virtually in 2020 with over 70 participants) since 2006 which attracts increasing numbers of delegates to present academic papers, network and discuss aspects of clinical and research policy pertaining to neuro-oncology.  BTNW believes that a UK regional organisation interested in neuro-oncology must be able to advocate its special mission to central decision makers in government and the NHS and would seek to work with local NHS trusts, charities, and other organisations to ensure that the regions with large patient populations act in a coordinated and organised way to maximise access and participation in evaluating new treatments for brain tumours for their patients within the context of a cash-limited NHS. Novocure-TTF is a new therapy that has shown significant benefit for patients with primary and, in an adjuvant setting, recurrent glioblastoma (see Regev et al, 2021 for a recent comprehensive review). It has FDA approval in the USA and is widely prescribed in the USA, parts of Europe, the Middle East and Japan. There are around 250 units across Europe providing this treatment and over 19,000 patients are undergoing Novocure-TTF therapy. It appears to be free of significant adverse effects and well tolerated even in elderly patients. It is planned to test its efficacy in brain metastasis, and some are strongly advocating that Novocure-TTF become the standard treatment for primary GBM in combination with the Stupp protocol.  Following the landmark Supreme Court case of Montgomery vs Lanarkshire Health Board in 2015, patient-centred decision making, supported by comprehensive clinician-delivered information must be front and centre in deciding the direction of clinical treatment. Within neuro-oncology this will inevitably lead to questions about access to effective, but potentially costly, new treatments for tumours like malignant glioma that have poor outcomes and limited therapeutic options - a situation that has barely improved in nearly half a century. Increasingly, individual clinicians and MDTs will be obliged to document that informed discussion between patient and their doctors has taken place including discussion of potential new treatments that are effective and safe but not yet available through the NHS because of cost. Of course, wider adoption of new treatments will lead to unit cost reductions, but initially organisations like BTNW must advocate to ensure that despite understandable caution about costs from Trusts does not lead to denial of access to safe and effective treatments for patients with otherwise few other options.  It is likely that Novocure-TTF is just the first of several innovative, safe and effective but expensive, new therapies for brain tumours that will become available over the next five years and are likely to lead to calls from patients and their families for these to be available to NHS patients. BTNW, through its growing network across the north west and north of England, would be in a prime position to rapidly evaluate these treatments within the context of the NHS and so as to be in a position to argue for more realistic pricing for the NHS with commercial organisations.  [***Ohad Regev***](javascript:;)***,*** [***Vladimir Merkin***](javascript:;)***,*** [***Deborah T Blumenthal***](javascript:;)***,*** [***Israel Melamed***](javascript:;)***,*** [***Tehila Kaisman-Elbaz***](javascript:;) ***(2021****)* Tumor-Treating Fields for the treatment of glioblastoma: a systematic review and meta-analysis Neuro-oncology Practice: **8:** 426–440 |
| 2 | British Society of Neuroradiologists (BSNR) | General | * The distinction between NICE and NIHR is important, but we do not think it is unreasonable that rather than deferring to NIHR, this current exercise considers discussing and including recommendations for research in quality statements to mitigate evidence gaps, rather than proceeding to define quality statements without the required evidence base. * GP access imaging might be by whichever cross-sectional modality is readily available but this is likely to be CT in most regions. * Any quality standard service improvement template will have to encapsulate the OPPORTUNITY COST and UNINTENDED CONSEQUENCES of implementing a quality standard of direct GP access to MRI. |
| 3 | British Society of Neuroradiologists (BSNR) | General | Other: Follow-up  Imaging  1. 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  - Already largely dealt with through NG99 and BSNR 2018 guidance.  - Consistent imaging schedules during treatment and surveillance  - Needs more research.  - Improve clinical information on requests for imaging e.g., via an electronic referral system  - A pragmatic sine qua non for radiology practice in general  - Ensure that imaging, reporting and consultation are carried out in one hospital visit to reduce delays  - See below – a laudable goal but one with enormous resource implications, and one which should perhaps be prioritised over direct GP access?  2. For discussion:  • Do you agree with our suggestion that these areas do not need to be discussed during the meeting given the recommendations available?  - “Ensure that imaging, reporting and consultation are carried out in one hospital visit to reduce delays”. This is laudable but currently impractical. It would be more useful to use radiology resources for a ‘one stop’ clinic such as this rather than divert them towards primary care MRI as in the Quality Statement. This would be worthy of discussion, particularly in the context of the proposed direct GP access.  - There really is no evidence for timing of follow-up and it could be seen as contrary to NHSE’s stated objective of personalised medicine . Being pragmatic, this will always need to be based on a more generic guideline as in NG99 which is aimed towards lowering inequality in healthcare, but this should aim to bring lower performing centres up and not be regression to the mean or a race to the bottom.  - Regarding advanced imaging, pragmatic, multicentre radiology research into the utility and uptake of ‘advanced’ imaging (which can do much to limit current uncertainty and delay to diagnosis) should be encouraged. There is not enough evidence available to include it in a quality standard but neither should it be ignored.  Front. Oncol., 09 February 2021 <https://doi.org/10.3389/fonc.2021.620070>  <https://www.england.nhs.uk/healthcare-science/personalisedmedicine/> |
| 4 | Compassion in Dying | General | In light of the fact that brain tumours may cause a person to have fluctuating capacity or lose capacity to make decisions about their treatment and care, it is disappointing that a decision was made to exclude advance care planning within this quality standard.  The NICE Quality Standard for Dementia (2019) rightly 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.” As such, we strongly recommend adopting a consistent approach to this core principle of person-centred care by identifying a way in which advance care planning can be integrated into the quality standard. |
| 5 | NHSE&I (CAHPO) | General | The office for the Chief AHP Officer (CAHPO) for England observe that the comments we forwarded on the 28th of April 2021 have been discussed at the prioritisation meeting on the 28th June 2021. We note a number of our suggestions have been explored with some actioned. |
| 6 | Royal College of Occupational Therapists (RCOT) | General | Occupational therapists have a unique role within palliative care as their dual training in physical and mental health enables them to support people through their illness and any resulting disability.  In recent years there has been an increased awareness of the importance of palliative rehabilitation as an aspect of palliative care. Palliative rehabilitation is a whole-team philosophy for use with people at end of life which integrates rehabilitation, enablement and self-management. It ensures that the individual is supported in living life as fully and meaningfully as possible, until the end of life. This aligns well with occupational therapy's core philosophy of enabling and enhancing a person's engagement in meaningful and purposeful occupations to improve their health and well-being.  Across the UK cancer incidences are increasing, however survival rates have improved thanks to advances in medical treatments, and the government prioritising earlier cancer detection and quicker diagnosis.  The importance of prehabilitation prior to commencing cancer treatment is a growing concept, with occupational therapists playing an important role in supporting patients through their cancer treatments in maintaining their occupational engagement in meaningful and purposeful occupations.  Patients can be seen at various points through their cancer journey providing a range of interventions such as fatigue management, breathlessness management, anxiety management, body image support and palliative rehabilitation.  Rehabilitation is the provision of personalised support to enable people to recover from periods of physical and mental ill-health. Rehabilitation ranges from supporting people to manage long-term health conditions and disabilities through primary care services to acute hospital settings preparing people to return home and back to their local community.    Acute and community rehabilitation is commonly delivered by multi-disciplinary health and social care teams, and occupational therapy is a vital part of these services.    Occupational therapists working in rehabilitation teams support people to re-gain and maintain independence in the occupations (activities of daily living) that matter to them.  The goals and activities are personalised to each individual, but could include:  • Self-care tasks e.g. washing, dressing and personal grooming.  • Productivity tasks e.g. education, employment, care giving and shopping.  • Leisure activities e.g. hobbies, sport, socialising or accessing community amenities.  Occupational therapists consider people in the context of the physical and social environments that they inhabit, and enable people to identify solutions that reduce or remove the barriers to participation that exist in their homes and communities.  Occupational therapists within rehabilitation are specialists in:  • Self-management approaches: Occupational therapists support people to adopt healthy behaviours and strategies that enable participation in daily life; achieve outcomes that have meaning for them and support people with complex needs to overcome barriers to accessing existing opportunities such as social prescribing.  • Personalised care: Occupational therapists embed personalised care through training and supervising others, such as support workers, informal carers, care home and home care providers.  • Independent living: The profession’s understanding and expertise on the relationship between occupations and the environment is pivotal in supporting people to return to living independent lives.  As the only profession to practice across physical and mental health with a focus on occupation (people’s everyday activities), occupational therapists are vital in ensuring people have the support and ability to live as independently as possible.  The Royal College of Occupational Therapists is one of the lead organisations in the [Right to Rehab campaign](https://www.sueryder.org/sites/default/files/2020-02/Manifesto%20briefing%20communtiy%20rehab.pdf) which is a collective of 24 charities, trade unions and professional bodies calling on all political parties to ensure there is equal access to high-quality community rehabilitation services for all. |
| 7 | The Brain Tumour Charity | General | The Brain Tumour Charity welcomes the draft quality statements, however we would like to highlight a few points for further consideration. |
| 8 | Wales Cancer Network | General | Disappointing that nutrition/dietetics is not mentioned more specially within the documents.  Certainly a significant role for dietetics within a CNRT service, but would argue that dietetics is pivotal throughout the entire cancer pathway and this needs to be reflected  Dietetics needs to be considered as a key member of the MDT within any guidance - Evidence suggests that patients with cancer managed by an MDT have a better outcome and increased satisfaction with their care. MDTs do not routinely include dietetics, despite us playing an active role in patient treatment and care.  Would like to see us acknowledged specifically within these documents alongside SLT and physio.    Significant dietetic implication to any funded service within this area.   * Dietetics have key role in pre-habilitation to improve treatment effectiveness and survival - Macmillan suggests that pre-habilitation should underpin the whole cancer pathway. * Note dietetics are listed as core member of the neuroscience brain and other CNS tumours MDT in guidance ‘Improving Outcomes for People with Brain and Other CNS Tumours’  therefore should be echoed here * Holistic needs assessment - Whilst the available evidence does not support the use of ketogenic diets for gliomas there are increasing numbers of patients wishing to pursue this and therefore potential for dietetic input to safely manage (some emerging evidence with complex epilepsy) * Would like to see dietetics mentioned in specific support - access to allied health professions section alongside SLT and physio * Dietetic role in symptom identification and onwards referral to GP/Key worker * Nutritional screening * Dietetic assessment of neurological status and the need for postoperative nutritional support e.g. ONS, NG, gastrostomy * Dietetic support with symptom management post treatments * Healthy lifestyle advice to decrease risk of stroke, particularly post cranial radiotherapy * Responsibility for education and liaison with other local specialist AHP |
| 9 | Wales Cancer Network | General | **Briefing Paper – Pg 10; 1.1.4**  Include CDKN2A/B gene analysis for astrocytomas  Include methylation arrays for meningioma, ependymoma  Include NGS panel for gliomas in both adults and children  Include BRAF testing for melanoma  Include PDL-1 testing for lung adenocarcinoma metastasis  Include NTRK gene analysis for CNS tumours in adults and children |
| 10 | Wales Cancer Network | General | **Briefing Paper – Pg 11; 4.2**  1.2.1 – Access to neuroradiological support **including fMRI, DTI and Tractography, MR Spectroscopy, PET imaging, MR Perfusion and Arterial Spin Labelling** |
| 11 | Wales Cancer Network | General | **Briefing Paper – Pg 12**  Treatment Pathway: post-surgery to radiotherapy pathway for primary brain cancer – it may not be practical for a 4 week pathway to be implemented. **We should probably leave this as 6 weeks.** |
| 12 | Wales Cancer Network | General | **Briefing Paper – Pg 17; 1.5.3**  For asymptomatic incidental meningioma: scan at 6 months (to assess for any growth) and then at 18 months and if no change, consider discharge or scan at 5 years. |
| 13 | Wales Cancer Network | General | **Appendix 1**  Replace Karnofsky performance status with **EORTC Performance Status of 0-2**  ALSO – This guidance is only applicable OUTSIDE of COVID related circumstances. In Wales we still follow our MDT’s COVID SOP which we will review once theatre spaces have opened up to almost normal levels. |
| 14 | Brain Tumour Research | Question 1 | The five areas selected by the quality standard represent important areas that relate to the delivery of care to brain tumour patients and their families and carers. We understand the need to set standards that are possible to deliver but at the same time provide a useful quality index of service delivery by those involved in delivering the service. We welcome the standards and hope that those tasked with delivering them will find the focus on these key areas helpful. However, we have concerns about how the quality standards will be implemented and assessed. |
| 15 | Brainstrust – the brain cancer people | Question 1 | Yes. |
| 16 | British Society of Neuroradiologists (BSNR) | Question 1 | YES |
| 17 | NHSE&I (CAHPO) | Question 1 | Yes, the standards accurately reflect a number of areas in the patient pathway that would benefit from the proposed quality areas- diagnostics, treatment, management, and long-term care |
| 18 | The Brain Tumour Charity | Question 1 | Yes, the quality statements reflect some very pressing needs for improvement in different areas across the brain tumour diagnosis and treatment journey. However, the exact wording of the quality statements is important to consider further, as it could reflect a more overarching approach to the involvement of healthcare professionals, alongside the distinction of encompassing all tumour types (high-grade and low-grade). These have been highlighted in the below responses where relevant to each quality statement.  **Signposting of support and support networks** is also crucial to improving patient experience. The Brain Tumour Charity’s (2020) Improving Brain Tumour Care Survey highlighted that the majority of people were not informed about basic support. Only 44% of people were signposted to counselling or emotional support, only 35% were offered support to access free prescriptions, only 28% were informed about financial support and benefits they could claim, and only 51% were told about support for coping with symptoms and side effects (sample: 586 people diagnosed or in active treatment during the last two years [since Oct 2018]).  As this topic is not proposed to receive a quality statement of its own, we feel this makes improving access to an easy-to-contact CNS or named healthcare professional for all brain tumour types (high-grade and low-grade) even more important. Our Improving Brain Tumour Care Surveys 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.  Data from our Improving Brain Tumour Care Survey collected in October 2020 also identified key areas for improvement as; diagnosis experience, Clinical Nurse Specialist (CNS) provision and access; signposting of support; Holistic Needs Assessments (HNAs) and care plans; and research participation.  The results of our Improving Brain Tumour Care Survey is available here: <https://assets.thebraintumourcharity.org/live/media/filer_public/d0/60/d060a530-02da-470a-81f3-4b8817e58810/improving_brain_tumour_care.pdf> It should be noted that whilst responses have now been analysed from 1582 patients, the survey sample was not representative of the whole population affected by a brain tumour in the UK, and so these results should be treated as indicative. |
| 19 | University College London Hospitals NHS Foundation Trust the National Hospital for Neurology and Neurosurgery | Question 1 | We are very supportive of Statements 2,4 and 5 being key areas for quality improvement.  However, we consider access to advanced molecular pathology for all patients to be a key area for quality Improvement  It is important that number of diagnostic biomarkers for testing brain tumours in adults have been mentioned. However, even the consistent application/testing for these markers returns diagnostically non-informative results in a significant proportion of patients with adult gliomas.  The upcoming revision of the NHS England test directory includes methylation arrays as an additional, diagnostically highly informative test method. It would be important to include recommendations to consider methylation array profiling for Brain tumours in which there is (i) no adequate information obtained from conventional markers (as listed) and (ii) for patients where a wider differential diagnosis remains after testing.  Such ambiguity remains for many intrinsic tumours of the midline, predominantly in young and middle-aged adults, a proportion of cerebellar tumours, and most spinal tumours.  It is also highly recommended by methylation profiling consistently for ependymal tumours |
| 20 | Brain Tumour Research | Question 2 | It is likely that local Trusts will be able to provide support for the data required as part of their service delivery and as such could be included in any quality delivery element associated with the Specialised Commissioning process with each NSU e.g., Late SE clinics, imaging data. We are concerned that encouraging CCG’s and GPs to take part may be more difficult without financial ‘fee for service’ arrangements e.g., data on referrals, and would recommend an independent agent to poll patients for issues such as ‘satisfaction’ with service, or the name of their designated ‘health and social care professional’. A simple poll of patients may require less time, less cost and be more reliable than an inaccurately targeted question from which we have to infer the result. |
| 21 | Brainstrust – the brain cancer people | Question 2 | Turnover and movement of staff may make the data hard to collect. Suggest that some of this responsibility sits with the patient who can be given a care plan that travels with them. |
| 22 | British Society of Neuroradiologists (BSNR) | Question 2 | YES in terms of GP referral for MRI, but NO if we need to capture the opportunity costs of this. If not, how feasible would it be for these to be put in place? This would depend on regional set up of e.g. Radiology Information Systems (RIS). It does not appear to be explicitly captured in current national data capture and audit. |
| 23 | NHSE&I (CAHPO) | Question 2 | We are unable to comment on how teams collect data locally. However, the office for the CAHPO notes that suggestions on how data could be collected are identified for each proposed quality statement. |
| 24 | University College London Hospitals NHS Foundation Trust the National Hospital for Neurology and Neurosurgery | Question 2 | We have local systems in place that could collect data for statements 2,3 and 4  Statement 1 would need to be set up as this involves GP data collection  Statement 5 would require communication between hospital and community neuro-rehabilitation teams |
| 25 | Brainstrust – the brain cancer people | Question 3 | Shortage of workforce is an issue. More neuro-radiologists and neuropsychologists are needed for regional access who have brain tumours as a specialism. However, investment in rehab care, managing expectations and ongoing assessments would reduce health costs as patients would have more confidence, reducing hospital admissions and GP visits. Interventions would be more timely and appropriate. |
| 26 | British Society of Neuroradiologists (BSNR) | Question 3 | NO – giving access to MRI from primary care would require dedicated health economic assessment to determine the resource implications, which would vary by region/trust. |
|  | NHSE&I (CAHPO) | Question 3 | If any of these quality standards represent a change in current processes and practice, they will need appropriate resourcing.  (A side note. For imaging strict referral criteria will need to be followed by GPs to ensure they are requesting MRIs appropriately especially given there is a request for the administration of contrast agent). |
| 27 | University College London Hospitals NHS Foundation Trust the National Hospital for Neurology and Neurosurgery | Question 3 | Statements 2, 3 and 4 are achievable  Statement 1 would require further resource as there is already a waiting list for MRI brain scans and a backlog of scans awaiting reporting. Will need more MRI scanners and neuroradiologists.  Statement 5 would require significant investment to provide neuro-rehab assessment in the community. |
| 28 | Association of British Neurologists | Statement 1 | While early MRI scans may have the potential to accelerate diagnosis of brain tumours, our concern is for the patients that have an abnormal scan arranged by their GP, but don’t have brain cancer – rather they have a non-specific lesion within the brain or an incidental meningioma. These patients far outnumber the patients with a genuine tumour and my impression is that these “cancer scare” patients get a bad deal in the straight to scan system. They often have to see multiple doctors: a neurosurgeon who doesn’t feel surgery is indicated but the patient needs follow up by a neurologist and then a neurologist to sort out the presenting symptoms. As neurologists, we have all had to see these patients and the difficulties in seeing these worried patients with a slightly abnormal scan that is not on the hospital system cannot be underestimated.  We already have a 2 week wait scheme for suspected cancer patients. It is difficult to see how the GP ‘straight to scan’ scheme would be able to improve on this.  One other aspect that raises concern is the delay in accessing brain scans for patients who have had a seizure and therefore may have a brain tumour but giving GPs ability to refer comes with all the other issues mentioned above if a tumour is found. |
| 29 | Brainstrust – the brain cancer people | Statement 1 | * GPs should have an ‘if in doubt’ policy and be ready to refer patients on the 2ww pathway, rather than waiting for multiple GP appointments. Suggest that the red flags for diagnosing a potential brain tumour are detailed, rather than progressive neurological deficit. * Concern exists about the lack of workforce to read and report on MRI scans. |
| 30 | British Neuro-Oncology Society | Statement 1 | Rationale – this approach won’t really significantly speed up diagnosis as GPs mostly already have access to CT and there are established 2ww pathways in place nationally which allow rapid opinion and MRI. It might possibly shave a few days off diagnosis, which is unlikely to be of any clinical benefit. (The rationale NHSE have used in making this recommendation is rather a reduction in unnecessary OPAs for neurology where there are significant workforce issues – thereby instead of first OPA then MRI, go direct to test (almost all patients referred to many 2ww clinics receive MRI in any case). |
| 31 | British Neuro-Oncology Society | Statement 1 | Service providers – there are already large delays for MRI post-covid and if this policy is introduced radiology departments have raised concern they would be potentially overwhelmed. The pick up rate for brain tumours in 2ww clinics currently is only about 2-5% and that is with clearly defined criteria for referral. |
| 32 | British Neuro-Oncology Society | Statement 1 | Commissioners – NHSE via their service transformation program in neurosurgery have though recommended a direct GP refer to MRI as part of 2ww pathway but this is for very clearly defined clinical scenarios that require more definition than are presented here – this can be shared to reduce negative impact and align NHSE with NICE, as required |
| 33 | British Society of Neuroradiologists (BSNR) | Statement 1 | * Rather than mandate access to MRI in primary care, consider evidence gathering clinical studies for the triaging of primary care patients with neurological presentations. Mandating MR over CT would be impractical, unnecessary, and have a major opportunity cost to many other patients. Further imaging of confirmed tumours will be required in any case. * An evidence-based approach to the selective use of brain imaging is clearly needed and this should be done in conjunction with the teams and stakeholders that diagnose and manage these neurological symptoms (i.e. patient groups, GPs, and neurologists,) and with an explicit examination of the wider health economic impacts. * The primary literature that is cited in the document recommends that “more research is needed”. A quality standard which directly extrapolates from the current (predominantly selective observational and audit) data would bypass the very research which is needed.   - Can we add anything to the existing quality statement on direct access to diagnostic tests in QS124?  - Yes – this needs to be qualified for CNS presentations, e.g. access to CT but not MRI. The RESOURCE IMPLICATIONS will be central to any discussion around this.  - What is the priority for improvement?  - Research into additional bedside (semantic verbal fluency, headache semiology) and remote (blood test/’liquid biopsy’) diagnostic features which will help to inform, triage, or modulate access to cross-sectional imaging.   * Research into clinical pathways optimising access to and flow though the imaging diagnostic pathway.   - What is the key action that will lead to improvement?  - Research into useful primary care biomarkers of likelihood of having a brain tumour.  - Can we develop a specific, measurable statement?  - Yes. As an example: “Properly funded, large scale clinical studies should be undertaken to establish the performance characteristics of additional brain tumour biomarkers in primary care. These can be evaluated by measuring their impacts on rates of referral and time to diagnosis, while taking into account health economic impacts, incidental or false outcomes, and importantly the lived experience of patients regarding quality of service and any additional anxiety.” |
| 34 | International Brain Tumour Alliance (IBTA) | Statement 1 | We very much welcome **Quality Statement 1** which focuses on direct access by GPs to standard structural MRI for adults with a suspected brain tumour. We believe that this will significantly cut down waiting times and indeed speed up diagnosis. But, because brain tumours are a rare cancer, not all GPs are aware of the potential signs and symptoms of a possible brain tumour. So how will GPs accurately triage patients for direct access MRI from the GP surgery? Robust training and increased awareness of GPs about the signs and symptoms of brain tumours needs to also be in place to ensure that GPs don’t dismiss a patient’s symptoms as “just a migraine” or “just stress” if the patient otherwise appears to be fit and healthy. |
| 35 | Royal College of General Practitioners | Statement 1 | Previous publications such as ‘Kernick D et al,. Should GPs have direct access to neuroradiological investigation when adults present with headache. BJGP 2011;61:409-411.’ Suggests that GPs can effectively order complex investigations. The RCGP has called for direct access to CT and MRI scans consistently and so we fully support this recommendation. |
| 36 | Royal College of General Practitioners | Statement 1 | Can the committee consider adding CT scan with or without contrast to statement 1 in addition to MR Scanning. Whist for a full diagnosis the use of MRIs is preferential over CT scans, there is already a long wait for MRIs and to prevent significant capacity and increased waiting times, we would also request that GPs have direct access to CT head (with contrast) as an initial test. |
| 37 | Royal College of General Practitioners | Statement 1 | If GPs have direct access to CT/MRI scanning, then the pathway around this must be clear. Can the committee consider adding further details on the expected reporting and referral pathway? The GP will of course retain responsibility for the scan result and will need inform the patient of the result, arranging appropriate onward referral. However, commissioners must also understand the GPs do not have the pictures of the scans available to them and so rely on the radiology report alone to determine onward care. It is therefore essential that within the direct access pathway, the scan reports are clear, not only in describing the anatomy and anatomical changes but what the implication of such changes are. This should ideally include referral recommendations and indicate the urgency of the referral e.g. routine/ 2 week wait. Alternatively, commissioners could consider direct access to discuss scan findings with local neurologists. |
| 38 | Society of British Neurological Surgeons | Statement 1 | This approach is being used by GP’s more and more now and will reduce the burden on the 2 week wait pathway whereby patients are seen by the neurologist. It is good that the sequences for a “standard MRI” scan are defined as most “initial screening MRI scans” don’t include a TI scan with contrast and patient need to then have a repeat MRI scan. It is also good that the GP’s takes responsibility for organising scan and managing the patients pathway till the scan is discussed in an MDT/by clinician and their care taken over.  Local providers – This will no doubt add to the workload of the MRI radiology departments which are already stretched. More so, it may likely shift suspected brain tumour patients who have an initial CT scan now as part of the 2 week wait to having MRI scans as their initial scan. GP’s will therefore need to be given clear, well defined criteria to request MRI scans for suspected brain tumour patients. |
| 39 | The Brain Tumour Charity | Statement 1 | The Brain Tumour Charity welcomes the inclusion of direct access to MRI for suspected brain tumours as an area for improvement in the quality statement, reflecting on the challenges that the diagnostic pathway poses for those with brain tumours.  Anecdotally this has been flagged as an issue by a number of clinicians, and a study by Nicholson, B.D., *et al*. (2016) provided evidence showing that direct access to MRI by GPs is patchy across England, ranging from 20% of GPs in the Wessex region having access compared to 85% in the Central Midlands region1. On average, 63% of GPs had direct access to MRI across England.  A survey by McKinlay, A., *et al.* (2019) also highlighted the importance of direct access, finding that GP direct access to scans was quicker than specialist referral for scanning2, and that GP direct access to imaging could reduce delays and avoid unnecessary referral to a secondary care pathway.  The [Rapid Cancer Registration Dataset](https://www.cancerdata.nhs.uk/covid-19/rcrd) (Accessed August 2021) indicates that for brain tumours in England, of the total diagnoses each month between April 2018-March 2019, only 1% were diagnosed via ‘2 week wait’ referrals. For the same time period, ‘emergency presentation’ accounted for an average of 43% of diagnoses, with an average of 20% from ‘GP referrals’, and an average of 35% from ‘other’ routes (e.g. opticians). Widespread direct access to MRIs for GPs will be beneficial in working towards reducing the diagnosis time for adults with brain tumours, however the biggest route to diagnosis for brain tumours remains emergency presentation. Improving direct access to MRIs should occur alongside significant work to improve both the identification of brain tumour signs and symptoms by GPs and the awareness amongst the general public to reach out to GPs for support.  We would welcome discussion as to whether the wording of the statement should be amended to say ‘GPs and healthcare professionals have direct access to standard structural MRI’ to reflect the wording of NG12, particularly as people with possible brain tumour symptoms can often present in other healthcare settings such as at opticians.  According to a 2017 Report by the Clinical Imaging Board, MRI systems in the UK have been particularly in need of replacement in comparison to other European countries, with 29% of clinical systems ten or more years old. Comparing the report’s data with data from the Organisation of Economic Cooperation and Development (OECD), the UK has the lowest number of MRI systems per million population (6.1) yet performs 56.3 scans per 1000 population, just slightly under the OECD average. This raises concerns around the reliance on MRI resource for diagnosis.  In order to achieve the outcome proposed in this quality statement, MRI availability would need to be able to provide for the level required. NHS Diagnostic Waiting Times and Activity Data, presented by NHS England, show that in December 2020, around 10,000 more people were on the MRI Waiting list compared to December 2019. Data from our Improving Brain Tumour Care Survey collected in October 2020 showed that out of a sample of 399 people diagnosed or in active treatment during the last 2 years, 27% waited 2 weeks or longer for MRI scans for diagnosis. In order to achieve the outcome proposed in this quality statement, increased funding and resource may therefore be needed to ensure sufficient provision of direct access to MRI is available for all GPs.   1. Nicholson B.D., Oke J.L., Rose P.W., and Mant D. (2016) ‘Variation in Direct Access to Tests to Investigate Cancer: A Survey of English General Practitioners’, PLoS ONE 11(7): e0159725. doi:10.1371/journal.pone.0159725 2. McKinlay A., Underwood R., Wojewodka G.,*et al.* (2019) ‘Should GPs have direct access to imaging for headache? A qualitative study of patients’ views in the UK’, BMJ Open 2019(9): e029376. doi:10.1136/bmjopen-2019-029376 |
| 40 | University College London Hospitals NHS Foundation Trust the National Hospital for Neurology and Neurosurgery | Statement 1 | Regarding Statement 1:  Although direct GP access to MRI scanning for patients with suspected brain tumours sounds like a good idea, we have concerns that this does not address treatment for the most common symptom that triggers such a referral i.e. headache. Furthermore, even if a tumour is found, it is more often than not an incidental benign tumour such as a meningioma which cause unnecessary anxiety for the patient, particularly if they are then referred on the 2 Week Wait pathway, and does not benefit from an early diagnosis. In addition, it is often difficult to access the MRI scan which has to be located and transferred from an external imaging provided to the neuroscience centre and then reviewed by clinicians who have never met the patient. We feel that it is better for the patient to see a specialist on a 2 Week Wait and then scanned if felt that this was clinically appropriate. |
| 41 | University College London Hospitals NHS Foundation Trust the National Hospital for Neurology and Neurosurgery | Statement 1 | As mentioned in Q1 we have concerns that direct GP referral for MRI does not address treatment for the most common symptom that triggers such a referral i.e. headache. It is also highly likely that the diagnosis of the majority of the referred patients will not be a glioma. If a tumour is found, it is most likely to be an incidental benign tumour such as a meningioma; this of course will inevitably cause unnecessary anxiety for the patient, particularly if they are then referred on the 2 Week Wait pathway, and does not benefit from an early diagnosis.  It is therefore very unlikely that the suggested quality measures (Number of GP direct referrals / number of referrals for brain MRI) will offer a meaningful insight into the efficacy, yield and value of Direct GP referral.  MR examinations of the brain performed outside of neuroscience centres are too often of limited quality, leading regularly to a repeat of the examination thus delaying diagnosis. Furthermore, reports by non-specialists, in this case non-neuroradiologists can lead to suboptimal reports. Finally, transferring MR images from external provider to the neuroscience centre can be challenging and time consuming.  In summary, it is most likely that direct GP referral will not lead to a substantial increase of identification of patients with Glioma, will use considerable resources, will often lead to images of limited quality and limited diagnostic value and will delay diagnosis of primary brain tumour and referral to a neuroscience centre. |
| 42 | Brain Tumour Research | Statement 1- Question 2 | This is a difficult question to answer for two reasons. Firstly, the described processes are not clear and open to question as to how valid these process audits are at addressing the issues. Secondly there is a large variation across England and Wales in the funding for GPs to access imaging, and for agents to access funding for delivery of services, hence it is difficult to see how feasible assessing service delivery will be. For example, in measuring the proportion of referrals for brain structural MRI that are direct GP referrals with the numerator being the number in the denominator that are GP direct referrals and the denominator being the number of referrals for brain standard structural MRI is data available now that will allow prospective comparison of the proportion of referrals for brain structural MRI that are direct GP referrals? We feel that this information should be available at individual GP/CCG level to ensure we get localised data and are able to identify post code lottery effects that need addressing.  b. We should be explicit, rather than saying ‘brain structural MRI’ they should state urgent referral as the patient is presenting with symptoms of brain cancer.  c. Anecdotal evidence suggests GPs find difficulty in directly accessing MRI imaging for suspected brain cancer. We recommend that CCGs and trusts record what proportion of patients with a brain tumour diagnosed in their catchment area had a GP referral scan to make this diagnosis, rather than from any other clinician or pathway. |
| 43 | Brainstrust – the brain cancer people | Statement 2 | * Clarification is needed on which patients should receive a named key worker for example – some people are diagnosed incidentally with a non-malignant brain tumour. Key worker support may be needed for a short time whilst the diagnosis is processed mentally but this cohort of people probably would not require key worker support for the longer term but could be signposted to other support. Not all people with brain tumours have complex needs. * Resources to implement this at a local level may be hard to find, and staff movement may confound this. Potential for the patient to take ownership of their care plan so that it travels with the patient. Touchpoints recorded to track the care pathway. |
| 44 | British Neuro-Oncology Society | Statement 2 | There is some confusion over this statement. Every brain tumour patient referred to a neuro-oncology MDT clinic will have an allocated key worker, usually a CNS or ANP. Is the role here described different to this and if so how? This is already recommended in NICE IOG. |
| 45 | British Neuro-Oncology Society | Statement 2 | The denominator is probably wrong or would mislead. Every neuro-oncology MDT will receive several referrals per week of patients with brain tumours, usually benign and found incidentally who will never be seen by a neuro-oncology service and not require any treatment or have any related health and social care needs. These should be excluded from the denominator. |
| 46 | British Neuro-Oncology Society | Statement 2 | Rationale – not all patients with brain tumours have complex needs or require health and social care support, see above. A significant number have no symptoms at all. |
| 47 | International Brain Tumour Alliance (IBTA) | Statement 2 | We are very glad to see that **Quality Statement 2** calls for a named healthcare professional to be available to all adults with brain tumours, as someone who coordinates their medical care and social care support. Providing the complex care required by brain tumour patients is crucial in order for them to maintain the best possible quality of life.  The named healthcare professional (whether a clinical nurse specialist or other person) should also be the vital link between the multidisciplinary team and the patient/the patient’s family. But Quality Statement 2 does not indicate that the named healthcare professional should always be a full member of the multi-disciplinary team nor does it indicate that the named healthcare professional should be available to people with *all* types of brain tumours, for example including those with a low-grade glioma.  Additionally, while it’s vital that this named healthcare professional has the comprehensive skills to deal with the complex and varied needs of brain tumour patients, there may be certain domains where that skill is lacking and, therefore, the ability to **signpost** to other resources outside of the medical care of brain tumour patients will be required. We believe that “signposting skills” - in order to make timely and productive referrals - are an essential element here and specialised training and resources should be allocated for this.  Similarly, we note that there is no mention in the Quality Statement of the valuable role which brain tumour patient charities and not-for-profits play in also providing access to additional crucial services including information, awareness and peer support. These organisations often fill some of the crucial gaps in care and support not addressed by healthcare systems.  We also believe that the named healthcare professional should be responsible for providing their brain tumour patients with a comprehensive survivorship plan which should regularly be reviewed and communicated to others involved in the patient’s care. The survivorship plan should include the patient’s physical, psychological, social, cultural and spiritual needs so the best support can be provided and tailored to each patient and their caregiver/family.  Finally, there is strong evidence (see some examples below) that caregivers of brain tumour patients require a significant amount of help and support too because brain tumour caregivers are central to the wellbeing of the brain tumour patient and instrumental in providing everyday practical support:   * Ramirez et al, *Caregivers’ quality of life and psychological health in response to functional, cognitive, neuropsychiatric and social deficits of patients with brain tumour: protocol for a cross-sectional study* <https://bmjopen.bmj.com/content/7/10/e016308> * Cochrane Library, *Interventions to help support caregivers of people with a brain or spinal cord tumour* <https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD012582.pub2/references> ) * NICE – *Brain Tumours (primary) and brain metastases in adults – evidence review for supporting people living with a brain tumour* <https://www.nice.org.uk/guidance/ng99/evidence/d-supporting-people-living-with-a-brain-tumour-pdf-4903134737> * Sterckx et al, *The impact of a high-grade glioma on everyday life: a systematic review from the patient’s and caregiver’s perspective* <https://www.ejoncologynursing.com/article/S1462-3889%2812%2900035-X/pdf>   Therefore, caregivers’ needs are very complex as well. The named healthcare professional should consider their role as pivotal in providing support and referrals to the caregiver as well. Support for family caregivers is mentioned in the NICE guidelines on *Brain Tumours (primary) and Brain Metastases in Adults* (2018), clause 1.9.5 but we feel caregivers’ needs should also be explicitly mentioned in Quality Statement 2 as well.  So we respectfully suggest that Quality Statement 2 should be reworded to clarify this and other points above: ie: **“**Adults with all types and grades of brain tumours and their caregivers have a named healthcare professional who is a full member of the patient’s multi-disciplinary team and who coordinates their health and social care support, including signposting to services provided by charity and not-for-profit brain tumour organisations.” |
| 48 | Royal College of Occupational Therapists (RCOT) | Statement 2 | Page 9, paragraph 6: ‘The named healthcare professional could be a key worker…’  The term ‘keyworker’ in this instance is confusing; ‘named healthcare professional’ has more clarity and is preferred.  Page 9, paragraph 6: ‘…most closely involved with a person’s care’  It is likely that the clinical nurse specialist will be one of the initial healthcare professionals involved and this statement may lead to the role defaulting to them. This will overburden nurse specialists where other healthcare professionals are capable; there should be allowance of the named healthcare professional to be transferred to another but remain ‘named’ to the patient, family, carers and the team.  This standard will not be sustainable without indication of when patients can be discharged from the caseload of the named healthcare professional.  Consider whether the named healthcare professional should also ensure advanced care planning and Lasting Power of Attorney discussions are considered (does not have to be conducted by the named healthcare professional but ensure the most appropriate clinician has actioned). |
| 49 | Royal College of Speech and Language Therapists | Statement 2 | In the equality and diversity considerations the mentions of “cognitive impairment” should be expanded to include people with communication difficulties.  Communication skills are fundamental and foundational. They enable us to understand and to be understood. They are central to our ability to make choices and have our needs met. At present the needs of people with communication difficulties, in the absence of cognitive challenges, are not taken into account.  We recommend that people with people with communication difficulties is added to the equality and diversity section. |
| 50 | Society of British Neurological Surgeons | Statement 2 | There are a couple of issues to consider here:  1.Symptomatic/asymptomatic intrinsic brain tumours referred to the MDT – these patients already have an allocated key worker. Both a named neuro oncology surgeon/oncologist and a Neuro oncology nurse specialist.  2.Asymptomatic incidental benign brain tumours –MDT’s see/discuss a lot of these cases regularly but these patients are not and don’t need to be seen by the neuro oncology team. If this quality statement is referring to this group of patients, then this would significantly increase the workload of neuro oncology services and presently they don’t have the capacity or manpower to deal with this. It also not required. These patients can be followed by their local physicians with any surveillance imaging as advised by the MDT. The local physician would be their “named health care professional” then and not a neuro oncology surgeon or oncologist. The present pathways are not clear about the responsibility of the “local physicians” and hopefully this quality standard will clarify that.  However, the wording of this quality standard will need to be more clear to reflect this. |
| 51 | The Brain Tumour Charity | Statement 2 | The Brain Tumour Charity welcomes the draft quality statements, however we would like to highlight a few points for further consideration – in particular to recommend that it is explicitly stated in Quality Statement 2 that adults with a high-grade or low-grade brain tumour should have a named healthcare professional who coordinates their health and social care support, and is easily accessible. |
| 52 | The Brain Tumour Charity | Statement 2 | The Brain Tumour Charity welcomes the inclusion of a quality statement on access to a named healthcare professional to co-ordinate patients’ care, as the evidence suggests this is a key area for quality improvement.  However, we would strongly encourage the quality statement to explicitly state that this includes adults with **high-grade and low-grade** brain tumours to ensure a consistent experience.  Data from our Improving Brain Tumour Care Survey collected in October 2020 showed that out of a sample of 690 people diagnosed or in active treatment during the last 2 years, 85% of respondents were given a named person (keyworker or CNS) who could answer questions, address worries and fears or help provide support. It is important that this is increased to 100%, as a named healthcare worker is crucial for continuity of care and support for those living with brain tumours.  However, the same survey identified that access to a named healthcare professional is significantly lower for patients with **low-grade brain tumours** at **just 75%**, compared to for patients with high-grade brain tumours at 93%. This discrepancy needs to be addressed urgently to ensure access is provided for all.  Data from our Improving Brain Tumour Care Survey suggests there may be differences between centres in regards to access to a named healthcare professional. In order to achieve the outcome proposed in this quality statement, increased funding and resource may be needed to ensure sufficient provision of named healthcare professionals for all patients across the UK.  It is also important to consider how accessible the named healthcare professional is to patients. The Improving Brain Tumour Care Survey found that only 64% of respondents felt they had a named person that they could reach at any time. We can again see discrepancies between high-grade and low-grade patients within this, with 72% of high-grade patients feeling they had a named person they could reach at any time, compared to 52% of low-grade patients. There was also an observable gap between this support for those undergoing radiotherapy and chemotherapy where 75% felt they had a named person they could reach at any time, compared to those undergoing surgery where only 63% felt they had a named person they could reach at any time. We would therefore also encourage that the quality statement make reference to support from a named healthcare professional being easily accessible e.g. “Adults with high-grade or low-grade brain tumours have a named healthcare professional who coordinates their health and social care support, and is easily accessible”.  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. The Brain Tumour Charity feels this makes the accessibility of an easy to contact CNS or named healthcare professional for all brain tumour types (high-grade and low-grade) even more important. We are therefore pleased to see the key actions of conducting **holistic needs assessments** at key transitions **and ensuring care plans are in place** have been included in the definition of a named healthcare professional – we would also welcome needs assessments and care and support plans being explicitly stated and included in the ‘rationale’ for this quality statement to highlight their importance in meeting patients’ needs.  In regards to data sources for measuring the outcomes against this quality statement, The Brain Tumour Charity is concerned about reliance on NHS England’s National Cancer Patient Experience Survey (NCPES). Previously the survey has unfortunately had a low sample size (e.g. 281 responses in 2019, which was around 2% of new primary brain tumour diagnoses). The NCPES excludes low grade brain tumour patients, and therefore will not help measure or understand the experiences of thousands diagnosed with a low-grade brain tumour each year in England. Improvement in the use of this survey is needed to be able to effectively understand performance against this quality statement. We would welcome the opportunity to explore whether our Improving Brain Tumour Care surveys – already being used to assess NHS centres as part of the Tessa Jowell Centres of Excellence designation process – could help measure progress towards this quality statement. |
| 53 | University College London Hospitals NHS Foundation Trust the National Hospital for Neurology and Neurosurgery | Statement 2 | This is best practice and we always ensure our patients have an assigned named health care professional appropriate to the stage of their treatment |
| 54 | Brain Tumour Research | Statement 2 – Question 2 | In measuring the 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 with the numerator being the number in the denominator who have the name and contact details of a healthcare professional who coordinates their health and social support and the denominator being the number of adults with brain tumours.  We have the following questions;  a. Where will this data be held i.e., will the MDT make sure that the patient knows who this is and record it.  b. How will this be recorded nationally?  c. What is the role of the GP in this designation – we would be concerned that they would be named as a healthcare professional by default, yet, what is needed are specific individuals responsible for both roles of ‘health coordination’ and ‘social care coordination’ to avoid the apparent current divide between the delivery and mechanisms of these services?  Could we measure this standard by a random survey of 100 brain tumour patients asking if they could spontaneously identify who their designated HC/Social care professional is? This way we can see if the process is working, where we can improve it by asking patients for their opinion and how to improve the standard’s outcomes.  Furthermore how will satisfaction be defined and specifically measured? We need to be careful not to ‘lead’ patients and their carers. This is undefined and should be defined by some specific criteria to allow for patients to make it clear what is good, what is bad and what needs improvement.  Also, we note that ‘satisfaction’ with the coordination of social care has been dropped in this outcome - we believe this should be included. |
| 55 | Brainstrust – the brain cancer people | Statement 3 | Agree – this should be a given. It has to be available at all neurosurgical centres. |
| 56 | British Neuro-Oncology Society | Statement 3 | Agree |
| 57 | International Brain Tumour Alliance (IBTA) | Statement 3 | We welcome Quality Statement 3 regarding 5-aminolevulinic acid-guided resection. |
| 58 | Royal College of Occupational Therapists (RCOT) | Statement 3 | It is recommended that minimum objective standards of discussions of risk are included, as without them it may lead to health inequality: some may have a comment whilst others who may have more time and have no communication challenges are provided with a more comprehensive risk assessment/discussion.  The requirement to share evidence of this discussion with the named healthcare professional (Quality Statement 2) would appear to be necessary. |
| 59 | Society of British Neurological Surgeons | Statement 3 | Good quality standard. |
| 60 | The Brain Tumour Charity | Statement 3 | We are very pleased to see the inclusion of a quality statement to ensure access to 5-aminolevulinic acid (5-ALA) guided resection for all eligible patients.  Surgical care and management is critical to brain tumour patient treatment, and the extent of tissue removal is the only factor surgeons can influence to order to improve survival. The use of 5-ALA is one of the few options available for high grade brain tumours and can potentially improve quality of life, and delay deterioration, enabling some patients to safely receive less intensive therapy. The Brain Tumour Charity has campaigned for many years to ensure equal access to 5-ALA across the UK.  Although all UK neurosurgery units now have access to 5-ALA, we have heard anecdotally that rates of usage may still vary despite NICE’s recommendation. In order to achieve the outcome proposed in this quality statement, increased funding and resource may be needed to ensure sufficient provision of clinicians who have received the necessary training to ensure 5-aminolevulinic acid (5-ALA) guided resection is available in all centres.  This quality statement is proposed to be measured by a 95% or greater reduction in tumour volume achievement flowing the use of 5-ALA on suitable adult patients, which we feel to be an appropriate measure against this quality standard. |
| 61 | University College London Hospitals NHS Foundation Trust the National Hospital for Neurology and Neurosurgery | Statement 3 | Regarding Statement 3:  Only a small proportion of patients with radiologically suspected High Grade Glioma (HGG) would be suitable for consideration of resection of all the radiological suspected tumour preoperatively. Complete radiological resection is often not possible because of proximity to critical structures and areas of eloquent brain function. We know that maximal resection of all radiological abnormality is also not curative in HGG.  In patients in whom the preoperative plan is to achieve a complete radiological resection 5‑ALA can be used as an adjunct to achieve this. 5 – ALA is an adjunct to achieving maximal resection and should be considered with other surgical strategies such as Interventional MRI and Awake Surgery with brain mapping as to how this alone or in combination may achieve this goal. The risks and expense of 5-ALA should always be factored in to any risk/benefit ratio for an individual patient. |
| 62 | University College London Hospitals NHS Foundation Trust the National Hospital for Neurology and Neurosurgery | Statement 3 | **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.  We would agree that this is available and are compliant with this. The enhancing component if any tumour maybe only a small fraction of the tumour present on a scan. The advantages of 5-ALA are only present if an attempt is being made to remove all the tumour and not all the enhancing tumour  **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.  Complete radiological tumour resection preoperatively is only the aim in a minority of suspected HGG patients though.  **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.  We would not agree with the statement ‘all enhancing tumour’ – see comment above.  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.  We would not agree with the statement ‘all enhancing tumour’ – see comment above**.**  **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.  Whether patients are suitable for complete radiological resection could be assessed at MDT. It may require functional imaging to further define this however and it will always be the individual surgeons choice. In these cases 5 ALA should be available and considered in the unit alongside other adjuncts to surgery such as interventional MRI and awake brain surgery. The extents of resections achieved in these cases can be assessed with pre and postoperative imaging. This is subject to artefact if delayed and most confidently assessed at resection in interventional MRI. |
| 63 | Brainstrust – the brain cancer people | Statement 4 | * This should be discussed prior to treatment so that patients have the option of no treatment and can make an informed choice. This sits with the shared decision-making agenda. * This discussion is mandated to happen at consent. |
| 64 | British Neuro-Oncology Society | Statement 4 | Rationale – this is a little odd as it is essentially mandatory as part of informed consent to clearly describe the early and late risks of radiotherapy to all patients who undergo this treatment. Would have been preferable to ensure this information was provided to all patients prior to treatment rather than afterwards, as part of the shared decision making process. |
| 65 | International Brain Tumour Alliance (IBTA) | Statement 4 | We welcome **Quality Statement 4** regarding the risk of late effects of treatment. But surely, specific discussions on the risk of late effects of treatment should take place between healthcare professionals and brain tumour patients prior to each phase of planned treatment and not at the first follow-up appointment only. Discussions about the risk of late effects of treatment should be documented not only in the patient’s written treatment summary but also in the patient’s survivorship plan, together with management proposals as to how patients might deal with these late effects. Shared decision-making models should also be followed when determining courses of action to deal with the late effects of treatment.  So we respectfully suggest that Quality Statement 4 is amended to read: “Adults who face ~~finish~~ treatment for brain tumours have an assessment and discussion about their risks of late effects of treatment prior ~~at their first follow-up appointment~~ to each phase of planned treatment.” |
| 66 | NHSE&I (CAHPO) | Statement 4 | P15 (healthcare professionals) – This should specifically say Therapeutic Radiographers |
| 67 | Royal College of Speech and Language Therapists | Statement 4 | Expand “cognitive decline” and include speech, language and communication difficulties.  The RCSLT strongly recommend that communication is added to the effects of treatment list. A person with a primary brain tumour can experience a change in their communication due to disease progression or treatment effects. For example, the speech functions around the dominant hemisphere can be affected.  We recommend that speech, language and communication difficulties is included. |
| 68 | Royal College of Speech and Language Therapists | Statement 4 | The mention of “reduced communication skills” should be changed to people with communication difficulties.  This term is incorrect and should refer to people with communication difficulties. |
| 69 | Society of British Neurological Surgeons | Statement 4 | This refers to both surgery and radio/chemo therapy – The risks/side effects (immediate/short term/long term) of any intervention/treatment are discussed with patient prior to embarking on the treatment so that patients are well consented. It is understandable that patients may not appreciate all the long term side effects of a treatment prior to the intervention. However, rather than at their “first follow up” appointment the quality statement could be worded as:  “Adults with brain tumours have a discussion about their risks of late effects of treatment prior to starting treatment and on a regular basis when on follow up with assessments after finishing their treatment”.  The numerator changes accordingly. |
| 70 | University College London Hospitals NHS Foundation Trust the National Hospital for Neurology and Neurosurgery | Statement 4 | The discussion regarding risk of late-effects of treatment is part of informed consent before any surgery, radiotherapy or chemotherapy.    With regards to radiotherapy:  Detailed tumour and site-specific information leaflets are given to the patients outlining the acute and late effects, and they are also documented on the consent form, and specific risks mentioned again in the clinic letter at the time of consent.  Following treatment patients are referred appropriately for ongoing surveillance for development of specific late effects (eg to endocrinology or ophthalmology).  We agree it would be useful to re-visit this discussion after treatment. At the time of consent patients will often be anxious and scared, and many will find it helpful to re-visit these conversations.  We are looking into the end of treatment summaries containing a detailed list of individualised late effects |
| 71 | Brain Tumour Research | Statement 4- Question 4 | Late effect reporting depends on the nature of the treatment being delivered. Late radiation effects can occur after the completion of radiation and continue for many years with the occurrence of secondary related tumours perhaps occurring up to 8-10 years post radiotherapy. For some treatments we are unsure of the nature of late side effects. Thus, we are concerned that one visit will not capture potential issues. We suggest producing a table of treatments for which a ‘Late effects’ follow-up program can be tailored to monitor e.g., for radiotherapy perhaps a 2 yearly review up to 10 years might be appropriate. |
| 72 | Brainstrust – the brain cancer people | Statement 4- Question 4 | Discussion needs to happen prior to treatment, not after treatment. It is too late then. It should be part of the consent process with patients given time to reflect and process. |
| 73 | NHSE&I (CAHPO) | Statement 4- Question 4 | We agree with statement four. However, we note that there MAYBE variation of being able to deliver this at a local level. |
| 74 | University College London Hospitals NHS Foundation Trust the National Hospital for Neurology and Neurosurgery | Statement 4- Question 4 | This would be feasible: please see comments below section 10 |
| 75 | Brainstrust – the brain cancer people | Statement 5 | * Agree there should be neurorehab available, so that there is parity with stroke services and it should be close to home or in the home. * It should be high quality, specialised and personised to meet the needs of those that need it, where-ever they are on the pathway. Brain tumours bring progressive neurological deficit so this assessment should be regularly reviewed or done when prompted by a change. It needs to be holistic review as sometimes the issues are minor but when seen together can impact significantly on quality of life. * Recognition that not every person with a brain tumour needs rehab. |
| 76 | British Neuro-Oncology Society | Statement 5 | Denominator may not be optimal. It might better be defined as the number of patients who require some neurological rehabilitation as most do not. Otherwise it possibly will make those delivering the worst clinical outcomes look the best i.e. if you cause harm to more patients, more require rehab so your numerator:denominator will be greater although your outcomes are actually worse. |
| 77 | International Brain Tumour Alliance (IBTA) | Statement 5 | We very much welcome **Quality Statement 5** on neurological rehabilitation. We would respectfully suggest, however, that the Quality Statement should be more specific about the types of neurological rehabilitation required by brain tumour patients because their needs are so highly varied and complex. While we appreciate that this is covered in the rationale, we believe that the Quality Statement will be stronger and more appropriate to brain tumour patients if the Quality Statement itself is amended to say: “Adults with any type and grade of brain tumour can access neurological rehabilitation assessment and supportive services in the community for their complex physical, cognitive and psychological needs.” |
| 78 | Royal College of Occupational Therapists (RCOT) | Statement 5 | This statement will be challenging to measure as there are teams who are not labelled as ‘community neurology teams’ who are able to provide ‘neurological assessment and treatment’. The term is not well defined in the statement as aspects of a ‘neurological assessment’ is standard within physiotherapy and occupational therapy practice. For example, a generalist community rehabilitation team, frailty team or specialist palliative care may all have the skills and potentially a patient may be under the care of several of these services at any one time. However the demands on hospital admission avoidance within these teams will be prioritised over rehabilitation.  A stronger requirement of what an assessment includes with follow-up intervention is recommended.  A multidisciplinary assessment is likely to support comprehensive and holistic interventions.  This statement needs to be clarified as to how it differs from Quality Statement 2 and the role of the named healthcare professional.  Use of the word ‘can’ is not strong enough, and whether the phrasing ‘Adults with brain tumours must be considered for referral to person-centred neurological rehabilitation in the community’ conveys the intent of the Quality Statement better.  Patients and their carers should have processes that allow them to access neurological rehabilitation assessment easily, flexibly and promptly based on their needs at any stage of their condition.  Services have limited resources to keep patients on caseloads indefinitely and conduct regular reviews; patients should be empowered to access services when required at all stages of their condition and treatment.  The Quality Statement should include ‘optimise their recovery and functional independence’.  Additionally, this may prompt clinicians to provide ‘prehabilitation’ prior to treatments for the brain tumour.  See the comments to Statement 5.    Key action: patients to be offered the opportunity to have a comprehensive review exploring quality of life, health and wellbeing which may then require assessment by a service with clinical expertise in neurological practice who must provide the required interventions to address the person-centred goals. |
| 79 | Royal College of Speech and Language Therapists | Statement 5 | The RCSLT recommend that communication impairment is added alongside cognitive under “Rationale” on page 18.  A person with a primary brain tumour can experience a change in their communication due to disease progression or treatment effects. We recommend that this is included. |
| 80 | Royal College of Speech and Language Therapists | Statement 5 | The mention of “reduced communication skills” should be changed to people with communication difficulties.  This term is incorrect and should refer to people with communication difficulties. |
| 81 | Society of British Neurological Surgeons | Statement 5 | Good quality standard. |
| 82 | The Brain Tumour Charity | Statement 5 | We welcome the inclusion of this quality statement in light of a study by Yu, J., et al. (2019) which suggested that intensive rehabilitation may help promote functional improvement following brain tumour surgery, regardless of malignancy, compared with stroke patients3. Further research is needed to better understand the potential impact of neurological rehabilitation assessment in the community.  We would welcome the opportunity to explore whether our Improving Brain Tumour Care surveys – already being used to assess NHS centres as part of the Tessa Jowell Centres of Excellence designation process – could help measure progress towards this quality statement.   1. Yu, J., Jung, Y., Park, J., Kim, J. M., Suh, M., Cho, K. G., & Kim, M. (2019). Intensive Rehabilitation Therapy Following Brain Tumor Surgery: A Pilot Study of Effectiveness and Long-Term Satisfaction. Annals of rehabilitation medicine, 43(2), 129–141. <https://doi.org/10.5535/arm.2019.43.2.129>) |
| 83 | University College London Hospitals NHS Foundation Trust the National Hospital for Neurology and Neurosurgery | Statement 5 | The need for neurological rehabilitation depends on the type of patients being seen and their individual requirements. Patients should be able to access neuro-rehabilitation at all stages along their pathways which may include an in-patient stay following surgery or prior to commencing adjunctive treatment. A short burst of rehabilitation may improve their functional performance and ability to be able to go on and have adjunctive treatment. *Are we able to change community to local services?*  There is great need for improved provision of neuro-specific intervention and rehabilitation in the community.  We consider vocational rehabilitation services also extremely important for our patient group, especially their expertise in enabling our younger patients to return to work and enhancement of QOL.  Neuro-rehabilitation should include physical, cognitive and psychological intervention and treatment.  Patients should be able to have quick access to equipment required to assist their quality of life e.g. wheelchairs and specialist seating, communication aids |
| 84 | Wales Cancer Network | Statement 5 | Adults who have had brain tumour resection will need the option of accessing **acute inpatient Neurorehabilitation** as well as rehabilitation in the community. This is particularly important for patients who have had low grade gliomas resected in eloquent areas whose rehab potential is immediate, extremely crucial, and unlikely to require it for more than 2-3 weeks. Practically, this will mean an inpatient transfer to the Llandough NeuroRehab facility for motor/speech/neuropsychological rehab. |
| 85 | Brain Tumour Research | Statement 5 -Question 5 | Our concern is whether patients have been given access to the appropriate requested services within a clinically useful time period. The danger of asking whether they have been referred is that it would not give a complete answer as to whether they have been able to access the rehabilitation resources that they need. We believe we should measure the number referred from MDT or specialised services for rehab who actually received the service within an appropriate time period, which should be no more than say two weeks. We should measure the date when the patient and the service have been notified of the request being sent and then the date when they actually received the service to identify if service levels are being met. We believe the patients and their carers would welcome being able to provide this information. |
| 86 | Brainstrust – the brain cancer people | Statement 5- Question 5 | You’d need to consider how this could be measured. You might have centres who deliver poor outcomes offering the most rehab so they would look better but their outcomes are still poor. |
| 87 | NHSE&I (CAHPO) | Statement 5- Question 5 | Yes, the focus is correct. |
| 88 | Royal College of Speech and Language Therapists | Statement 5- Question 5 | The RCSLT agree that there is an urgent need to improve access to neurological rehabilitation for adults. There is currently unacceptable variation across the country in access to neuro rehabilitation services. This affects people’s ability to access the right treatment, care and support when they need it.  Alongside this, investment in a specialist health and care workforce is needed to address the current shortages. |
| 89 | University College London Hospitals NHS Foundation Trust the National Hospital for Neurology and Neurosurgery | Statement 5- Question 5 | The need for neurological rehabilitation depends on the type of patients being seen and their individual requirements. There is great need for greater provision in the community. We consider vocational rehabilitation services also extremely important for our patient group, especially their expertise in enabling our younger patients to return to work and enhancement of QOL. |

Note: Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its staff or its advisory committees.

## Registered stakeholders who submitted comments at consultation

* Association of British Neurologists
* Brain Tumour Northwest (BTNW)
* Brain Tumour Research
* Brainstrust – the brain cancer people
* British Neuro-Oncology Society
* British Society of Neuroradiologists (BSNR)
* Compassion in Dying
* International Brain Tumour Alliance (IBTA)
* NHS England & NHS Improvement (The office for the Chief Allied Health Professions Officer)
* Royal College of General Practitioners
* Royal College of Occupational Therapists (RCOT)
* Royal College of Speech and Language Therapists
* Society of British Neurological Surgeons
* The Brain Tumour Charity
* University College London Hospitals NHS Foundation Trust, the National Hospital for Neurology and Neurosurgery
* Wales Cancer Network