NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

NICE Centre for Guidelines

Equality and health inequalities assessment (EHIA)

Meningitis (bacterial) and meningococcal disease

The considerations and potential impact on equality and health inequalities have been considered throughout the quality standard development, process according to the principles of the NICE equality policy and those outlined in <u>Quality Standards</u> <u>process guide</u>.

STAGE 1. Topic engagement

Date of completion: 22/11/2023

1.1 What approaches have been used to identify potential equality and health inequalities issues during development of the topic engagement proforma?

Review of the EHIA for the source guideline <u>Meningitis (bacterial) and meningococcal</u> <u>disease : recognition, diagnosis and management. NICE guideline in</u> <u>development.</u> (Publication date expected to be 21 February 2024)

- 1.2 What potential equality and health inequalities issues have been identified during development of the topic engagement proforma?
- 1) Protected characteristics outlined in the Equality Act 2010 (age, disability, gender reassignment, pregnancy and maternity, race, religion or belief, sex, sexual orientation):

Race: There is a potential equality issue for people with black or brown skin, for example of African, African-Caribbean, Middle Eastern and South Asian origin, as the detection of the typical rash associated with meningococcal disease can be harder to identify on black or brown skin.

Disability / race: It is important that parents and carers and people with suspected or confirmed meningitis (bacterial) or meningococcal disease receive accessible information about the symptoms, diagnosis and treatment of meningitis.

Age: Some older people may present with atypical features. Some older people may find accessing care more difficult as services cannot be designed with their needs in mind.

Age: Symptoms in young people can be missed because sometimes the assumption is made that confusion, delirium or aggressive or subdued behaviour may be caused by drink or drugs.

Gender reassignment / pregnancy and maternity / religion or belief / sex / sexual orientation: No issues identified.

2) Socioeconomic status and deprivation (for example, variation by area deprivation such as Index of Multiple Deprivation, National Statistics Socio-economic Classification, employment status, income):

Socio-economic factors: People from lower socio-economic and disadvantaged backgrounds, as well as being at higher risk of disease, experience a higher risk of

loss to follow up. One of the reasons for this is the navigation of a complex care system.

3) Geographical area variation (for example, geographical differences in epidemiology or service provision- urban/rural, coastal, north/south):

Geographical: Meningococcal disease should be considered in people who have recently travelled from countries with the highest burden of disease (meningitis belt of Sub Saharan Africa) and those who have attended large gatherings or events or events (eg pilgrimages, university and sporting events) where there is an increased risk of developing the disease.

4) Inclusion health and vulnerable groups (for example, vulnerable migrants, people experiencing homelessness, people in contact with the criminal justice system, sex workers, Gypsy, Roma and Traveller communities, young people leaving care and victims of trafficking): No issues were identified at this stage of development.

1.3 How can the identified equality and health inequalities issues be further explored and considered at this stage of the development process?

Race: The guideline EHIA notes that recommendations have been written about recognising bacterial meningitis and meningococcal disease and emphasised the need for more careful investigations in order to identify non-blanching rashes on black or brown skin. These highlight the need for practitioners to look for rashes all over the body and include reminders of this throughout the tables of symptoms and signs. If quality statements in this area are taken forward, similar considerations will be made for the quality standard.

Disability / race: The guideline EHIA notes that the guideline refers to the information and support needs of family, parents and carers in a number of recommendations ranging from identification of symptoms, early hospital care, planning for discharge and follow up care. The guideline highlights the importance of sharing and discussing information to ensure it is understood, as well as signposting. The guideline also refers to NICE guidelines on patient experiences in adult NHS services and babies, children and young people's experience of healthcare. If quality statements in this area are taken forward, similar considerations will be made for the quality standard.

Age: The guideline EHIA notes that the guideline recommendations about recognising bacterial meningitis and meningococcal disease emphasise the signs and symptoms that are sometimes missed in older people with delirium, and some symptoms and signs that are more or less common in older adults.

The guideline EHIA notes that although the guidelines does not include specific recommendations about follow up care for older people, the recommendations are

mindful of being inclusive to all needs and ensuring that older people have very clear guidance about what they can expect in terms of follow up investigations and care.

The guideline EHIA notes that recommendations have been included to remind practitioners that symptoms in young people could be indicators of meningitis when seen together with other signs, symptoms and risk factors.

If quality statements in this area are taken forward, similar considerations will be made for the quality standard.

Socio-economic factors: The guideline notes there are a number of recommendations about follow up care, setting out very clearly what a person can expect in terms of follow up care and when. There are also recommendations about what information and support should be offered both before and after confirmation of a diagnosis.

As older people and people from disadvantaged socio-economic backgrounds are at higher risk of being lost to follow-up care and support the recommendations focus on the most critical follow up assessments, information and support needed and to be clear about the responsibilities of the hospital team before discharge to help set these up.

If quality statements in this area are taken forward, similar considerations will be made for the quality standard.

Geographical: The guideline EHIA notes the inclusion of a recommendation to seek advice from an infection specialist for people who have recently travelled outside of the UK to an area with a higher burden of disease, or to a large gathering (eg pilgrimage) and may be at risk of antimicrobial resistance. If quality statements in this area are taken forward, similar considerations will be made for the quality standard.

Further consideration of these, and any additional equality and health inequality issues raised during development of the quality standard, will take place following topic engagement with stakeholders, at the Quality Standards Advisory Committee (QSAC) and throughout development of the quality standard.

1.4 Do you have representation from stakeholder groups that can help to explore equality and health inequalities issues during the topic engagement process including groups who are known to be affected by these issues? If not, what plans are in place to address gaps in the stakeholder list?

Two lay members have been appointed. One has personal lived experience of having meningitis, the other has worked as a director of a meningitis charity.

2 key patient stakeholders identified: Meningitis Research Foundation and Meningitis Now. These stakeholders were identified with input from the NICE Public Involvement Programme.

1.5 How will the views and experiences of those affected by equality and health inequalities issues be meaningfully included in the quality standard development process going forward?

As above, a lay member with lived experience will input into the QS throughout development.

We will work with key patient stakeholders, and actively chase these organisations for a response if needed, to ensure their views are also presented to the committee.

1.6 Has it been proposed to exclude any population groups from coverage by the quality standard? If yes, could these exclusions further impact on people affected by any equality and health inequalities issues identified?

No groups have been excluded at this stage.

Completed by lead analyst: Eileen Taylor

Date: 22/11/2023

Approved by NICE quality assurance lead: Mark Minchin

Date: 30/11/2023

STAGE 2. Consultation

2.1 How inclusive was the topic engagement process in terms of response from stakeholders who may experience inequalities related to the topic (identified in 1.2)?

12 stakeholders and 5 specialist committee members responded at topic engagement. One of the specialist committee members who responded is a lay committee member. The stakeholder organisations included patient organisations, service providers and professional bodies.

NHS England provided responses from 4 of their teams, including the learning disabilities team. Two patient charities also provided responses.

In total, 2 specialist committee members, 2 stakeholders and the QSAC raised 13 areas relating to equalities and health inequalities.

2.2 From the topic engagement exercise and the committee's considerations thereof, what were the main equality and health inequalities issues identified?

1) Protected characteristics outlined in the Equality Act 2010 Age:

There is variation in delirium recognition with many older patients who arrive through the emergency pathway not having an initial assessment. Older adults with frailty often do not present with typical symptoms of bacterial meningitis or sepsis which can easily be missed or mistaken for other problems leading to missed diagnosis and delayed treatment (SCM)

Timely hearing test assessment is not routinely carried out, especially for adults and older people. (SCMs)

There is a lack of follow-up after discharge from hospital, particularly for adults (Stakeholder)

There is a lack of information, particularly for adults, regarding what to expect during recovery and where to access further support. (Stakeholder)

It is important to listen to children and young people if the child has other disabilities already or has new health conditions as a result of these conditions. (Stakeholder) There may also be an issue with transition between services if adult and children and young people's services are different (QSAC) *Disability:*

Reasonable adjustments should be made for people with learning disabilities. (Stakeholder)

Some people may be non-verbal and therefore unable to describe how they feel when speaking to healthcare professionals. (Stakeholder) *Gender reassignment:* None identified by stakeholders or committee *Pregnancy and maternity:* None identified by stakeholders or committee *Race:* It can be difficult to recognise and / or identify meningitis in darker skin. (QSAC) *Religion or belief:* None identified by stakeholders or committee *Sex:* None identified by stakeholders or committee *Sex:* None identified by stakeholders or committee

2) Socioeconomic status and deprivation (for example, variation by area deprivation such as Index of Multiple Deprivation, National Statistics Socio-economic Classification, employment status, income)

People from lower socio-economic backgrounds may need adjustments to ensure they can attend follow-up appointments. (QSAC)

- Geographical area variation (for example, geographical differences in epidemiology or service provision- urban/rural, coastal, north/south) There can be an issue with access to services for people who live in rural and urban areas. (QSAC)
- 4) Inclusion health and vulnerable groups (for example, vulnerable migrants, people experiencing homelessness, people in contact with the criminal justice system, sex workers, Gypsy, Roma and Traveller communities, young people leaving care and victims of trafficking):

It is important that carers are listened to and that parent carers are also cared for. (Stakeholder)

- 5) Please also state if there were any gaps in the guideline recommendations for any particular groups within each of the dimensions above which were highlighted by committee. None identified
- 2.3 How have the committee's considerations of equality and health inequalities issues identified in 1.2 and 2.2 been reflected in the quality standard?

Statement 1 on safety netting advice: The equality and diversity considerations section notes that one of the symptoms of bacterial meningitis or meningococcal disease that should be included in the safety-netting information is a non-blanching rash. It highlights the need for the information to clearly explain how this symptom may present differently depending on skin colour, and how best to identify this rash on different skin tones, such as where on the body to look for it. It also includes some examples of resources that can be used to help people identify this symptom on different skin tones. This helps to address the concerns regarding identifying meningitis in different skin tones.

Statement 4 on audiological assessment: this statement notes that everyone should have prompt audiological assessment following bacterial meningitis or meningococcal disease. This helps to address the concern that there is variation in practice, particularly for adults and older people.

Statement 5 on follow-up: This statement highlights that everyone who has had bacterial meningitis or meningococcal disease should have follow up in secondary care within 6 weeks of discharge from hospital. This helps to address the concern that there is variation in practice, particularly for adults.

The equality and diversity considerations for quality statements 1 and 5 note that people should be provided with information that they can easily read and understand themselves, or with support, so they can communicate effectively with health care services. Information should be in a format that suits their needs and preferences. It should be accessible to people who do not speak or read English, and it should be culturally appropriate and age appropriate. People should have access to an interpreter or advocate if needed. For people with additional needs related to a disability, impairment or sensory loss, information should be provided as set out in NHS England's Accessible Information Standard or the equivalent standards for the devolved nations. This helps to address the concerns about making reasonable adjustments for people and ensuring it is possible for people to communicate with healthcare professionals.

Appointments should be arranged taking into account the person's circumstances, or that of their family members or carers. Where possible appointments should be scheduled to take account of their work patterns so that they do not lose pay unnecessarily by attending.

Areas not addressed in the quality standard:

Age: the additional areas around age (section 1.2 - symptoms in young people can be missed because sometimes the assumption is made that confusion, delirium or aggressive or subdued behaviour may be caused by drink or drugs. Section 2.2 - older adults presenting with symptoms, information provision regarding what to expect during recovery / further, listening to children and young people, transition if adult and children and young people's services are different) have not been addressed in the quality standard. This is because quality statements specific to these areas were not prioritised.

Vulnerable groups: The area raised in section 2.2 around listening to carers, caring for parent carers who may also have other children has not been addressed in the quality standard. This is because quality statements specific to this area were not prioritised.

Geographical: Section 1.2 notes that meningococcal disease should be considered in people who have recently travelled from countries with the highest burden of disease (meningitis belt of Sub Saharan Africa) and those who have attended large gatherings or events or events (eg pilgrimages, university and sporting events) where there is an increased risk of developing the disease. This has not been addressed in the quality standard because quality statements specific to this area were not prioritised.

Geographical: Section 2.2 notes that there can be an issue with access to services for people who live in rural and urban areas. Access in this context relates to availability of facilities which is outside the remit of quality standards and NICE.

2.4 Could any draft quality statements potentially increase inequalities?

No issues regarding this have been identified.

2.5 Based on the equality and health inequalities issues identified in 1.2 and 2.2, do you have representation from relevant stakeholder groups for the quality standard consultation process, including groups who are known to be affected by these issues? If not, what plans are in place to ensure relevant stakeholders are represented and included?

Patient groups including Meningitis Now and the Meningitis Research Foundation are included in the stakeholder list and responded at topic engagement. Efforts will be made to ensure they can also contribute at consultation.

2.6 What questions will you ask at the stakeholder consultation about the impact of the quality standard on equality and health inequalities?

We will be asking stakeholders the following:

Please provide your comments on the equality and health inequalities assessment (EHIA) and the equality and diversity considerations section for each quality statement. Please confirm any issues that have been missed and how they can be addressed by health care services and practitioners.

Completed by lead analyst: Eileen Taylor

Date: 23/04/2024

Approved by committee chair: Dr Sunil Gupta

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Approved by NICE quality assurance lead: Mark Minchin

Date: 10/06/2024

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