NATIONAL INSTITUTE FOR HEALTH AND
CARE EXCELLENCE

Quality standards

Consultation summary report: Meningitis (bacterial) and meningococcal disease update

Quality Standards Advisory Committee post-consultation meeting: 10 September 2024

1. Introduction

The draft quality standard for meningitis (bacterial) and meningococcal disease (update) was made available on the NICE website for a 4-week public consultation period between 25 June and 23 July 2024. 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 14 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. Can data for the proposed quality measures be collected locally? Please include in your answer any data sources that can be used or reasons why data cannot be collected.

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.

4. 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.

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

5. For draft quality statement 4: Due to difficulties in measuring whether a person is well enough for audiological assessment, the quality standard suggests that for measurement purposes, this could take place within 4 weeks of discharge from:

- hospital if the person had an uncomplicated acute admission

- a high dependency area, for example, an intensive care unit or a paediatric intensive care unit.

The quality standard also notes that preferably this assessment should take place prior to discharge.

Are these timescales appropriate and measurable? If they are not, please provide a definition or specific timings when this could occur.

1. General comments

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

* agreement in general with the quality statements within this quality standard
* the quality standard does not adequately emphasise the importance of an accurate and timely diagnosis of meningitis
* a stakeholder felt that as this is a rare condition, more robust guidance on named clinicians needs to be quantified, for example named rehab consultants.

### Consultation comments on data collection (consultation question 2)

* a stakeholder noted that data can be collected.

### Consultation comments on equality and health inequalities (consultation question 4)

* suggestion to include more information about meeting the specific, different presenting needs of children and adults.
1. Summary of consultation feedback by draft statement
	1. Draft statement 1

People sent home after clinical assessment indicates they are unlikely to have bacterial meningitis or meningococcal disease are given safety netting advice. [2012, updated 2024]

### Consultation comments

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

Statement

* agreement with the quality statement in principle
* comment that people are not usually discharged with ‘not bacterial meningitis’
* clarity on the wording of the statement was suggested to show that it relates to people who have been clinically assessed for bacterial meningitis or meningococcal disease and are considered unlikely to have one of these conditions. Otherwise there were concerns that people for whom these conditions would not need to be considered would be given the safety netting advice
* comment that safety netting is standard practice for children who are discharged home after attending with fever. Leaflets can be adapted to include links to online resources and there was a query of whether NICE will suggest which sources to use.

Measures

* current measurement is not practical
* some data is already routinely collected as part of the Emergency Care Data Set (ECDS)

Audience descriptors

* the audience descriptor states the information should be given if appropriate. Comment that it is always appropriate to make parents and carers aware of symptoms of serious illnesses such as meningitis therefore if appropriate should be removed.

 Definitions

* there was a suggestion for NICE to define what good quality information to patients should contain.

Equality and diversity considerations

* brief safety netting advice given in busy clinical settings may not be understood properly by vulnerable people with communication difficulties, for example people living with cerebral palsy and learning difficulties. Suggestion for guidance on safety netting advice for these vulnerable groups
* quality standard states non-blanching rash and the equality and health inequalities assessment refers to pale, mottled skin or cyanosis being difficult to see on different skin tones, this needs to be consistent
* the Bliss and Meningitis Research Foundation information linked relates to children with no information linked relevant to adults.

### Issues for consideration

#### For decision:

* does the quality statement need to be reworded to make it clear the safety netting advice is only given when people have been assessed for bacterial meningitis or meningococcal disease, for example, People sent home after clinical assessment for bacterial meningitis or meningococcal disease indicates they are unlikely to have one of these conditions are given safety netting advice?
* are additional equality and diversity considerations needed? A stakeholder noted that vulnerable people with communication difficulties may not understand the brief information given in a busy clinical setting. Please review the current considerations which highlight the importance of information being easy for the person to read and understand, as well as the additional information on the NHS England Accessible Information Standard. Any additional information added to the equality and diversity considerations section needs to be specific to this topic and not to general information provision.
	1. Draft statement 2

People with suspected bacterial meningitis do not have neuroimaging before lumbar puncture unless clinically indicated. [New 2024]

### Consultation comments

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

Statement

* mixed views on whether this statement would ensure that lumbar puncture (LP) is carried out as soon as possible, and before antibiotics are administered, with comment that in most emergency departments antibiotics will be commenced first and that organising a LP takes time
* suggestion to highlight that it is routine neuroimaging that should not be carried out and to clarify that imaging should not be undertaken to rule out raised intracranial pressure, as this should be a clinical diagnosis
* this may not increase the overall rates of LPs being performed or blood samples taken prior to administration of antibiotics
* suggestion to highlight in the statement that the person should not have any risk factors for an evolving space-occupying lesion, or symptoms or signs of raised intracranial pressure
* comment that it may be helpful to specify that infants with open fontanelles may present or behave with raised intracranial pressure differently.

Measures

* suggestion to reword to include confirmed and suspected bacterial meningitis
* suspected bacterial meningitis is part of the ECDS dataset, as are ‘suspected viral meningitis’ and ‘suspected encephalitis’. These conditions have overlapping symptoms and, at the point of making a diagnosis in the emergency department, when not all test results are back, there may be a certain randomness to which of these diagnoses is chosen. This will lead to concerns about data quality
* process b – suggestion to state ‘valid’ clinical indication.

Definitions

* 'clinically indicated' is inadequately defined as the risk factors, symptoms and signs are more difficult to identify than the quality standard suggests
* it would be helpful to give examples of risk factors for an evolving space-occupying lesion.

Equality and diversity considerations

* the quality standard assumes people will have capacity and give consent but there can be significant issues due to previous trauma with invasive procedures, such as injections or LP, meaning reasonable adjustments may be needed.

### Issues for consideration

#### For discussion:

* the definition of ‘clinically indicated’ is taken from the guideline recommendation. Is the definition clear enough? Are risk factors for an evolving space-occupying lesion or the signs of raised intracranial pupillary reactions in the definition relatively easy to recognise for a clinician or is a specific speciality needed to identify these?
* comment that a clinical assessment for raised intracranial pressure needs to take place. Would this be carried out and documented prior to LP?
* comment received that suspected bacterial meningitis, suspected viral meningitis and suspected encephalitis have overlapping symptoms and, at the point of making a diagnosis in the emergency department, when not all test results are back, there may be a certain randomness to which of these diagnoses is chosen. Is this the case and what is the impact of this on the quality standard?

#### For decision:

* based on feedback at consultation, should the quality statement remain in the quality standard?
	1. Draft statement 3

People with suspected bacterial meningitis or suspected meningococcal disease receive intravenous antibiotics within 1 hour of arrival at hospital. [2012, updated 2024]

### Consultation comments

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

General

* agreement that prompt antibiotic treatment is important but concerns were raised regarding a potential contradiction with the NICE guideline on sepsis which has a more nuanced approach to antibiotics, based on a NEWS2 score. This does not require antibiotics to be given to all people with suspected sepsis within 1 hour as this is based on risk of severe illness or death.
* the statement should acknowledge this only relates to those people who did not receive antibiotics prior to arrival at hospital
* there can be differences in opinion of when a person arrives at hospital and suggested this is clearly defined, for example the time they register at the hospital
* suggestion that the statement should include the specific antibiotics to be given.

Measures

* should the measure be confirmed and suspected bacterial meningitis or meningococcal disease
* as previously noted, we received comments that suspected bacterial meningitis and suspected meningococcal disease are part of the ECDS dataset and that due to overlapping symptoms there may be a certain randomness to the diagnosis chosen.

### Issues for consideration

#### For discussion:

* stakeholder suggested the measure should be confirmed and suspected bacterial meningitis or meningococcal disease. Is it likely that there would be a confirmed diagnosis of bacterial meningitis before antibiotic administration if this was done within 1 hour of arrival at hospital?

#### For decision:

* should a definition of arrival at hospital be included? If so, the following was suggested by an SCM previously, and this can be discussed and agreed at the committee meeting:

Arrival at hospital can be defined as:

* on check in to the emergency department, hospital assessment unit or acute admission ward if the person has been referred with suspected meningitis by an external healthcare professional, such as GP, nurse, pharmacist or, paramedic
* from time of triage if the person arrived at the emergency department without being referred by an external healthcare professional
* comments were received that this quality statement, and the corresponding source guidance recommendations, contradict the sepsis guideline recommendations. This will be discussed at the committee meeting. The NICE team are obtaining input from NICE clinical advisers and will feed this back at the meeting.
	1. Draft statement 4

People who have had bacterial meningitis or meningococcal disease are offered an audiological assessment within 4 weeks of them being well enough for testing. [2012, updated 2024]

### Consultation comments

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

General

* agreement that this is an important statement, with a suggestion to merge with statement 5
* comment that people sometimes wait longer than 4 weeks, with a query on whether availability of appointments for audiology assessment is an issue in some areas
* concern that audiology services may be delivered by community trusts and hospital follow-ups and that if they are not well organised, this could cause the transfer of work to primary care.

### Consultation question 5

Due to difficulties in measuring whether a person is well enough for audiological assessment, the quality standard suggests that for measurement purposes, this could take place within 4 weeks of discharge from:

- hospital if the person had an uncomplicated acute admission

- a high dependency area, for example, the intensive care unit or paediatric intensive care unit.

The quality standard also notes that preferably this assessment should take place prior to discharge.

Are these timescales appropriate and measurable? If they are not, please provide a definition or specific timings when this could occur.

Stakeholders made the following comments in relation to consultation question 5:

* nothing has been omitted
* ‘uncomplicated admission’ should be defined
* disagreement that being fit for discharge is the only way to define being well enough for audiological assessment and concern that this would miss those people who had an appointment before discharge.

### Issues for consideration

#### For discussion:

* concern that if audiology services weren’t available, primary care would be responsible for carrying this out. Is this the case?

#### For decision:

* a robust definition, for measurement purposes, of being well enough for testing is needed if this statement is to remain in the quality standard. Few comments were received from stakeholders on the draft definition, this can be discussed at the committee meeting.
	1. Draft statement 5

People who have had bacterial meningitis or meningococcal disease have a follow-up appointment in secondary care within 6 weeks of discharge from hospital. [2012, updated 2024]

### Consultation comments

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

General

* agreement with the inclusion of this quality statement, with comments that this often does not happen for adults
* stakeholders noted different complications that can be caused by bacterial meningitis or meningococcal disease, commenting that people should be assessed for all of them. These include assessment of mobility, activities of daily living, communication, cognition, mood, weakness, spasticity, seizures, control of bladder and bowel and adjustment to hearing changes where appropriate. Referral to specialised rehabilitation is needed for these conditions
* some comments asking which healthcare professional would be best placed to carry out the assessment, due to the variety of issues to be considered
* adults can be treated in a variety of ward settings, and many health professionals will have little experience in treating a patient with meningitis. A stakeholder queried how the requirement for follow-up would be communicated to relevant healthcare professionals

Resource impact

* follow up in secondary care within 6 weeks may be difficult to achieve due to waiting time pressures in the paediatric population meaning additional resources may be needed to achieve this

Equality and diversity considerations

* people may need reasonable adjustments as a result of the impact of the illness, or the adjustments they need may change because of the illness
* risk of significant issues for people with a learning disability in arranging follow-up. This population are known to have significant issues accessing healthcare with many relying on others and these issues are compounded for those from ethnic communities.

### Issues for consideration

#### For discussion:

* clarification of which healthcare professionals would carry out this follow-up appointment. The guideline specifies a paediatrician for babies, children and young people and a hospital doctor for adults
* should the equality and diversity considerations be amended to include the issues raised around the difficulties faced by people with a learning disability?
* comment that this may cause a resource impact issue in paediatric secondary care, is this likely to be the case?
1. Suggestions for additional statements

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

### Steroids

A stakeholder commented that steroid indications in bacterial meningitis are not covered in the quality standard.

The use of steroids was discussed at the first quality standards advisory committee and was not prioritised for inclusion in the quality standard. This was because the use of specific steroids suggested by stakeholders was not considered to be a key area for quality improvement. In addition, the committee also noted limited evidence of the impact of steroids in preventing hearing loss in people strongly suspected of having meningitis.

### Primary care

A stakeholder commented that the quality standard does not include the actions to be taken if meningitis is identified in primary care, particularly around ensuring antibiotic administration within 1 hour.

This was discussed at the first quality standards advisory committee and was not prioritised for inclusion in the quality standard due to concerns about the measurability of a statement covering antibiotics administered before arrival at hospital.

### Additional guidance

A stakeholder felt a key area for quality improvement is the management of long-term complications after meningitis, noting that there is currently no guideline for management of longer term complications. Another noted that there are no specific guidelines about safety netting advice for people living with long term disabilities.

Guideline development is outside the remit of quality standards. The comments will be passed on to the guideline development team for consideration.

Within the quality standard, it is anticipated that long-term conditions not identified prior to discharge from hospital would be identified at the follow-up appointment detailed in quality statement 5 and relevant referrals made.

In addition, the equality and diversity considerations section of quality statement 1 on safety netting advice highlights the importance of ensuring the information given suits the person’s needs and highlights the importance of meeting the requirements of [NHS England's Accessible Information Standard](https://www.england.nhs.uk/ourwork/accessibleinfo/).

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

| ID | Stakeholder | Section | Comments |
| --- | --- | --- | --- |
| General comments |
| 1 | British Society of Physical and Rehabilitation Medicine | General  | The guidelines do not include statements on screening for longer term disabilities like weakness, spasticity, cognitive issues and communication difficulties. |
| 2 | Faculty of Intensive Care Medicine | General | Thank you for the opportunity to comment on this draft quality standard. The FICM Professional Affairs and Safety Committee provided feedback on question 1 only.  |
| 3 | Meningitis Research Foundation | General | Whilst we largely agree with the quality statements within this quality standard, we feel that as a whole, the Quality Standards do not adequately emphasise the importance of an accurate and timely diagnosis of meningitis.Accurate and timely diagnosis of meningitis was an area which stakeholders deemed extremely important in their suggestions on key areas for quality improvement, yet this is not proportionately reflected in the final quality standard. For example, there were a total of 15 comments supporting improvements to the timing and accuracy of diagnostic testing within the areas of CSF & blood samples (4), unnecessary CT scans (5) and reducing time to LP (6), with only 1 quality standard reflecting this. In comparison, 2 quality standards in the area of after-care (Statements 4 and 5) reflect 8 stakeholder comments identifying these as key areas for quality improvement. Whilst we agree that improvements to after care are vital, there is a risk that if meningitis is not confirmed in the first place, then patients might not receive any follow up at all, regardless of what quality statements exist in this key area. Accurate and timely diagnosis is vital for antimicrobial stewardship, driving appropriate acute treatment for patients and providing them with the diagnosis they need for access to appropriate follow-up care. As diagnosis is key to appropriate downstream patient care and could therefore have an impact on a larger number of patients, we would like to see a statement about the importance of performing timely LP and blood samples included in the QS. |
| 4 | NHS England – Clinical Programme Team | General | Need to emphasize the importance of reasonable adjustments and accessible communication throughout the standard, ensuring care is tailored to meet people’s needs. If the Quality Standard is all age does it need to include more information about meeting the specific (different) presenting needs of children and adults? Deterioration can be more acute in people with a learning disability and clinicians should be acting more quickly where people have a learning disability to escalate concerns.The guidance appears to assume a patient will have capacity / give consent. There can be significant issues relating to previous trauma in contact with health care for invasive procedures such as injections – lumbar puncture etc. Guidance would be strengthened with reference to reasonable adjustments for blood tests and lumbar puncture. Given known issues around diagnostic overshadowing with people with a learning disability it would be helpful to give a low threshold (assuming clinically safe) for proceeding with treatment – similarly for autistic people who may not be able to describe symptoms. In line with the diagnostic overshadowing – consider comorbidities and impact on signs well as race – does a petechial rash present as clearly in all case?  |
| 5 | Royal College of Nursing - Emergency Care Forum Committee | General | As above – this is a rare condition. More robust guidance on named clinicians need to be quantified i.e. Ambulance Service to receiving department Named Rehab consultants. Physician to Audiology. |
| 6 | UK Health Security Agency | General | Pages 7 and 11 refers to ‘Adapted’ from NICE’s guidelines on meningitis (bacterial) and meningococcal disease: recognition, diagnosis and management’ in what way is text being adapted? Shouldn’t this be a straightforward reference to NICE? |
| Question 1 responses  |
| 7 | Association of Paediatric Emergency Medicine (APEM) | Question 1 | Yes, but we are wondering where the standard sits with the current move towards targeting antibiotics in people who aren’t in septic shock and aiming to give antibiotics between 1 and 3 hours? |
| 8 | Faculty of Intensive Care Medicine | Question 1 | No, this draft quality standard does not accurately reflect the key areas for quality improvement.(See quality statements 2 & 3 for FICM comments) |
| 9 | Meningitis Now | Question 1 | We agree that the draft quality standard reflects the key areas for improvement. In particular, safety netting information, hearing assessment and follow-up are often problematic for those who we support. |
| 10 | Royal College Emergency Medicine | Question 1 | No comments |
| 11 | Royal College of Nursing - Emergency Care Forum Committee | Question 1 | Reflects key areas of Quality Improvement (QI) but time of re-assessment of standard needs to be quantified. |
| Question 2 – data collection |
| 12 | Royal College Emergency Medicine | Question 2 | No comments |
| 13 | Royal College of Nursing - Emergency Care Forum Committee | Question 2 | Yes. However, key departments in each organisation responsible for Multi-disciplinary Team (MDT), data sharing agreements, audit standards and local QI could be quantified or at least given and a guide example. |
| 14 | [Royal College of Paediatrics and Child Health](http://niceplan2/guidelines/Stakeholders.aspx?GID=2521&PreStageID=9341)   | Question 2 | I am being conservative on that  |
| Question 3 – resource impact |
| 15 | Royal College Emergency Medicine | Question 3 | No comments |
| Question 6 – challenges using the guideline |
| 16 | Meningitis Now | Question 5 | We believe, that given meningitis is a relatively rare disease, ensuring that all relevant health professionals are aware of these standards may be problematic. This may be more challenging in adult settings, where many health professionals have less experience in treating/caring for patients with meningitis or meningococcal disease. As a charity, we are keen to help in the promotion of these quality standards in whatever way we can.  |
| 17 | Royal College Emergency Medicine | Question 5 | No comments |
| 18 | Royal College of Nursing - Emergency Care Forum Committee | Question 5 | Yes. we have no further comments on this matter.  |
| 19 | [Royal College of Paediatrics and Child Health](http://niceplan2/guidelines/Stakeholders.aspx?GID=2521&PreStageID=9341)   | Question 5 | 1.Climate Change is a challenge for spread and management of bacterial meningitis and meningococcal disease2. The wars especially, the devastating war in Palestine which targets children, women, men, neonates, elderly, hospitals, health centres, medical and nursing staff and the unjust blockade on food, medicine and water which violated all the recommendations of United Nations, WHO, UNICEF and human Rights is the greatest challenge to implementing of this guidelines  |
| Statement 1 |
| 20 | Association of Paediatric Emergency Medicine (APEM) | Statement 1 | Safety netting is standard practice for children who are discharged home after attending with fever. Leaflets can be adapted if necessary to include links to online resources. Will NICE be suggesting which online sources of information can be used? |
| 21 | British Society of Physical and Rehabilitation Medicine | Statement 1 | Safety netting advice: This is currently done in clinical practice. The issue is that the brief safety netting advice given in busy clinical settings may not be understood properly by vulnerable people with communication difficulties such as people living with cerebral palsy, learning difficulties, those with language of communication other than English. The statement should include guidance on safety netting advice for these vulnerable groups.There should be a more robust advice for people who are immunocompromised such as those on steroids, disease modifying drugs for multiple sclerosis, cancer etc. |
| 22 | Meningitis Now | Statement 1 | Data Source: will assessment be dependent on the quality and consistency of information recorded by individual health practitioners in the patient records? How will these variables this be accounted for? |
| 23 | Meningitis Research Foundation | Statement 1 | We are very pleased to see this quality standard include a statement about the importance of safety netting advice. Within the quality standard there is wording that says “Healthcare professionals (such as GPs and emergency department clinicians) provide safety netting advice to people who are being sent home after clinical assessment without a diagnosis of bacterial meningitis or meningococcal disease, and their parents and carers **if appropriate**”.  We would argue that it is always appropriate to make parents and carers aware of symptoms of serious illnesses such as meningitis and so suggest that the words if appropriate are removed. We would also advise that the word “clinical” should be replaced with the word assessment (including full clinical evaluation and investigations as indicated). In young children, clinical assessment alone is often not adequate to exclude meningitis or sepsis and tests are required.  |
| 24 | NHS England -Antimicrobial Prescribing and Medicines Optimisation Team | Statement 1 | Should the quality statement read ‘People *with suspected bacterial meningitis or meningococcal disease* who are sent home after clinical assessment indicates that they are unlikely to have bacterial meningitis or meningococcal disease are given safety netting advice’? Otherwise it reads that any patient who is clinically assessed (perhaps for headache/migraine) and who is unlikely to have bacterial meningitis will need to be given safety netting advice about bacterial meningitis/meningococcal disease, when this was never a possible differential diagnosis? “Denominator – the number of people sent home after clinical assessment shows it is unlikely that they have bacterial meningitis or meningococcal disease” – see above point. Suggest this should be narrowed down to only include those where there was a clinical suspicion of meningitis rather than all patients discharged who are unlikely to have meningitis?Would it make sense to define what good quality information to patients should contain rather than having the current very unspecific recommendation to give “advice” on signs / symptoms to look out for and when to return to hospital? The bliss MRF information linked only pertains to children with no information linked relevant to adult patients.  |
| 25 | NHS England – Clinical Programme Team | Statement 1 | Greater reassurance for children and families needed. It’s very transactional at a very difficult time for people and their families and carers. What if there are disagreements? Should Martha’s Rule be referenced here?4.5 Information and support – this links to earlier general statement about diagnostic overshadowing and impact of co morbidities on signs and symptoms, information should include spotting signs of acute deuteriation – and provided to families / paid carers  and adhere to the NHS Accessible Communication standard.  |
| 26 | Royal College Emergency Medicine | Statement 1 | Quality statement 1: Safety netting adviceAgree in principle, however as patients tend to present with symptoms rather than labels. Similarly, they do not get discharged home with labels of ‘not bacterial meningitis’; effectively this standard almost becomes meaningless. There is significant complexity when considering children. A standard that references discharging patients who present with a fever or rash might be more practical.MeasurementAs currently configured measurement is not practical. We note specifically that the suggested data collection makes no use of information that is already routinely collected as part of the Emergency Care Data Set (ECDS) submission required of all emergency departments. |
| 27 | Royal College of General Practitioners   | Statement 1  | We believe that GP access and the delays due to workforce challenges require attention, as it is important to be able to identify who among the presenting patients may have meningitis. The entire system, including 111/999 and other services, need to work collectively to reduce long delays that impact individual patient health. Additionally, it is important to consider all elements of safety netting as we would for other conditions, as well as descriptions of red flag symptoms. |
| 28 | UK Health Security Agency | Statement 1 | Under ‘Equality and diversity considerations’ on page 7 it states ‘non-blanching rash’, NICE also refers to ‘Pale, mottled skin or cyanosis may be difficult to see on brown, black or tanned skin’ |
| Statement 2 |
| 29 | Association of Paediatric Emergency Medicine (APEM) | Statement 2 | We wondered if it may be sensible to reorganise the statement to read: People with suspected bacterial meningitis should have lumbar puncture before neuroimaging if they do not have any risk factors for an evolving space-occupying lesion, or symptoms or signs of raised intracranial pressure. We also wondered if it would be helpful to stipulate that infants with open fontanelles are a different group of patients who may present or behave with raised intracranial pressure differently.  |
| 30 | Faculty of Intensive Care Medicine | Statement 2 | **Quality Statement 2**The Faculty of Intensive Care Medicine's Professional Affairs and Safety (FICMPAS) Committee has concerns regarding the guidance standard that *'People with suspected bacterial meningitis do not have neuroimaging before lumbar puncture unless clinically indicated.'*'Clinically indicated' is inadequately defined for this to be a meaningful sentence.*'Risk factors for an evolving space-occupying lesion'* or *'any of these symptoms or signs of raised intracranial pupillary reactions'* are far less easy to identify than the guidance recognises.It would be useful to give examples of risk factors for an evolving space-occupying lesion as we do not think this can be presumed knowledge. Clarity would also be essential from an audit perspective, which is what you are trying to promote in relation to these standards.Our main concern is that as a guidance statement it perhaps is defensible but as an audit standard it is not.In real world terms we are concerned the guidance (and worse the planned audit) on - lumbar puncture before neuroimaging will become ‘lumbar puncture must occur before antibiotics’ which means patients will have delay before receiving lifesaving antibiotics.We understand the science, but we consider the guidance inadequately accounts for how, where and when the guidance must be used, i.e. the reality of the emergency department and hospital environment.Organising a lumbar puncture and finding those with the skills to rapidly and safely perform one, takes time and resources. In comparison, CT scans do not.Trying to organise a lumbar puncture risks delaying antibiotics in ways that a CT scan is much less likely.Long and well [established intensive care clinical practice](https://www.nbt.nhs.uk/sites/default/files/ICU%20Lumbar%20Puncture%20LocSSIP.pdf) is to CT scan, or at least consider very carefully, before lumbar puncture.We strongly consider that the priority treatment is the commencement of antibiotics/antivirals as soon as there is a suspicion of meningoencephalitis; i.e. before lumbar puncture or CT scan; especially in patients with altered GCS or neurology. This we consider is the safest, pragmatic and professionally defensible course of action. We accept that the patient cohorts for which you are trying to provide guidance are not the same as intensive care patients (our cohort). However, the real world conditions healthcare professionals will be working in when applying your guidance will mean they risk being left confused and morally distressed by the decision making burden; and patients will be placed at risk by antibiotic/antiviral delay.At the very least we do not think lumbar puncture before neuroimaging is robust enough to be a quality standard that is audited.We would value the specific opinion of the Royal College of Emergency Medicine on this issue, especially if they can provide some ‘real world’ feedback.  |
| 31 | Meningitis Research Foundation | Statement 2 | We agree that this statement is important for reducing delays to LP. The word “routine” should be added prior to neuroimaging. Also imaging should not be undertaken to rule out raised intracranial pressure. We are not sure that this statement in isolation addresses the priority of ensuring that an LP is carried out/blood sample taken before antibiotics are administered as soon as possible.  |
| 32 | Meningitis Research Foundation | Statement 2 | Quality statement 2 could help reduce delays to LP which is vital to improving the diagnosis of meningitis. However, this QS on its own does would not increase overall rates of LPs being performed or blood samples taken prior to administration of antibiotics, which is the key action required in order to increase confirmed cases of meningitis and identify the causative pathogens. We also consider that scans are often undertaken in the mistaken belief that they will show whether it is safe to perform a LP. The quality statement should make it clear that raised intracranial pressure is a clinical diagnosis.  |
| 33 | NHS England – Clinical Programme Team | Statement 2 | The guidance appears to assume a patient will have capacity / give consent. There can be significant issues relating to previous trauma in contact with health care for invasive procedures such as injections – lumbar puncture etc. Guidance would be strengthened with reference to reasonable adjustments for blood tests and lumbar puncture.  |
| 34 | Royal College Emergency Medicine | Statement 2 | Quality statement 2: Lumbar punctureBroadly agree in principle, however the reality in most emergency departments is that if bacterial meningitis or meningococcal disease is suspected then antibiotics will be commenced before LP is performed (this highlights the tension between quality statement 2 and quality statement 3). Whilst this widespread practice might be at odds with the NICE recommendations ([Recommendations | Meningitis (bacterial) and meningococcal disease: recognition, diagnosis and management | Guidance | NICE](https://www.nice.org.uk/guidance/ng240/chapter/Recommendations#recognising-bacterial-meningitis-and-meningococcal-disease) 1.4.9) it is pragmatic given the logistical and resource issues of getting an LP performed within 1 hour of arrival at hospital triggered based on symptoms and clinical assessment alone. The usual course of events would be antibiotics given +/- antivirals, neuroimaging if indicated and then LP later on, usually performed by the admitting medical team. We would therefore question the stated rationale that performing lumbar puncture without delay reduces the time in starting antibiotic treatment.MeasurementShould this be confirmed and suspected bacterial meningitis ? Suspected bacterial meningitis is part of the ECDS dataset, as are ‘suspected viral meningitis’ and ‘suspected encephalitis’. All three conditions have overlapping symptoms and at the point of selecting a diagnosis in the emergency department, when not all test results are back, there may be a certain randomness to which of these diagnoses is chosen. This will lead to concerns about data quality. |
| 35 | UK Health Security Agency | Statement 2 | Page 9 under Data source part b) - should it be ‘valid’ clinical indication? |
| Statement 3 |
| 36 | Association of Paediatric Emergency Medicine (APEM) | Statement 3 | We feel that this may difficult to achieve in the more well group of children in whom meningitis may be suspected and who require lumbar puncture prior to antibiotics. Obviously in children with septic shock or features of raised intracranial pressure there will be no challenge. We also wondered where this sits with the current move towards targeting antibiotics in people who aren’t in septic shock and aiming to give antibiotics between 1 and 3 hours? |
| 37 | Faculty of Intensive Care Medicine | Statement 3 | **Quality Statement 3**We do not disagree with the timing of antibiotics, and its auditing, but would highlight that the approach seems different to recent antibiotics sepsis guidance by NICE and the AoMRC. This guidance emphasised the use of NEWS2, and highlighted that the evidence base for one hour administration of antibiotics was less than has been previously advocated.  There is a high risk of confusion or perceived contradiction here. |
| 38 | NHS England -Antimicrobial Prescribing and Medicines Optimisation Team | Statement 3 | This standard contradicts the NICE guidance on sepsis, which is advocating a more nuanced approach to immediate antibiotics based on the NEWS2 score.It also appears that the guidance (and therefore this quality standard statement) is extrapolating the evidence on outcome data on timing of antibiotics for patients with bacterial meningitis and / or meningococcal sepsis to a wider group of patients with “suspected” bacterial meningitis and / or meningococcal sepsis and assuming that there will be the same risk/benefit ratio in both groups – this wouldn’t be expected to be true and is challenging to monitor as there is no clear definition of “suspicion of meningitis” within the standards. There will be patients who are relatively well in whom there is a low level of suspicion of meningitis, which would not necessitate antibiotics within an hour, but some thought / investigation. How is this accounted for in the quality standards to support targeting quick antibiotic administration to those most likely to benefit whilst avoiding the harms associated with overtreatment in those unlikely to benefit?Does this statement still hold true if the patient has received antibiotic treatment in community prior to transfer to hospital (e.g. IM benzylpenicillin)? |
| 39 | NHS England – Clinical Programme Team | Statement 3 | What if the triage does not work or the ambulance waits mean children and adults cannot get the antibiotics within an hour? Is this covered in another standard to reduce the risk?Noted statement on reasonable adjustments and language and communication – they should be actively part of the standard to ensure that people can access the support they need – too often people are not given access to tests because they are perceived to present as challenging or not giving consent when actually no adjustments have been made.    |
| 40 | Meningitis Research Foundation | Statement 3 | We agree that this is a very important quality statement for inclusion |
| 41 | Royal College of General Practitioners | Statement 3 | There has been a change from giving antibiotics through IM as opposed to now using IV routes. We do not feel that GP is set up to give IV antibiotics and that delays may be caused by attempts to vaccinate when the patient could be transferred to a more appropriate setting. We question the evidence around this and are concerned about the impact of delivering this in general practice. The estimated time of reaching the hospital within an hour is further complicated by rurality and ambulance response times.  |
| 42 | Royal College Emergency Medicine | Statement 3 | Quality statement 3: Antibiotic treatmentAgree. There is no reference to in the standard regarding patients who have had pre-hospital antibiotics.MeasurementShould this be confirmed and suspected bacterial meningitis, meningococcal disease ? Suspected bacterial meningitis and suspected meningoccocal disease are part of the ECDS dataset, as are ‘suspected viral meningitis’ and ‘suspected encephalitis’. All three conditions have overlapping symptoms and at the point of selecting a diagnosis in the emergency department, when not all test results are back, there may be a certain randomness to which of these diagnoses is chosen. This will lead to concerns about data quality. |
| 43 | Royal Pharmaceutical Society | Statement 3  | The statement of receiving IV antibiotics 1hr after arrival at hospital is a little loose. When a patient thinks they arrive and when different members of the multidisciplinary team think they have arrived is always varied. Considering this is a disease of reasonably high mortality and morbidity it may be best to be more directed e.g. 1 hr of registering at the hospital. |
| 44 | Royal Pharmaceutical Society | Statement 3  | This statement currently just say ‘receive antibiotics’. There are different antibiotics depending on the circumstances (allergy, neonates, listeria etc) and thus as a minimum it should be “all appropriate antibiotics” unless all are happy that it is the major antibiotic that must be within 1hr. |
| Statement 4 |
| 45 | Association of Paediatric Emergency Medicine (APEM) | Statement 4 | No comments |
| 46 | Meningitis Now | Statement 4 | We are aware of people waiting for longer than 4 weeks (of being well enough for testing). Will availability of appointments for audiology assessment be an issue in some areas thereby preventing timely assessment? |
| 47 | Meningitis Research Foundation | Statement 4 | We agree that this is an important statement, but think that it would be possible for this to be covered by statement 5 by including additional wording to that QS. This would free up space for an additional QS that covers the importance of performing timely LP and blood samples and ensuring a clinical assessment for raised intracranial pressure |
| 48 | Royal College Emergency Medicine | Statement 4 | No comments |
| 49 | Royal College of General Practitioners | Statement 4  | We are concerned that many audiology services may be delivered by community trusts and hospital follow-ups, when not organised well, could cause the transfer of work to primary care. This will result in an unacceptable workload for primary care and delays to the process. |
| Question 5 (on statement 4)  |
| 50 | Royal College Emergency Medicine | Question 5 | No comments |
| 51 | Royal College of Nursing - Emergency Care Forum Committee | Question 5 | Nothing has been omitted.  |
| 52 | UK Health Security Agency | Question 5 | Page 14 under Process part a) - please define ‘uncomplicated’. Where it states ‘within 4 weeks of discharge from hospital’ - NICE states '.12.7Offer an audiological assessment within 4 weeks of the person being well enough for testing (and preferably before discharge).' Are we saying that being fit for discharge is the only way of defining as patient as being 'well enough'. Also, this measurement would miss those that had an earlier appointment (accept numbers may be small given that such services are not widely available) |
| Statement 5 |
| 53 | Association of Clinical Psychologists | Statement 5 | ACP-UK is pleased to see that there is now reference that there must be a follow up and an assessment, which would look to identify psycho-social, neurological, neurodevelopmental aspects, and that would be used to make onward referrals.   |
| 54 | Association of Clinical Psychologists | Statement 5 | ACP-UK is also pleased that there is acknowledgment of post-infection review and care. However, we feel it should be more specific and robust in terms of a review of mood/cognition and adjustment to hearing changes (if appropriate), and around post-severe illness adjustment for the individual and family, which is particularly significant in children and young people. |
| 55 | Association of Paediatric Emergency Medicine (APEM) | Statement 5 | No comments |
| 56 | Association of Paediatric Emergency Medicine (APEM) | Statement 5 | Follow up in secondary care within 6 weeks as per statement 5 may be difficult to achieve due to current waiting time pressures in the paediatric population. Additional resources may need to be put in place to achieve this.  |
| 57 | British Society of Physical and Rehabilitation Medicine | Statement 5 | Assessment during follow up should include assessment mobility, activities of daily living, communication, cognition and control of bladder and bowel. If the patient has any such issues, they need referral to a specialized rehabilitation medicine team. |
| 58 | British Society of Physical and Rehabilitation Medicine | Statement 5 | People with meningitis develop longer term complications such as weakness, spasticity, seizures and cognitive impairment in addition to audiological issues. Please include guidance for all patients to be assessed for mobility, activities of daily living and cognition prior to discharge. If the patient was found to have anu of these issues please refer to a specialist rehabilitation medicine team. They may need transfer to a specialist rehabilitation facility or ongoing community rehabilitation. |
| 59 | Meningitis Now | Statement 5 | We are pleased to see a quality standard relating to follow-up. This is an area which has been problematic, particularly for adults who have had bacterial meningitis or meningococcal disease, who often report no follow-up after discharged from hospital. However, how will the requirement for follow-up be communicated to the relevant health professionals, given that adult patients can potentially be treated in a variety of ward settings, and that many health professionals will have little experience in treating a patient with meningitis? |
| 60 | Meningitis Research Foundation | Statement 5 | We are pleased to see inclusion of this quality statement on follow-up care, but think this could be amended so that hearing tests are also covered E.g People who have had bacterial meningitis or meningococcal disease have a follow-up appointment in secondary care within 6 weeks of discharge from hospital which includes a discussion about results from hearing tests.  |
| 61 | NHS England -Antimicrobial Prescribing and Medicines Optimisation Team | Statement 5 | Who should this follow up appointment be with? The discharging team, the neurology team, someone else? Given the variety of the issues to be considered in the review (bones & joint damage, neurological problems, psychosocial problems etc.), who is best placed to conduct the review? |
| 62 | NHS England – Clinical Programme Team | Statement 5 | Re discharge – everyone to be invited for a follow up – risk of significant issues for people with a learning disability “21% of people with bacterial meningitis arranged a follow up appointment themselves and 26% did not have follow up but stated they would have liked this.” When they are known to have significant issues accessing healthcare – with many relying on others and for those from ethnic communities these issues are compounded. At the very least, everyone who is either a) on GP learning disability register or b) has a reasonable adjustment digital flag on their health record.  |
| 63 | NHS England – Clinical Programme Team | Statement 5 | Care after hospital discharge – will this include reference to reasonable adjustments – people may need reasonable adjustments as a result of the impact of the illness or they may have changed.  |
| 64 | Royal College Emergency Medicine | Statement 5 | No comments |
| Additional areas |
| 65 | British Society of Physical and Rehabilitation Medicine | Additional areas | A key area for quality improvement is management of long term complications after meningitis. The patients with meningitis are oftem managed by the infectious disease teams or acute medical teams . The current practice is to complete the course of antibiotics and discharge. Unfortunately around 20% experience long term sequalae. The document has no mention about long term sequalae other than audiological damage. Around 20% suffer from long term complications such as weakness, cognitive decline, spasticity, seizures. Currently, there is no guideline for management of longer term complications. This draft do not address this key aspect which requires improvement. Reference: https://doi.org/10.1016/S1473-3099(10)70048-7. |
| 66 | British Society of Physical and Rehabilitation Medicine | Additional areas | Specific guidelines about safety netting advice for people living with long term disabilities. |
| 67 | Royal College of Nursing - Emergency Care Forum Committee | Additional areas | There is mention of primary care (PC). There is no mention of urgent primary care (UPC) (Out of Hours – (OOHs)) settings. There is no mention of Intravenous (IV) in the community or establishing IV access whilst awaiting emergency transfer. There is no mention of transfer delay action plans including Intramuscular Injections (IM) antibiotics or telephone consultation advice between PC or UPC OOHs with community staff experiencing delays of achieving golden hour antibiotics administration.  |
| 68 | [Royal College of Paediatrics and Child Health](http://niceplan2/guidelines/Stakeholders.aspx?GID=2521&PreStageID=9341)   | Additional areas | I think steroid indications in bacterial meningitis not covered and my comment to include that in this guidelines  |

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 Clinical Psychologists
* Association of Paediatric Emergency Medicine
* British Society of Physical and Rehabilitation Medicine
* Faculty of Intensive Care Medicine
* Meningitis Now
* Meningitis Research Foundation
* NHS England - Antimicrobial Prescribing and Medicines Optimisation Team
* NHS England – Clinical Programme Team
* Royal College of Emergency Medicine
* Royal College of General Practitioners
* Royal College of Nursing - Emergency Care Forum Committee
* Royal College of Paediatrics and Child Health
* Royal Pharmaceutical Society
* UK Health Security Agency