**National Institute for Health and Care Excellence**

**Quality Standards Advisory Committee 3 meeting**

**Date:** Wednesday 16 June 2021

**Brain tumours (primary) and brain metastases in adults** – prioritisation of quality improvement areas

**Minutes:** Draft

**Quoracy:** The meeting was quorate

**Attendees**

**Quality Standards Advisory Committee 3 standing members:**

Gita Bhutani (Chair), Jim Stephenson (vice chair), Ivan Bennett, Malcolm Fisk, Madhavan Krishnaswamy, Keith Lowe, Ann Nevinson, David Pugh, Julia Thompson, Phil Taverner, Jane Dalton, Christine Camacho, Mark Devonald, Hazel Trender, Jane Dale, Linda Parton, Umesh Chauhan, Tim Cooper

**Specialist committee members:**

Stuart Smith, Ingela Oberg, Isabella Robbins, Alison Cameron, Shanika Samarasekera, Helen Bulbeck, David Summers

**NICE staff**

Sarada Chunduri-Shoesmith (SCS), Melanie Carr (MC), Nicola Greenway (NG), Rick Keen (RK), Jamie Jason (JJ) notes

**NICE observers**

Charlotte Fairclough

**Apologies**

Deryn Bishop, Carolyn Chew-Graham, Jane Scattergood

1. **Welcome, introductions objectives of the meeting**

The Chair welcomed the attendees and the Quality Standards Advisory Committee (QSAC) members introduced themselves. The Chair informed the committee of the apologies and outlined the objectives of the meeting, which was to prioritise areas for quality improvement for the Brain tumours (primary) and brain metastases in adults quality standard.

The Chair welcomed the public observers and reminded them of the code of conduct that they were required to follow.

1. **Confirmation of matter under discussion and declarations of interest**

The Chair confirmed that, for the purpose of managing conflicts of interest, the matter under discussion was Brain tumours (primary) and brain metastases in adults specifically:

* Investigations
* Management/treatment
* Follow-up
* Care needs of people with brain tumours
* Neurorehabilitation
* Surveillance for late-onset side effects of treatment

The Chair asked standing QSAC members to declare verbally any interests that have arisen since the last meeting and all interests specifically related to the matters under discussion. The Chair asked the specialist committee members to verbally declare all interests.

1. **Minutes from the last meeting**

The committee reviewed the minutes of the last QSAC 3 meeting held on 28 April 2021 and confirmed them as an accurate record.

1. **Prioritisation of quality improvement areas – committee decisions**

MC provided a summary of responses received during the Brain tumours (primary) and brain metastases in adults topic engagement, referred the committee to the full set of stakeholder comments provided in the papers and the committee then discussed each of the areas in turn. The committee discussed the comments received from stakeholders and specialist committee members at topic engagement **(in bold text below)**.

**Investigations**

* Rapid access to MRI- Prioritised
* Additional imaging/testing – Not prioritised

The committee discussed the importance of early diagnosis and that currently around 60% of brain tumours are diagnosed following an emergency presentation (e.g. National Cancer Diagnosis Audit 2014- 65%). The committee heard that late diagnosis following repeated visits to a GP can result in a lack of trust. The committee discussed that GP direct access to MRI can help and is still patchy in some areas. However, a lack of clear guidance on symptoms means that it is difficult for GPs to know when to refer for MRI. Without clearer guidance on when to refer and clearer pathways there could be a significant resource impact if there were an increase in referrals for MRI but no improvement in detection and diagnosis.

The committee also highlighted that some people are being referred to a multi-disciplinary team without the required MRI scan e.g. only a CT scan, which then causes a delay while they wait for the MRI. It was clarified that 5% of people cannot tolerate having an MRI e.g. due to claustrophobia.

The committee agreed that rapid access to MRI is an important area but recognised that it may be difficult to develop a measurable statement given the limited scope of the recommendations available. The committee asked the technical team to explore what may be possible, including whether we could include a link to the existing statement in the suspected cancer QS (QS124).

**Management/Treatment**

* Multidisciplinary team – Not prioritised
* Treatment pathway – Not prioritised
* Maximal safe surgical resection – Prioritised
* Stereotactic radiosurgery for multiple brain metastases – Not prioritised.

The committee agreed not to discuss treatment pathway and stereotactic radiosurgery for multiple brain metastases as there are not sufficient recommendations available to develop a quality statement.

The committee discussed multidisciplinary teams (MDTs). It was suggested that most people are discussed at an MDT before treatment except when it is extremely urgent. It was agreed that access to allied health professionals and neuropsychology in some MDTs remains poor. The committee agreed there should not be an individual statement on this but it should be addressed in other areas.

There was support for progressing a statement on 5-ALA as there is good evidence that it improves progression free survival and overall survival and use varies across the country. The committee discussed the resource impact of 5-ALA. It was confirmed that there would be no further resource impact over and above the costs in the guideline and funding has been agreed by the Department of Health and Social Care. It was suggested to use recommendation 1.2.36 from NG99. The committee agreed to develop a statement on 5-ALA guided resection.

**Follow-up**

* Imaging – Not prioritised
* Advanced imaging – Not prioritised

The committee noted that all the recommendations are consider recommendations. It was suggested that decisions on timing of follow-up will be dependent on the individual and their conversations with their healthcare professional.

The committee agreed that this was not a priority area and this will not be progressed.

**Care needs of people with brain tumours**

* Holistic needs assessment – Not prioritised
* Named healthcare professional – Prioritised
* Specific support– Not prioritised

The committee agreed that it is important for people with a brain tumour to have a named healthcare professional to coordinate their care throughout their journey. This should include people with a low-grade tumour. This will help to ensure their care is seamless and that needs assessments are carried out. It was recognised that there are not enough resources or trained staff for keyworkers in some areas.

The committee discussed whether it would be appropriate to focus on a care plan given the limited resources for keyworkers. It was agreed, however, that access to a keyworker should be the priority as it is very important for this population with complex needs.

The committee agreed that we should not be prescriptive about who the healthcare professional should be as it will depend on local systems. It should however be someone who has an understanding of brain tumours.

The committee agreed that having a named keyworker is an important area that should be progressed.

**Neurorehabilitation**

* Assessment for neurorehabilitation – Prioritised
* Access to neurorehabilitation services – Not prioritised

The committee suggested that access to community-based rehabilitation is a priority. It is important for people to have an assessment and then they can be referred. There was concern that people with brain tumours are not able to access neurorehabilitation services currently as it is incorrectly seen as a progressive condition that rehabilitation cannot help. This is not helpful as some people could really benefit. Access to allied health professionals and neuropsychology were particular areas of need. Family and carers should be part of the focus for this area.

The committee agreed that assessment for neurorehabilitation is an important area that should be progressed.

**Surveillance for late-onset side effects of treatment – Prioritised**

The committee agreed that surveillance for late onset side effects of treatment is an important area that should be progressed. There was strong support for writing down the person’s potential late effects and explaining this to them and their family or carers. The ideal time to discuss this is at the first follow up appointment after treatment. Suggestion to use recommendation 1.11.2.

**Additional quality improvement areas suggested by stakeholders at topic engagement**

The following areas were not progressed for inclusion in the draft quality standard.

Participation in clinical trials/research - Remit of the National Institute for Health research

End of life care - Existing QS on end of life care

Employment Support - Existing QS on workplace health

Quality of life questionnaires - Focus on actions that demonstrate high quality care or support not data collection

**Resource impact and overarching outcomes**

The committee considered the resource impact of the quality standard and agreed it is appropriate to get feedback on this at consultation.

**Equality and diversity**

The committee agreed the following groups should be included in the equality and diversity considerations:

Age

Gender reassignment

Pregnancy and maternity

Religion or belief

Marriage and civil partnership

Disability

Sex

Race

Sexual orientation

The committee also highlighted:

Ensuring that cultural needs are met via community rehabilitation services.

Geographical remoteness can make access to neurorehabilitation and imaging difficult.

1. **AOB**

No other business.

1. **Close of the meeting**