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NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

NICE guidelines

Equality impact assessment

Primary brain tumours and cerebral metastases

The impact on equality has been assessed during guidance development according to the principles of the NICE equality policy.

3.0 Guideline development: before consultation (to be completed by the developer before draft guideline consultation)

3.1 Have the potential equality issues identified during the scoping process been addressed by the Committee, and, if so, how?
The major equality issue identified during the scoping process was inequality due to age. There were two age-related equality issues; the committee believed that it was possible that older adults might disproportionately not be receiving treatment they might benefit from, and that younger adults might be encountering gaps in their treatment as they transitioned from paediatric to adult services. To address concerns that older adults might be disadvantaged by not being able to access treatment, the committee searched for and made specific recommendations for older adults (meaning those older than around 70) based on trial evidence. In the experience of the committee, the reason older adults might not be able to access treatment was a misunderstanding about the expected response to treatment in these age groups, and therefore the expected balance of risks and benefits to offering treatment. In particular, those aged over around 70 were very disadvantaged as they were often excluded from clinical trials and therefore clinicians were reluctant to extend the findings of these trials into these age groups, assuming that the balance of risks and benefits must greatly favour non-intervention. The committee therefore made direct recommendations for those aged over around 70 wherever there was trial evidence that a different treatment regimen improved outcomes, and otherwise deliberately made no reference to hard age cutoffs in any recommendations to make it clear that they were intended to apply to all age groups. Recommendations such as 2.2.2, 3.2.1 and 3.2.3 will improve

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access to services by making it clear that there are many factors other than age that should determine management options, and that therefore services cannot justify refusing treatment on the grounds of age alone. In particular, there are eight recommendations which mention specific age cutoffs as a guide to treatment. Although only the second set of recommendations (1.2.19 – 1.2.23) specifically address the equality issue listed in earlier sections of this document, the presence of an age cutoff in the first set of recommendations (1.2.6 – 1.2.8) could therefore generate an equality concern at this new cutoff, and so is also addressed below. These recommendations are: • 1.2.6 – This recommendation suggests only offering a certain treatment to people with a particular mutation and who are around 40 years old or older (or who have residual tumour). This is based on moderate quality evidence that this treatment improved overall survival and progression free survival. The trial upon which this evidence was sourced used the age of 40 as the cutoff for entry. The committee were therefore sure that there was benefit to offering this treatment to those aged over 40, but unsure about the benefit of this treatment in those aged under 40 who did not meet the other entry criterion for the trial (residual tumour). Since the committee were uncertain about the benefits in this group of patients, they agreed that clinical judgement should be used at around the age cutoff of 40. • 1.2.7 – This recommendation is the same as 1.2.6, but for people without the specific mutation referenced in 1.2.6. This recommendation was made on the basis of the same trial as 1.2.6 but the confidence interval in this subgroup was wider and the committee less certain, therefore the committee made a ‘consider’ recommendation. • 1.2.8 – This recommendation suggests considering active monitoring in those aged around 40 and under who have no tumour on their residual scan. This recommendation was made on the basis of committee experience, based on a desire to offer guidance to those who fell outside the inclusion criteria of the trial. Taken together, the recommendations constituting this potential equality issue are proportionate and justified with respect to the evidence. The committee highlighted that the balance of harms of treatment versus risk of no treatment favours non-intervention in younger patients and that therefore in the absence of evidence of benefit, people who are younger than the inclusion criteria for the trial (with no risk from residual tumour) should be especially considered for a non-intervention

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approach. This therefore means different recommendations in different groups are made only on the basis of differing clinical evidence in these groups.

- 1.2.19 – This recommendation specifies the combination of radiotherapy and drug dosing that is appropriate for those with good performance status (KPS >70) and lower age (aged around 70 and under). This is based on a variety of very low to moderate quality pieces of evidence showing this technique improved overall survival and progression free survival in which the age cutoff for inclusion in the trial was either 65 or 70. The committee discussed how the best quality evidence typically came from trials with a 70 year cutoff, and therefore agreed that clinical judgement should be used around this age range.

- 1.2.20 – This recommendation suggests that those aged around 70 or over with a good performance score and a particular kind of mutation (MGMT methylation) should be offered the same treatment as 1.2.19 but at a lower radiotherapy dose. This is because there is evidence that those aged >65 benefit from this treatment, but subgroup analysis show that the group aged >70 benefit more from the addition of temozolomide to their treatment. Another trial shows that there is no clinically important difference in outcomes between standard radiotherapy (60 Gy) and short-course radiotherapy (40 Gy) in those aged >65. Since lower doses of radiotherapy are likely to lead to better outcomes, the committee justified a recommendation to use clinical judgement at around age 70 and over on the basis that there was specific evidence on optimal treatment in those aged >70 and indirect evidence that the same therapies at a lower radiotherapy dose would therefore be appropriate in this group.

- 1.2.21 – This recommendation is the same as 1.2.20 but for people without the specific mutation referenced in 1.2.20. This recommendation was made on the basis of the same trial as 1.2.20, but justified with reference to a subgroup analysis showing that those without the MGMT methylation had a response to treatment that was not statistically significant and that therefore the evidence was less compelling.

- 1.2.22 - This is a recommendation to consider best supportive care alone in those aged around 70 and over with a low performance status (KPS < 70). This recommendation was based on clinical consensus, based on a desire to provide guidance for those who fell outside the inclusion criteria of a trial which considered radiotherapy versus radiotherapy and best supportive

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care in those aged around 70 and over with good performance status (KPS > 70). • 1.2.23 – This is a recommendation to consider temozolomide alone in those aged around 70 and over with a particular kind of mutation (MGMT methylation). It is thought this group might benefit from temozolomide alone on the basis of the inclusion criteria of a trial, but the committee cautioned that this was not direct evidence as the population intended to be covered by this recommendation was not covered by this trial and therefore the recommendation was weak and not intended to prevent this group accessing the other treatments in 1.2.23. Taken together, the recommendations constituting this potential equality issue are proportionate and justified by evidence. While people of different ages are recommended treatment which is mutually exclusive, these recommendations are only made where there is evidence that this differentiation will improve outcomes in a particular group. The only case where there is no related evidence is recommendation 1.2.22, and this does not prevent any individual receiving any treatment as it is only a weak 'consider' recommendation, intended to highlight the decreasing balance of risks and benefits to treatment as KPS drops (which is to say, age is not the differentiator of when treatment is recommended and not; KPS is). To address concerns that the gap in service provision between paediatric and adult services could cause equality issues, the committee agreed to consider evidence on those aged 16 years and upwards where the transition between services could present an equality issue (for example, where people may transition between paediatric and adult surgical units). However no recommendations were specifically made about the 16-18 age group that would be affected by this change.

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During development, committee members emphasised that there was variability in the availability of services. This was most explicit (but not limited to) neurorehabilitation assessment services. This could present an equality issue if someone with a brain tumour is unable to access neurological rehabilitation in their area, for example because there is no provision for neurological rehabilitation given their age, tumour type or other symptoms. Where possible, the committee used the recommendations and discussion sections to emphasise the importance of providing these services, and where the evidence did not support such recommendations the committee made a series of research recommendations outlining areas for further study to reduce clinical variation. Additionally, it was discussed how the complexity of treating brain tumours and the potential for the tumour itself to affect parts of the brain responsible for interpreting complex language meant that people with tumours could sometimes feel overwhelmed and unable to make well-informed choices about their care. As far as possible, language choice in the recommendations reflects the needs of the service user and the guideline includes numerous 'preference-sensitive decision tables' to support shared decision making.

3.3 Were the Committee's considerations of equality issues described in the consultation document, and, if so, where?
The committee's discussions of equality issues have been recorded in the relevant parts of the 'The committee's discussion of the evidence' sections of the evidence reports. While this convention was followed throughout the development of the guideline, equality issues were a particular concern in questions on the care needs of people with tumours and the neurorehabilitation assessment needs of people with tumours, and so the discussion sections on these documents are correspondingly detailed.

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3.4 Do the preliminary recommendations make it more difficult in practice for a specific group to access services compared with other groups? If so, what are the barriers to, or difficulties with, access for the specific group?
The recommendations do not make it any more difficult for specific groups to access services. In many areas, the committee's recommendations should drive equity of access.

3.5 Is there potential for the preliminary recommendations to have an adverse impact on people with disabilities because of something that is a consequence of the disability?
Many people with brain tumours have tumour- or treatment-related disabilities, and many of those who do not have an officially recognised disability have disability-like difficulties with activities of daily living (such as being legally unable to drive and experiencing severe fatigue). Consequently the committee acted on the assumption that multi-system disability might affect any person for whom the guideline covers, and this is emphasised by ensuring recommended treatment and follow-up plans prioritise the wishes of the person receiving the treatment or follow-up with respect to frequency and travelling to access treatment.

3.6 Are there any recommendations or explanations that the Committee could make to remove or alleviate barriers to, or difficulties with, access to services identified in questions 3.1, 3.2 or 3.3, or otherwise fulfil NICE's obligation to advance equality?
A number of recommendations developed by the committee aimed to alleviate or remove barriers to, or difficulties with, access to services, particularly in the evidence review on care needs of people with tumours. The committee discussed issues of equality of access to services. It was noted that access to and support of people with the complex needs presented by a brain tumour was not easily available to some black and minority ethnic (BAME) groups and especially non-English speakers. The committee discussed how a review question on the specific

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access needs of BAME people was not within the scope of the guideline, and consequently they were unable to investigate if any particular intervention improved access in this group. However from their clinical experience the committee knew that access and support could be greatly improved by improving the provision of information and support offered to inequitably served groups. Consequently they made recommendation 4.1.3, 4.1.4, 4.1.5 and 4.1.6 to explicitly ensure that every individual in the brain tumour care pathway had access to adequate support, regardless of social circumstances that might otherwise make it difficult to access this support (such as not speaking English as a first language, or at all), and various other recommendations such as 1.2.14 and 1.2.28 to ensure that patient preferences and circumstances were taken into account during clinical decision-making. Consequently the committee made no specific recommendations on improving access for BAME people, since they had not reviewed evidence on this complex topic and believed that existing recommendations such as 4.1.3, 4.1.4, 4.1.5 and 4.1.6 would promote a national standard such that BAME access needs were better served. As described above, there are also research recommendations aimed at developing an evidence base in topic areas for which there are significant barriers to access and limited evidence currently.

Completed by Developer: Alex Bates, Guideline Lead

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Approved by NICE quality assurance lead: Fiona Glen

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