

Meningococcal Working Group

**Raising awareness of the signs and symptoms, and ensuring
early diagnosis and treatment of meningococcal disease**

Report to the Secretary of State for Health & Social Care

30 April 2018

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Executive Summary

The Meningococcal Working Group was established in January 2018 at the request of the Secretary of State for Health & Social Care to assess what more needs to be done to raise awareness of the signs and symptoms of meningococcal disease among parents, young people and healthcare professionals with a view to improved assurance of early diagnosis and treatment.

The Group consisted of experts in the field and representatives from the relevant Royal Colleges, Arms' Length Bodies, meningitis charities, and families affected by meningococcal disease. The Group met three times during January to April 2018. It was not asked to carry out an evidence-based review but to build on experience and expertise and come up with suggestions to improve things further.

The Group makes 12 recommendations. Four are general recommendations and eight are aimed at different organisations/bodies who have a role to play in improving awareness and early diagnosis of sepsis and meningococcal disease:

Recommendation 1(Sepsis Board) - Approaches to the recognition, early diagnosis and treatment of meningococcal disease should be included under the umbrella of the cross-system Sepsis Board. The Board should consider how to include appropriate input from the meningitis charities and incorporate this into their on-going work programme.

Recommendation 2 (CQUIN) - The Sepsis CQUIN should continue for the foreseeable future. In addressing screening for sepsis and timely initiation of treatment, the CQUIN will impact on the recognition and early diagnosis of meningococcal disease, potentially at a stage when the disease is not readily distinguishable from other forms of sepsis as meningococcal disease.

Recommendation 3 (Think Sepsis) - To identify, or rule out, sepsis there needs to be:

- a broader culture of routinely using structured observations and recording of physiological measurements such as respiratory rates, perfusion, level of consciousness in all tiers of medical practice, to guide recognition of possible sepsis;
- implementation of the NICE fever guideline in children under five years of age, with evidence available in patient notes to demonstrate to CQC during inspections that this guideline was being systematically implemented by healthcare professionals in primary and secondary care.

Recommendation 4 (Safety-netting) - Documentation (in addition to verbal instruction) should be given to any patient (particularly parents/carers of a child or teenager), who has been assessed because of concerns about infection and is being sent home. This information should:

- set out what to look for in terms of deterioration or causes for concern for the child in question;
- empower patients and carers with appropriate knowledge so they can seek further advice and assessment if concerned.

It should be recorded in the patient's notes that this information has been provided and there should be mechanisms in place to monitor and audit that this is taking place so that, for example, the CQC could consider this metric during inspections of acute trusts and primary care.

Recommendation 5 (mass gatherings) - Organisations providing first aid/medical services at mass gatherings targeted at teenagers and young adults (especially those that span a number of days) should be able to demonstrate that their staff/volunteers are appropriately trained to recognise the signs and symptoms of meningococcal disease and sepsis and CQC should check this as part of the registration and inspection process.

Recommendation 6 - PHE should:

- review its general leaflets and literature on vaccination (including information on signs & symptoms of meningitis & septicaemia and vaccination-related messages) in partnership with meningitis charities, test revised literature with young people and parents and include links to meningitis charity info pages;
- review the template letters sent out following a case or cluster of meningococcal disease, to ensure information about signs & symptoms and action required is clear, testing this with the meningitis charities and a sample of families and healthcare professionals, include links to the meningitis charity website for further information and produce a checklist of standard points to consider for use by the local authors of these letters;
- engage with meningitis charities at the earliest stage possible if there is a cluster or outbreak of meningococcal disease to facilitate sharing messages and providing advice and support to the local community.

Recommendation 7 - Meningitis charities should:

- work with PHE as it reviews what messages should be included in its vaccination-related literature;
- consider strategies to make parents and young people aware of, and direct them to, the literature and resources already available at the right time and work with PHE to seek to deliver these strategies;
- consider how to improve their alignment with broader system-wide efforts to reduce sepsis and recognise it early, including working with the cross-system Sepsis Board;
- work with the Royal Colleges as needed when they review their sepsis-related training material.

Recommendation 8 - The Royal Colleges represented on the Group should:

- ensure that when relevant literature, tools and training packages are scheduled for review they:
 - consider if and how to promote the message to ‘listen to parents, carers and family members’ and that ‘parents know their child best’ and to record parental views in the patient’s notes, where that was not already done;
 - engage with the meningitis charities for ideas on content and include a link to the charities’ websites;
 - take on board feedback from the cross-system Sepsis Group.
- consider having a champion (or equivalent), if they don’t already have one to drive work forward on the recognition and diagnosis of sepsis;
- consider whether they should recommend to their individual membership that they consider the value of additional training in sepsis identification and whether this needs to be achieved by all clinical members or specific subgroups.
- reflect on how best to promote a culture where staff feel empowered to challenge within and between professional groupings and across different levels of seniority; and where staff are also open and responsive to challenge and to learning from mistakes and near misses whether via training or other means.

Recommendation 9 - NHS Improvement should:

- facilitate and support an open and learning culture within healthcare settings;
- support the dissemination and implementation of learning strategies that are most likely to bring about behavioural change.

Recommendation 10 - HEE should:

- facilitate and support an open and learning culture within healthcare settings;
- support the dissemination and implementation of learning strategies that are most likely to bring about behavioural change;
- engage with sepsis champions (or equivalent) in Royal Colleges and provide advice and information as needed.

Recommendation 11 - CQC should look for evidence that:

- the NICE fever guideline in children under five years is being systematically implemented by healthcare professionals in primary and secondary care, in particular that safety netting information is being given to parents and carers;
- organisations providing first aid/medical services at mass gatherings targeted at teenagers and young adults (especially those that span a number of days) use staff/volunteers who have been appropriately trained to recognise the signs and symptoms of meningococcal disease and sepsis.

[Note - The CQC is an organisation for whom a recommendation is made that was not represented on the Group. It has since been identified as an organisation with a key role to play in improved assurance of early diagnosis and treatment of sepsis and meningococcal disease and a recommendation is therefore directed to it].

Recommendation 12 - NHS England should:

- Ensure that the cross-system Sepsis Board considers this report in full and reports back to the Secretary of State (SofS) on its conclusions and action it plans to take as a result within a timescale set by the SofS;
- Liaise with other organisations for whom this report has also made recommendations, to ensure their actions are considered and built into any wider plans related to sepsis as appropriate.

Some of the recommendations (especially for the charities, Royal Colleges and PHE) involve reviewing and updating literature and training materials. This will have a small cost and can only take place as and when the organisations/bodies in question have the resource and capacity to do this. The Group noted that a financial contribution from Government, if possible, would help to expedite this work.

Background

1. On 29 November 2017 you met the families of Layla-Rose Ermenekli, Izzy Gentry and George Zographou who all, very tragically, died (aged 6, 16 and 18 respectively) after contracting Meningococcal Group B (MenB) disease. Whilst recognising that the families' stories may not be fully representative of all meningococcal deaths in the UK, all three nevertheless highlighted issues of late and missed diagnosis. As a result you asked that a task and finish group be set up to build on existing work and guidance and to advise you on what more needs to be done to raise awareness of the signs and symptoms of meningococcal disease among parents, young people and health care professionals and to ensure early diagnosis and treatment.

Terms of Reference

2. The terms of reference are at Annex A, Vaccination policy was out of scope as this needed to be based on the advice of the Joint Committee on Vaccination & Immunisation (JCVI). Vaccination-related messaging, however, was in scope. The Group also agreed that their considerations would cover all meningococcal disease as MenB is indistinguishable clinically from other forms of meningococcal disease, and can present as meningitis or septicaemia/sepsis.

Membership

3. The group consisted of experts in the field and representatives from relevant Royal Colleges, arms' length bodies, meningitis charities, and, most importantly, the families of Layla-Rose, Izzy and George (see Annex B).

Meetings

4. The group met three times. It started by hearing the extremely sad stories of Layla-Rose, Izzy and George. The Group were very grateful to family members for the brave and powerful accounts they shared. Their experiences were invaluable in helping to identify themes and issues to consider further. At the second meeting, the various organisations/bodies shared what they already do and possible further actions to raise awareness and share good practice in early diagnosis and treatment. The Group also started to discuss the recommendations it would want to make. At the final meeting the Group discussed a draft report with potential recommendations.

Final report

5. This is the final report. It includes 12 recommendations. **The Group hopes you will support these recommendations which, if implemented, should contribute to earlier recognition, diagnosis and treatment of meningococcal disease.**

What is Meningococcal disease?

6. Meningococcal disease is a bacterial infection that can cause meningitis, sepsis (blood poisoning) or both. The human brain and spinal cord are surrounded by membranes which act as a protective barrier. When organisms such as viruses or bacteria cause these membranes to become inflamed, this is known as meningitis. Viral meningitis is common, generally mild and rarely leads to death. However, bacterial meningitis is a serious medical condition where prompt recognition and treatment is required.
7. Meningococcal disease is caused by infection with the bacterium *Neisseria meningitidis*. Meningococcal infection is a cause of sepsis – anecdotally, it is estimated that it accounts for about 2% of all sepsis. There are 13 groups of meningococci of which just six account for the majority of serious human infections (groups A, B, C, W, X and Y). Groups B, C and W are the most common in the UK with MenB currently accounting for around 80% of all laboratory-confirmed cases reported to Public Health England (PHE). Vaccines exist for groups A, B, C, Y, and W although they do not necessarily protect against all strains within a group and are not 100% effective. In addition, UK vaccination policy for meningococcal disease varies by age group.
8. Meningococcal disease often presents with non-specific symptoms such as fever, lethargy and vomiting. Other initial symptoms may include general malaise, weakness, myalgia (muscle pain), headache, nausea, cough, sore throat, conjunctivitis and limb pain. This makes early recognition difficult as meningococcal disease is indistinguishable from many other common infections. The characteristic skin rash, indicative of meningococcal septicaemia (meningococcal blood stream infection) may be a relatively late phenomenon and does not occur in all cases. Skin rash may progress from a few ill-defined lesions to widespread purpuric eruption (a rash that does not fade under pressure) within a few hours. Some cases of meningococcal disease present as meningitis (brain infection) with or without a rash and meningococcal meningitis may present alone or with meningococcal septicaemia.
9. Although most people will make a good recovery, meningococcal disease (especially with septicaemia) can result in death or leave people with severe and disabling side-effects such as hearing/sight loss and brain damage. When sepsis has occurred, there can be organ damage and loss of digits/limbs. Some survivors have memory loss, learning difficulties, anxiety and depression.

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10. Meningococcal disease can strike at any age, but most cases occur in babies and young children. The next most vulnerable group is teenagers and young people. Early recognition of signs and symptoms of both meningococcal disease and sepsis and early action by parents, young people and healthcare professionals is vital to save lives and reduce after-effects.

Key themes from the cases of Layla-Rose, Izzy and George

11. The group heard the stories of Layla-Rose (aged 6), Izzy (aged 16) and George (aged 18) who all, very tragically, died from meningococcal disease. These stories are summarised at **Annexes C, D and E** respectively. Whilst each story was different, a number of themes arose:
- a) **Sepsis/the deteriorating patient** – management of cases would be the same whether there was an initial diagnosis of sepsis (of unknown origin) or meningococcal disease. As only a small proportion of sepsis is related to meningococcal disease, the key should be to see whether sepsis could be excluded and to be alert more generally to deterioration in a patient (whatever the cause) and how to manage that.
 - b) **Messaging for parents, young people and healthcare professionals** – more thought needs to be given to: who should be receiving messaging; when they should receive it; what that messaging should be; and how best to get it across so that it is not just understood but acted on.
 - c) **Communication between parents/young people and healthcare professionals and between healthcare professionals/clinical teams** – more thought needs to be given to how parents/young people and healthcare professionals communicate with each other as well as how healthcare professionals in the same or in different clinical teams communicate – encouraging the right to challenge and the acceptance of challenge is key.
 - d) **Triggers for care** – healthcare professionals need to ‘think sepsis’ and, unless sepsis can be ruled out, equally, meningococcal disease cannot be ruled out. This should trigger sepsis detection/exclusion and management at an early stage in an unexplained illness, before any more specific diagnosis is confirmed. Additionally, PHE letters sent to close contacts of single sporadic cases of meningococcal disease (including schools/universities when cases occurs in people from their environments) and GPs/hospitals following a local cluster were key to putting people on alert for potential cases.
 - e) **Systems** – healthcare professionals need to have the necessary training and continuing professional development to help them recognise and effectively manage potential meningococcal disease/sepsis from an early stage (or be aware that such a diagnosis sometimes cannot be definitively ruled out). There also needs to be appropriate ‘safety netting’ to ensure parents had the information they needed to empower them to return for help and suitably challenge healthcare professionals.

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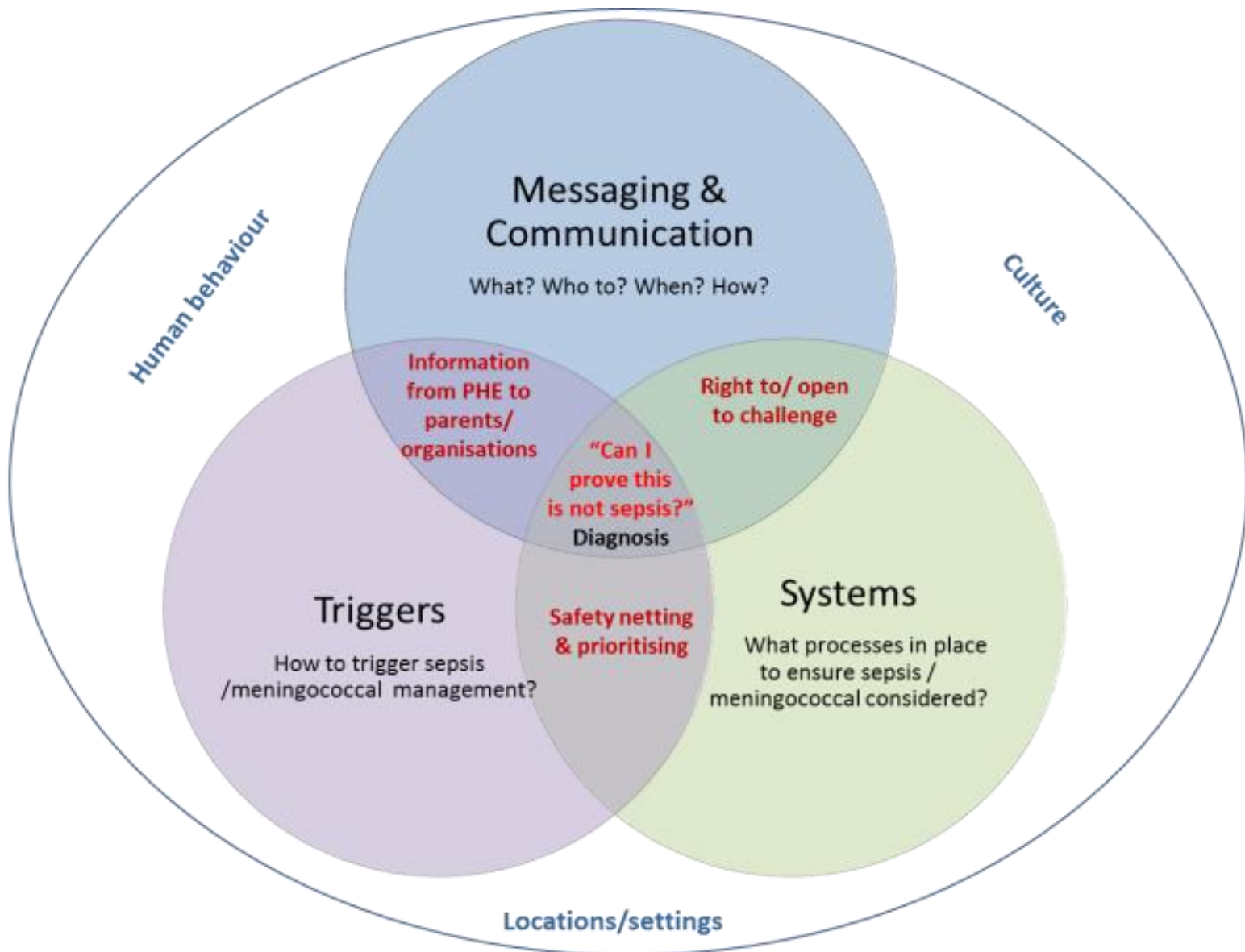
These themes overlap and action to improve any one of these areas should have positive impacts on the others.

12. Three cross cutting issues that impact on the diagnosis and treatment of meningococcal disease were also identified:

- a) **Human behaviour** – how to ensure that information and training actually result in behavioural change. This issue applies more widely than in just meningococcal disease and sepsis, and is something that organisations such as HEE and NHS Improvement need to consider more generally.
- b) **Culture** – parents and staff needed to be empowered to challenge, and staff needed to be open and responsive to challenge and to learn from mistakes and near misses. Again, this issue applies more widely than in just meningococcal disease and sepsis, and is something that the Royal Colleges in particular might wish to reflect on further.
- c) **Location/setting** – different strategies might need to be considered to raise awareness of signs & symptoms and promote early diagnosis and treatment in different settings. A&E or GP practices are the most likely settings for people with suspected meningococcal disease or sepsis to present, and staff at NHS 111 and paramedics are also likely to have to deal with suspected cases. However, consideration also needs to be given to managing cases that present in atypical settings such as mass gatherings (music festivals, and cultural and sporting events etc.) especially those that span a number of days.

These themes and cross-cutting issues are represented diagrammatically below:

Themes and cross-cutting issues



These themes and issues are discussed in more detail below.

Sepsis and the deteriorating patient

13. Much of the Group's discussion was about the diagnosis and treatment of sepsis, rather than uniquely meningococcal disease. Clinical experts on the Group confirmed that the need to quickly recognise a deteriorating patient is the same whether the initial diagnosis was sepsis or meningococcal disease.

14. The Group agreed that the key should be to:

- a) *'think sepsis'* i.e. a cultural shift to actively look for sepsis and consider whether or not it can be ruled out;
- b) *'recognise and respond quickly to the deteriorating patient'* whatever the cause of deterioration.

Taken together it was agreed these two actions should facilitate early diagnosis of sepsis, therefore the early recognition and treatment of meningococcal disease, and that this was a better approach than focusing purely on meningococcal disease which can be recognised late and represents a small proportion of the overall sepsis burden.

15. It was noted that NHS England had already generated considerable momentum, by leading work on sepsis via a cross-system Sepsis Board established in January 2015. The Group agreed that the biggest and quickest gain would be to ensure work on meningococcal disease was brought under the umbrella of the cross system Sepsis Board due to the common clinical pathway for early meningococcal disease and other forms of early sepsis, significant overlap in the relation to awareness and management of patients, and the opportunity to promulgate simple messages to the public.

16. The Group did however note that the terms 'meningitis' and 'septicaemia' have strong currency with the public and parents – parents have recognised these terms for several decades and know they mean that something serious is happening and that action needs to be taken quickly; in comparison sepsis is a relatively new term. Whilst the Group agreed that alignment on the sepsis work would be highly desirable and beneficial, it advised that some 'meningitis' related messages should be retained to ensure appropriate recognition and treatment. It is important for treating clinicians to be alert to the possibility of bacterial meningitis, especially when assessing febrile children, because the diagnosis and management of meningitis and sepsis can differ. It was even suggested by one of the charities that work undertaken under the auspices of sepsis could be given increased public prominence itself by association with meningitis.

17. Some members of the Group had concerns that aligning to the sepsis work might dilute the message on meningococcal disease especially as the majority of people with sepsis would be older people. However, the Group heard that the direction of travel of the sepsis work was to focus on identifying the sick or deteriorating patient more generally. The Group was supportive of this approach.

Recommendation (Sepsis Board) - Approaches to the recognition, early diagnosis and treatment of meningococcal disease should be included under the umbrella of the cross-system Sepsis Board. The Board should consider how to include input from the meningitis charities and incorporate this into their on-going work programme.

Secondary Care

18. The Group was alerted to the Sepsis Commissioning for Quality and Innovation (CQUIN) payment which seeks to incentivise hospitals to act quickly on sepsis. This CQUIN is a financial incentive to reward acute trusts for prompt identification and treatment (e.g. rapid application of antibiotics) for adults and children (both emergency admissions and in-patients). The Group agreed that such an incentive was vital while the 'think sepsis' work was bedding down and would be hugely beneficial to the speedy management of meningococcal disease. It was also hoped that the CQUIN might encourage providers to prioritise sepsis-related training for those most likely to need it. The Group strongly supported the continuation of this CQUIN.

Recommendation (CQUIN) – the Sepsis CQUIN should continue for the foreseeable future. In addressing screening for sepsis and timely initiation of treatment, the CQUIN will impact on the recognition and early diagnosis of meningococcal disease, potentially at a stage when the disease is not readily distinguishable from other forms of sepsis as meningococcal disease.

Primary Care & Secondary Care

19. The Group noted that out of about 360 million GP contacts about 46,000, would be sepsis and that meningococcal disease forms only a small proportion of these presentations and represents an extremely rare cohort in primary care (probably only 1-2%)¹. The meningitis charities noted however that they had multiple examples of parents with children eventually diagnosed with meningococcal disease where their GP had not initially thought they had a serious infection due to the non-specific features.

20. The Group agreed that, in general, it was better for GPs to focus on recognition of the really sick child amongst all the children they see rather than specifically focus on meningococcal disease. Rapidly recognising deteriorating health in a child should help identify those with meningococcal disease. It was noted that the NICE clinical guideline for the assessment and initial management of children

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under 5 years of ageⁱⁱ is validated to identify those at very low risk of serious infection. It was also noted that excluding serious bacterial infection is possible using the NICE Fever “Traffic Light system”. Validation studies have shown that children with “Green” features (and no Red/ Amber features) are at very low risk of serious bacterial infection (although they need a urine sample to exclude urine infection). This system was designed for children less than 5 years of age with fever or a history of recent feverⁱⁱⁱ which should capture cases of meningococcal.

21. There was some concern expressed that this guideline could ‘over trigger’ and risk large numbers of children being referred to hospital and therefore the really serious cases could be missed. However, family representatives noted the importance of ruling out potentially serious infection as a priority.
22. The Group agreed that the ‘Think Sepsis’ initiative was vital and needed to be embedded long-term within the NHS (primary and secondary care) supported by the education, appraisal and revalidation system.

Recommendation (Think Sepsis) - To identify, or rule out, sepsis there needs to be:

- **a broader culture of routinely using structured observations and recording of physiological measurements such as respiratory rates, perfusion, level of consciousness in all tiers of medical practice, to guide recognition of possible sepsis;**
- **implementation of the NICE fever guideline in children under five years of age, with evidence available in patient notes to demonstrate to CQC during inspections that this guideline was being systematically implemented by healthcare professionals in primary and secondary care.**

23. The Group noted that there was no paediatric early warning scores (PEWS) for use in general practice or tools to help GPs rule out sepsis. It was also noted that experience of PEWS in hospital showed that they do not rule out sepsis and that a child could still die from sepsis who had had a low PEWS score throughout their assessment. Despite this, the Group was supportive of on-going work by NHS England, NHS Improvement and relevant experts to develop a PEWS or similar system for England, and were supportive of the dedicated Board that NHS England was setting up to focus on this.

Messaging

Parents and young people

24. PHE conduct national surveys of parental attitudes to childhood vaccinations. These show that a significant proportion of parents consider both meningitis and septicaemia to be 'very serious'^{iv}. Meningitis charities have done a significant amount of work in recent years to raise awareness of meningococcal disease in the public. However, anecdotal evidence suggests that this awareness is not progressing to recognition of signs and symptoms.
25. Additionally, there is a lack of recognition of signs and symptoms within young people. In a recent Meningitis Now survey, 90% of people aged 18 to 24 years said they had heard of the disease, yet only a quarter knew the signs and symptoms, and, possibly most concerning, 60% said they didn't know they were at risk^v. Around 25% of adolescents carry the meningococcal bacteria in the back of their throats, compared to approximately 10% of the UK population. Whilst most carriers do not become ill, in an age group where more people are carrying the bacteria, there will be more disease,^{vi} so awareness is vital.
26. PHE and the meningitis charities (supported by universities in relation to young people), have and continue to promote meningococcal disease awareness amongst parents and young people using a range of routes including social media. They also take action to try and increase uptake of the MenACWY vaccine that is targeted specifically at young people and the MenB vaccine that is targeted at infants.
27. There is anecdotal evidence of uncertainty and, potentially even, false assurance, among young people and parents about the protection provided by current vaccinations. For example if a young person has received the MenACWY vaccine at school there was confusion over whether this also provided protection against MenB. There was therefore a danger that parents/families/ the individual might consider themselves protected against all meningococcal disease having "had the 'meningitis' vaccine" when in fact they would only be protected against meningococcal groups specific to the vaccine they had been given; this false reassurance may lead to a failure to consider or recognise disease symptoms quickly enough.
28. The on-going lack of recognition of signs and symptoms and potential confusion over protection from vaccination means that this has been identified as an area that would benefit from further consideration including messaging about the vaccines currently being used and what they do and do not protect against as well as where, when and how to get these messages to the right audiences.
29. More generally, it was noted that early recognition of meningococcal disease is challenging. A non-blanching rash is often focused on because it is specific characteristic of meningococcal disease whereas other symptoms are general

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and non-specific e.g. lethargy and headache. However, a characteristic rash is not always present, might appear late or not be immediately recognisable as such.

30. It was also noted that the classic features of rash, stiff neck, and impaired consciousness develop late (median onset 13-22 hours)^{vii} whereas symptoms less well recognised by the public (limb pain, pale skin, and cold hands and feet) often appear earlier. For example, 72% of children develop symptoms of sepsis such as leg pains, cold hands and feet, abnormal skin colour at a median time of 8 hours, much earlier than the average time to hospital admission of 19 hours^{viii}.
31. The Group noted that there is already an array of leaflets, posters and social media material targeted at parents and young people. These are set out at **Annex F**. The Group agreed that some organisations could do even more to raise awareness among parents and young people:

Recommendation (PHE) – PHE should review its general leaflets and literature on vaccination (including information on signs & symptoms of meningitis & septicaemia and vaccination-related messages) in partnership with meningitis charities, test revised literature with young people and parents and include links to meningitis charity info pages.

Recommendation (Meningitis charities) – Meningitis charities should:

- work with PHE as it reviews what messages should be included in its vaccination-related literature;
- consider strategies to make parents and young people aware of, and direct them to, the literature and resources already available at the right time, and work with PHE to seek to deliver these strategies;
- consider how to improve their alignment with broader system-wide efforts to reduce sepsis and recognise it early, including working with the cross-system Sepsis Board;

32. In reviewing their information both PHE and the meningitis charities agreed that they needed to:

- a) be clear who is eligible for what vaccination and what each vaccine does and doesn't prevent in relation to meningitis (i.e. the different strains) and that no vaccine provides 100% protection against meningitis;
- b) give a clear message to parents to 'trust your instincts';
- c) find ways to clarify that meningitis is not just about a rash;
- d) consider how best to use social media and video clips to target young people.

Healthcare professionals

33. The Group agreed that there was a need to increase awareness among healthcare professionals, particularly in A&E and general practice but also for NHS 111 and paramedics, of the range of symptoms that can be associated with meningococcal disease and sepsis. It was noted that there is already an array of guidance and training material for healthcare professionals – this is summarised at **Annex F and G**.
34. The Group was supportive of the suggestion by Health Education England (HEE) that clinicians should be encouraged when presented with a child or young person with an unclear diagnosis to ‘prove this is not sepsis’. The Group agreed that work to raise awareness of meningococcal disease among healthcare professionals and to ensure prompt recognition would best take place as part of HEE’s ‘Think Sepsis’ campaign (training material for which was launched in April 2018) and the cross-system Sepsis Group (see Recommendation at para 17).
35. The Group also noted that more could perhaps be done to encourage healthcare professionals to ‘listen to parents’ and ensure that their comments have been recorded in patient notes.

Recommendation (Royal Colleges): The Royal Colleges represented on the Group should ensure that when relevant literature, tools and training packages are scheduled for review they:

- consider if and how to promote the message to ‘listen to parents, carers and family members’ and that ‘parents know their child best’ and to record parental views in the patient’s notes, where that was not already done;
- engage with the meningitis charities for ideas on content and include a link to the charities’ websites;
- take on board feedback from the cross-system Sepsis Group.

Communications

Communications between parents/families and healthcare professions

36. In the cases of Layla-Rose, Izzy and George, it was clear to their families that they were behaving in a way that was not normal for them and they had serious concerns. Parents, carers and family members are likely to be very familiar with the patient and their observations should be valued by healthcare professionals. This familiarity with the patient can provide valuable intelligence to support diagnosis. Recognising and listening to parental and family concerns should be encouraged and healthcare professionals should respect those concerns.
37. The value of listening to the parent is picked up in Recommendation to the Royal Colleges after para 35 as well as in the section on 'Triggers for Care' at para 41.

Communications between healthcare professions

38. The time-window for diagnosis of meningococcal disease or sepsis is narrow. Children can have only non-specific symptoms in the first 4-6 hours, but a small number can be close to death by 24 hours. The process of diagnostic investigations can be challenging such as the time it takes to receive blood test results. There is national guidance and protocols with clearly defined pathways but these may not always be followed.
39. Timely availability of senior/experienced staff to support junior colleagues with diagnosis is important. In some health care settings, hierarchies can be dominant, whether that is between professionals (paramedics and doctors, doctors and nurses) or within a profession (junior doctors and consultants). We heard anecdotal evidence of junior doctors, paramedics and nurses raising concerns but these being ignored or overlooked by more senior medical colleagues. In order to provide the best levels of care, it was noted that a culture of being comfortable raising concerns with senior members of staff and staff in a different professional group was key. Staff also needed to be open to challenge to facilitate improved care for patients.
40. The Group stressed the need to ensure that healthcare professionals, as well as family members and patients, are supported and empowered to 'challenge' and that senior healthcare professionals are open to challenge. This goes wider than meningococcal disease and sepsis and links to wider work on culture post the Francis Inquiry into Mid Staffs. This is covered in the section on human behaviour & culture later in the report.

Triggers for care

41. The Group noted the importance of having triggers for healthcare workers to 'think sepsis' and, unless that could be ruled out, then meningococcal disease could not be ruled out. Having such triggers should mean that sepsis/ meningococcal management should commence at an early stage, most probably before any diagnosis is confirmed. It was agreed that this work was already being picked up more generally by the cross-system Sepsis Board.

However, a couple of triggers the group wanted to highlight were:

- a) to encourage staff to listen to parents who know their child best – this has been addressed in the Recommendation to Royal Colleges at para 35;
- b) PHE letters following a case or cluster of cases of meningococcal disease (see below).

PHE letters

42. PHE has standard guidance on how to respond to a case or cluster of cases of meningococcal disease in a locality. This includes raising awareness with those at risk in the community and with local healthcare providers. A template letter is provided that local teams can use to inform individuals/organisations about cases in the vicinity and to remind people of the signs and symptoms to look out for. The group discussed the pros and cons of standardising these template letters further but agreed that they needed to be case specific. However, it was agreed that a checklist of the type of information that should always be considered for inclusion could be produced so that the local author could consider if that information was relevant for that case.

43. It was agreed that a PHE letter to schools/universities and families in the area, following a case of meningitis, was an important way to raise awareness among young people and families. It was, however, noted that such a letter had been sent out after Izzy had contracted meningococcal disease but that perhaps it had not given all the information parents needed such as about the different types of meningococcal disease and whether or not they were all vaccine preventable. It was also suggested that such letters needed to provide information that a parent or carer could share with healthcare workers if their child felt unwell and needed to attend the GP or A&E.

44. It was agreed that a PHE letter to local GP practices, NHS 111, and emergency departments might be useful in some circumstances so that they can keep a particular eye out for signs and symptoms after a local case and perhaps have a low threshold for concern for those presenting where perhaps there was diagnostic uncertainty and serious infection could not be ruled out. However, it

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was also noted that if such letters were sent out too frequently they would lose impact. It was agreed that communications with healthcare professionals needed to be proportionate. Whether to send them out should be based on local professional judgement about the size and severity of the cluster.

45. It was agreed that the content of PHE letters should be used as a tool to:

- a) give parents/families/individuals enough information about what symptoms to look out for;
- b) empower an individual or their family to seek medical help if they are concerned about an illness – taking the letter if necessary;
- c) provide healthcare professionals in the locality (where appropriate) with a trigger to ‘think sepsis’/ think ‘can I prove this is not sepsis?’ i.e. to have a lower threshold for suspicion than normal to trigger meningococcal/ sepsis management.

Recommendation (PHE): PHE should:

- **review the template letters sent out following a case or cluster of meningococcal disease, to ensure information about signs & symptoms and action required is clear, testing this with the meningitis charities and a sample of families and healthcare professionals and including links to the meningitis charity website for further information and producing a checklist of standard points to consider for use by the local authors of these letters.**
- **engage with meningitis charities at the earliest stage possible if there is a cluster or outbreak of meningococcal disease to facilitate sharing messages and providing advice and support to the local community.**

Systems

46. The Group noted two systems that were particularly important to ensure early recognition and treatment of meningococcal disease/sepsis:

- a) safety netting;
- b) training and continuing professional development (CPD) for healthcare professionals;

Safety netting

47. 50% of children with meningococcal disease are seen by a doctor but not admitted to hospital, during the early phase of the illness^{ix}. Safety netting is a strategy or technique to help manage diagnostic uncertainty. It helps ensure patients undergoing investigations for, or presenting with symptoms which could indicate serious disease, are followed up in a timely and appropriate manner. It can encompass a wide range of actions and procedures. It is particularly important for potential meningococcal disease or sepsis where initial symptoms can be non-specific.

48. NICE's Quality Standard (QS) on 'Fever in under 5s' sets out that parents and carers should be given safety net advice. The Group agreed that this was particularly important for children (not just those with fever) where a decision was being made to send them home as they had been assessed as not having a serious infection but did not have a clear diagnosis. The QS notes that there should be local arrangements to ensure that written and verbal safety net advice is given to parents and carers so that they are clear what to look out for and what to do to seek help if their child's condition deteriorates or if they need more support - this is intended to empower them.

49. The Group noted that parents and carers might not absorb verbal messages during a stressful situation and strongly supported them being given written material to take home, including a description of what 'getting worse' means/looks like (which is likely to be specific to the child being assessed) and to be clear that if that happens how they should access further medical review. The Group felt that it should be recorded in the patient's notes that such information had been handed out. This was a measureable outcome consistent with the NICE QS and applicable to both primary and secondary care. Ideally the Group would like the handout of such information to be mandated but it recognised the challenges that such an approach might face. They therefore strongly supported a mechanism to audit locally that information is printed and given and to ensure that, at the very least, individuals or organisations could demonstrate to CQC during inspections that this had taken place, for example, recording such action in patient records.

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50. The Group also noted that there might be other information that parents and carers could helpfully be directed to such as videos that are in the process of being developed by NHS England and the RCGP to help identify a really sick child quickly. The group was also supportive of ideas such as the development of apps to support parents and noted that research to test out which materials would most likely exact the required change in behaviour would be worthwhile.
51. Overall the Group was keen to see stronger and more comprehensive safety netting with some flexibility as to how this is achieved locally.

Recommendation (Safety-netting) – documentation (in addition to verbal instruction) should be given to any patient (particularly parents/carers of a child or teenager), who has been assessed because of concerns about infection and is being sent home. This information should:

- set out what to look for in terms of deterioration or causes for concern for the child in question;
- empower patients and carers with appropriate knowledge so they can seek further advice and assessment if concerned.

It should be recorded in the patient's notes that this information has been provided and there should be mechanisms in place to monitor and audit that this is taking place so that, for example, the CQC could consider this metric during inspections of acute trusts and primary care.

52. Other suggestions to ensure that there is a way to monitor or review if health deteriorates and therefore facilitate earlier diagnosis included:
- a) seeking a second or senior clinician's opinion if there was an unscheduled 'returning child' in secondary care;
 - b) that clinical teams in secondary care should be prepared to observe for a period of time rather than send a child home with an unknown or uncertain diagnosis. Having the capacity to 'watch and wait' was supported by the Group although it was noted that given current system capacity constraints this might not be feasible. It should however be an aspiration and should always be implemented in the case of a 'returning child'.
 - c) that in some cases GPs might want to consider scheduling a review for a child with an unknown or uncertain diagnosis to augment safety netting.

It was hoped the cross-system Sepsis Board would reflect on these suggestions.

Training & Continuing Professional Development (CPD)

53. A range of healthcare professionals already have some training relevant to recognition of potential meningococcal disease and/or sepsis and its management. For example:

- a) recognition of sepsis and deteriorating patients is within the curriculum of the membership exam for the Royal College of General Practitioners;
- b) sepsis is a mandatory part of training for all junior doctors in the specialty of emergency medicine;
- c) Advanced Paediatric Life Support (APLS) is part of core medical training for paediatricians and is refreshed every 3 years, they also have mandatory training in recognising the sick child;
- d) recognition and management of sepsis is often included in clinical diagnostic CPD courses which many nurses working in sepsis care undertake to support their role

54. It also became clear that most of the Royal Colleges have a range of e-learning packages and guidance to support healthcare professionals with their CPD and that some of this should improve the ability of staff to recognise meningococcal disease and sepsis in children. These courses were mainly designed to 'reinforce and remind'. Some examples are listed at Annex G. More recently, HEE launched in April new learning materials raising awareness of the signs of sepsis in children to support healthcare professionals to spot and treat sepsis quicker. These materials will call on those in healthcare to 'think sepsis'. This new learning resource will help support improvements in the rates of accurate diagnosis and management of sepsis in children.

55. Some of the Royal Colleges' existing packages were due for, or might benefit from, review for example:

- a) to include patient stories/videos for greater impact;
- b) to include links to the meningitis charities websites;
- c) to be brought in line with the direction of the wider cross-system Sepsis Board.

The representatives from the Royal Colleges were open to these packages being reviewed (although noted that this would have resource implications – see Conclusion). They were also keen to find ways to signpost healthcare professionals in primary and secondary care at both induction and appraisal to appropriately standardised training on sepsis. It is hoped that this might be an outcome from the wider cross system Sepsis Board work.

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56. It was noted that these Royal College training packages tend to be optional and the Group did debate whether they should form part of mandatory training. There were pros and cons for this option. One con was that with mandatory training people can just 'go through the motions' to tick the box. The Group wanted staff to recognise the importance of such training and proactively seek it out such that they learn and there is behaviour change as a result. Training as teams was also thought to add value, as were incentives for organisations to ensure such training is prioritised for those most likely to need it (see **Recommendation on the CQUIN** at para 17).
57. The Group also wondered if an interactive tool for senior managers and trust executives might be beneficial to reinforce why it is so important to ensure that their organisations and departments have the necessary systems in place to identify sepsis and to identify if there is more that could or should be done locally such as learning from near misses. This was something for the cross-system Sepsis Group to consider.

Recommendation (Royal Colleges) – The Royal Colleges represented on the Group should:

- **consider having a champion (or equivalent), if they don't already have one to drive work forward on the recognition and diagnosis of sepsis;**
- **engage with the meningitis charities for ideas on content when relevant training packages come up for review, take on board feedback from the cross-system Sepsis Group and include a link to the charities' websites;**
- **consider whether they should recommend to their individual membership that they consider the value of additional training in sepsis identification and whether this needs to be achieved by all clinical members or specific subgroups.**

Recommendation (HEE): HEE should engage with sepsis champions (or equivalent) in Royal Colleges and provide advice and information as needed.

Human behaviour & culture

58. The Group stressed that speaking up and challenging is vital to patient safety and that both parents/staff need to be empowered to challenge. Staff also need to be open and responsive to challenge and to learning from mistakes and near misses. As noted at para 40, this goes wider than meningococcal disease and sepsis and the Group noted that a range of work had taken place across the health system on this issue following the Mid Staffordshire Inquiry^x including around whistleblowing, a Duty of Candour and a learning culture.

59. However, the Group also noted that the personal accounts they had heard of Layla-Rose's, Izzy's and George's case highlighted that work to address and improve behaviour and culture was not yet complete and needed to remain an on-going mission for the NHS. The Group also noted that it doesn't matter how much information and training is provided if it does not result in behavioural change. Again, this goes wider than meningococcal disease and sepsis. More creative learning strategies are needed.

Recommendation(Royal Colleges): The Royal Colleges represented on the Group should reflect on how best to promote a culture where staff feel empowered to challenge within and between professional groupings and across different levels of seniority; and where staff are also open and responsive to challenge and to learning from mistakes and near misses whether via training or other means.

Recommendation (NHS Improvement and HEE): NHS Improvement and HEE should:

- facilitate and support an open and learning culture within healthcare settings;
- support the dissemination and implementation of learning strategies that are most likely to bring about behavioural change.

Atypical locations/settings

60. The Group noted that patients may present at a wide range of settings but most likely A&E, GP practice, walk-in centres/minor injuries units, 111 or ambulance. It was also noted that some might present at first aid/medical facilities at mass gatherings such as festivals or cultural and sporting events (particularly where these span a period of days) and that the quality and focus of medical care in any setting (not just the NHS) is important.
61. It was noted that staff at such events should have guidelines on what they are able to treat and what should be diverted to the nearest emergency department. The group heard anecdotal concerns that if an event sent too many patients to the local emergency department they might lose their license. It was noted that, if true, that was a potentially dangerous disincentive and should be strongly discouraged.
62. Guidance for medical cover at events is available^{xi}. However, the group identified this as an issue that would benefit from further work including assessment of the current guidance and what training and support is in place for staff covering such events.
63. The Group were particularly concerned that the presentation of meningococcal disease at atypical locations can provide an additional challenge to diagnosis as healthcare professionals are more likely to be alert to conditions most likely to be encountered at such events, for example, alcohol and/or drug related problems, sun stroke, minor trauma and crush injuries at festivals. It was suggested that events that were predominantly aimed at young adults such as music festivals (particularly where these span a period of several days) should be a particular target for messaging to those providing first aid/medical assistance about the signs and symptoms of meningococcal disease and sepsis, given the above average carriage of meningococcal disease in this age group.
64. The Group understood that the providers of health/medical services for such events should be registered with the Care Quality Commission (CQC) and should therefore have systems in place to demonstrate to the CQC that the individuals they use are appropriately trained for the role they are given. In addition individual healthcare professionals have a responsibility to ensure that they themselves have the necessary skills for the role they are taking on. The Group agreed that this should include awareness of the signs and symptoms of sepsis and meningococcal disease if they were going to be attending mass gatherings aimed at young adults.

65. The Group also agreed that:

- a) HEE should ensure appropriate training materials are available for healthcare professionals, irrespective of whether they work for the NHS or other sectors, to 'Think Sepsis' if that is appropriate for the clinical role they have including providing medical services at mass gatherings.
- b) PHE should signpost organisations providing first aid/medical services at mass gatherings (especially those where the target audience is teenagers and young adults) and healthcare professionals providing such services to appropriate information and training materials such that they are aware of, and alert to, the possibility of sepsis (including meningococcal disease).

Recommendation (mass gatherings) – Organisations providing first aid/medical services at mass gatherings targeted at teenagers and young adults (especially those that span a number of days) should be able to demonstrate that their staff/volunteers are appropriately trained to recognise the signs and symptoms of meningococcal disease and sepsis and CQC should be asked to check this as part of the registration and inspection process.

Conclusions

66. The members of this group valued the opportunity to come together to discuss this important issue. The Group was not asked to carry out an evidence-based review, nor was there time to do so, but to build on experience and expertise in the room and come up with suggestions to improve things further.
67. The Group noted that there was already relevant NICE guidelines and other guidance and that, generally, the system works well and there are positive developments involving the Royal Colleges and relevant arms' length bodies. Most recently there has been publication of new training materials by HEE to support healthcare professionals to spot and treat sepsis in children quicker and to help improve the rates of accurate diagnosis and management of sepsis in children^{xii}.
68. Although the Group generally agreed that the system works well for most patients, it noted that sometimes things can, and do, go wrong. The cases of Layla-Rose, Izzy and George showed that when things do go wrong the consequences can be devastating. There remains a need to further minimise the risk of missed or delayed diagnosis and the Group agreed that the biggest gain would be made by bringing work on raising awareness and ensuring early diagnosis and treatment of meningococcal disease under the umbrella of the wider work on sepsis and recognising the sick or deteriorating child.
69. There is also more that a range of organisations/bodies could do to raise awareness and support earlier diagnosis and treatment. Recommendations are made to these organisations/bodies. Some of these recommendations involve reviewing and updating literature and training materials. This will have a small cost and can only take place as and when organisations have the resource and capacity to do this. The Group noted that a small contribution from Government, if possible, would help to expedite this work.
70. Assuming you accept the main recommendation in this report that meningococcal disease should be considered under the umbrella of the cross-system Sepsis Group, the Group makes a final recommendation to ensure this report is taken forward:

Recommendation (NHS England): NHS England should:

- **Ensure that the cross-system Sepsis Board considers this report in full and reports back to the Secretary of State (SofS) on its conclusions and action it plans to take as a result within a timescale set by the SofS;**
- **Liaise with other organisations for whom this report has also made recommendations, to ensure their actions are considered and built into any wider plans related to sepsis as appropriate.**

Meningococcal Disease Working Group
Terms of Reference

Scope and Responsibilities

1. This group was set up at the request of the Secretary of State for Health & Social Care to, build on existing work and guidance and advise him on:
 - a) what action needs to take place to further raise awareness among the public or professionals of the signs and symptoms of meningococcal disease and clarify vaccination-related messages;
 - b) good practice in the early diagnosis and treatment of meningococcal disease and how this can best be spread to health care professionals and other staff to whom potential cases might present;
 - c) the challenges in diagnosing meningococcal disease and how these might best be overcome.

In scope:

- All meningococcal disease (not just meningococcal group B).

Out of scope

- detailed review of specific cases (although lessons learned can be fed in);
- vaccination policy for meningococcal disease.

Meeting Frequency

2. The working group would meet on three occasions (January, February and March) with telecons arranged in between if needed.

Deliverable

3. A short report (5-10 pages) to the Secretary of State with recommended actions and reasoning to be delivered by 31 March 2018.

Meningococcal Working Group: Membership

Prof Jonathan Van Tam	Deputy Chief Medical Officer – Chair
Clinical Experts (some representing Royal Colleges)	
Dr Andrew Riordan	Consultant in Paediatric Infectious Diseases and Immunology at Alder Hey Children's NHS Foundation Trust
Prof Malcolm (Calum) Semple	Professor of Child Health and Outbreak Medicine, University of Liverpool; Consultant Respiratory Paediatrician, Alder Hey Children's Hospital, Liverpool.
Dr Jeff Keep	Sepsis Lead, Royal College of Emergency Medicine
Dr Simon Stockley	General Practitioner, Lead for Sepsis, Royal College of General Practitioners
Prof Robert Read	Representing Royal College of Physicians
Stephen Flanagan	Senior Health Protection Practitioner, Public Health England North West. Representing Royal College of Nursing
ALB representatives	
Dr Andrew Frankel	Post Graduate Dean, Health Education England
Linda Dempster	Head of Infection Control, NHS Improvement
Meera Sookee	Strategy Lead, Quality Strategy Team, NHS England
Dr Mary Ramsay	Consultant Epidemiologist & Head of immunisation, Public Health England
Charity & Family Reps	
Rob Dawson	Meningitis Research Foundation
Mark Hunt	Meningitis Now
Kirsty Ermenekli Paul Gentry Nicole Zographou	Family representatives
DH Secretariat	
Cheryl Cavanagh	Immunisation Policy Lead, DHSC
Emily Dibble	Immunisation Policy Team, DHSC

Layla-Rose Ermenekli - aged 6

Personal account by Kirsty Ermenekli (Layla-Rose's mum)

[Inquest held]



Layla-Rose's brother had tonsillitis and her sister had a urinary infection.

Layla-Rose then became unwell with head and tummy ache and was given Calpol.

She continued to complain of feeling poorly on and off for a few days with on-going headache, tummy ache and noted that her legs were hurting.

She developed a very high temperature (>40o) and was given Ibuprofen while her mum phoned 111. It took over an hour for 111 to call back to say they were going to send an ambulance. Layla-Rose's mum had already made their own way to the hospital.

At A&E Layla-Rose was triaged. Her temperature had reduced to 38.1o and the staff wanted a urine sample which was difficult as Layla-Rose was not drinking. Her condition seemed to go up and down. Layla-Rose's mum later found out that at triage Layla-Rose's heart had been racing but she had not been told.

Layla-Rose was checked periodically. For example, after an hour and 15 minutes she was hot again so her observations were checked. She also took, and failed, the fluid challenge.

After another hour a doctor checked her - she was very grey and vomited. It was noted that it was likely a viral infection (especially given the illnesses of her siblings) and it was suggested that she do the fluid challenge again either at the hospital or at home. Layla-Rose's mum was given the impression she was wasting the doctor's time.

A nurse asked a junior paediatric doctor to look at Layla-Rose. That doctor spotted a mark on Layla-Rose's hip. That junior doctor mentioned it to a more senior doctor but they noted it was a bruise. Eventually, Layla-Rose was sent to HDU and given an antibiotic drip. In HDU she went into cardiac arrest.

The inquest concluded that Layla-Rose's death from [meningococcal](#) sepsis could have been avoided.

Summary message from Kirsty Ermenekli:

- Sepsis could have been picked up at least 3.5 hours earlier and antibiotics started.

Izzy Gentry - aged 16
Personal account by Paul Gentry (Izzy's dad)
[Inquest held]



Izzy was complaining of headaches and not feeling very well.

There had been a case of MenB at her college 2 weeks earlier and Izzy's mum had received a PHE letter.

Izzy developed a very high temperature, became lethargic, her headache became very severe with nausea and she developed neck & limb pain.

Izzy's mum phoned a medical helpline but Izzy collapsed so she then called an ambulance. She mentioned the PHE letter and the ambulance was coded as attending a potential meningococcal case. The paramedics recorded potential sepsis on notes.

Izzy arrived at A&E. She had improved slightly but still had a high temperature, headache, limb pain and a high heart rate. She had no rash. At triage the doctor made an initial examination and a diagnosis of gastroenteritis and discharged her with fluids and painkillers. The doctor made no reference to meningitis.

At home Izzy worsened and suffered a fit/convulsions. The paramedics returned and took her back to hospital. She was unconscious when she arrived at A&E.

The doctors said it was serious and she was taken to ITU. Within 20-30 minutes they advised that they thought it was meningitis.

Izzy was stabilised and sedated but deteriorated and her organs shut down.

The inquest concluded that Izzy's death had been contributed to by neglect. The Trust has since changed some of their policies and protocols to raise awareness of meningitis among A&E doctors.

Summary messages from Paul Gentry:

- Izzy was 16 and there was an initial delay when deciding whether to take her to adult or child A&E – she initially went to adult A&E
- When she first attended A&E she was in the early stages of sepsis - the A&E doctors involved later said that they had not been aware that limb pain was a possible symptom of meningitis
- Izzy was not given intravenous antibiotics during her first attendance

George Zographou - aged 18
Personal account by Nicole Zographou (George's sister)
[Awaiting Inquest]



George had previously had an undiagnosed infection in his blood and had been tested for meningitis. He wasn't feeling great but neither were the rest of the family.

He went to a music festival but felt sick and shaky – he started to be sick so thought he had a bug. He had not had any alcohol. He spent the night in his tent being sick and had cramps in the back of his legs. He could only crawl on his hands and knees. He was unable to walk without assistance.

Security alerted the medical team who took George to a medical tent on a buggy. George continued to vomit, had slightly low blood pressure and an increased heart rate. George's heart rate was normally very low due to a medical condition.

George's mum was phoned and she explained that his heart rate was too high. He was given morphine and his heart rate went down slightly.

A mottled bruise/rash was noticed on George's left foot. He was diagnosed with dehydration and a stress fracture.

George became agitated and was put on the floor. His mum (via the phone) asked that he be sent to hospital. The doctor said it was not an emergency so he would need to go in a taxi and pay. His mum googled a closer hospital than suggested but George told his mum he wanted to come home.

George's mum tried to persuade the medical team over the phone that George's condition was more serious but they refused to send George to hospital. His parents therefore left to pick him up and he was moved from the medical to a welfare tent via a buggy to await his parents. The medic noted he was alert and talking.

In the welfare tent George became agitated and aggressive with the medical team then lost consciousness and was thought to be sleeping. Staff in the welfare tent were told to provide 1:1 observation and the medical team left. George was in fact in a coma and soon after went into cardiac arrest. He was blue lighted to hospital and on life support for 5 days.

Summary messages from Nicole Zographou:

- Importance of protecting those who fall ill at mass gatherings outside of hospital e.g. knowledge of front-line staff, regulation
- Need for compassion from staff and listening to parents/self-advocacy
- Implications of multiple handovers between teams e.g. security, medical, welfare

Meningitis-related material targeted at parents, young people and healthcare professionals.

Published information and resources

- General resources
- Leading charity information
- Post-illness support and guidance

Many of these documents relate to a number of different stages of the pathway. These stages are:

- General awareness
- Signs and symptoms
- Prevention
- Public health management
- Diagnosis and treatment
- Post-illness support and guidance

General resources

Ref	Publication/ resource title	Audience	Web link	Additional information	Source	Stage
01	NICE guidance: Fever in children younger than 5 years, updated 2017	Public	https://www.nice.org.uk/guidance/cg160/ifp/chapter/About-this-information	Refers to Meningitis Research Foundation, and Meningitis Trust, as sources for further information. Symptoms information available in NICE Guidance ref 5	NICE	General awareness Signs and symptoms Diagnosis & treatment Post-illness support and guidance
02	Meningococcal disease: guidance, data and analysis: Public Health England (PHE) website	Clinicians Public Public Health Departments	https://www.gov.uk/government/collections/meningococcal-disease-guidance-data-and-analysis#diagnosis-and-management	PHE website includes links to Meningitis Research Foundation and Meningitis Now web sites This is more about Public Health Management of cases rather than signs and symptoms	PHE	Signs and symptoms Diagnosis & treatment

03	A Guide to immunisations up to one year of age: features the new MenB vaccination and the immunisation schedule from July 2016	Public	https://www.gov.uk/government/publications/a-guide-to-immunisations-for-babies-up-to-13-months-of-age	This contains no symptoms information	PHE NHS	Prevention
04	A guide to immunisations up to one year of age: features the immunisation schedule for babies born on or after 1 August 2017	Public	https://www.gov.uk/government/publications/a-guide-to-immunisations-for-babies-up-to-13-months-of-age		PHE NHS	• Prevention
05	NICE guidance: Meningitis (bacterial) and meningococcal septicaemia in under 16s: recognition, diagnosis and management: Clinical guideline [CG102], updated 2015	Healthcare professionals Under 16s with bacterial meningitis or meningococcal septicaemia, and their families and carers	https://www.nice.org.uk/guidance/cg102		NICE	General awareness Signs and symptoms Diagnosis and treatment Post-illness support and guidance
06	NICE Pathway: Bacterial meningitis and meningococcal	Healthcare professionals	https://pathways.nice.org.uk/pathways/bacterial-meningitis-		NICE	General awareness Signs and symptoms Diagnosis and

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	septicaemia overview		and-meningococcal-septicaemia			treatment Post-illness support and guidance
07	NICE guidance: Sepsis: recognition, diagnosis and early management, updated 2017	People with sepsis, their families and carers Healthcare professionals working in primary, secondary and tertiary care	https://www.nice.org.uk/guidance/ng51	Linda Glennie – MRF – was part of the NICE Guideline Development Group	NICE	Diagnosis & treatment Signs and symptoms Post-illness support and guidance
08	Guidance on the prevention and management of meningococcal meningitis and septicaemia in higher education institutions: Raising awareness, promoting immunisation and planning ahead, Public Health England and Universities UK, 2016	Higher education institutions	http://www.universities.ac.uk/policy-and-analysis/reports/Documents/2017/prevention-management-meningococcal-meningitis-septicaemia-higher-education.pdf	Includes links to MRF and Men Now	PHE Universities UK	General awareness Prevention Public Health Management
09	The UK joint specialist societies guideline on the diagnosis and management of acute	Hospital based clinicians	http://www.journalofinfection.com/article/S0163-4453(16)00024-	Guidelines produced by a working party consisting of infectious diseases physicians, neurologists, acute physicians,	The UK joint specialist societies	Prevention Diagnosis and treatment Post-illness support

	meningitis and meningococcal sepsis in immunocompetent adults, Working Party, 2016		4/fulltext	microbiologists, public health experts and patient group representatives. Written in collaboration with MRF (Linda Glennie co-author)	MRF	and guidance
10	Early Management of Suspected Meningitis and Meningococcal Sepsis in Immunocompetent Adults, The UK Joint Specialist Societies Guideline on the Diagnosis and Management of Acute Meningitis and Meningococcal Sepsis in Immunocompetent Adults, Jan 2016	Clinicians	https://www.britisheinfection.org/files/5414/5674/3289/algorithm.pdf	Includes information on signs and symptoms. Also included on the Meningitis Research Foundation website Also refers to follow up care	Published by MRF	Diagnosis and treatment
11	Guidance for public health management of meningococcal disease in the UK, Health Protection Agency, Meningococcus and Haemophilus Forum, updated 2012	Public Health Departments	https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/322008/Guidance_for_management_of_meningococcal_disease.pdf		HPA	Public Health Management
12	Interactive tool commissioned by the Department of Health	Health care professionals	http://www.spottingthesickchild.com/	The tool was taken over by the Royal College of Paediatric and Child Health in 2014-5.	Royal College of	Diagnosis & treatment

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	and Health Education England to support health professionals in the assessment of the acutely sick child				Paediatric and Child Health	
13	National Early Warning Score (NEWS) 2 to improve detection of acutely ill patients	Health care professionals	https://www.rcplondon.ac.uk/news/nhs-england-approves-use-national-early-warning-score-news-2-improve-detection-acutely-ill	Early warning system for identifying acutely ill patients, including those with sepsis		Diagnosis & treatment

Leading Charity Information

Information / resource available on the Meningitis Research Foundation website (<https://www.meningitis.org/healthcare-professionals/resources>) and Meningitis Now website ([Meningitis Now](#))

Ref	Publication / resource title	Audience	Additional information	Source	Stage
Meningitis Research Foundation Resources					
14 A	Student symptoms	Young people 15 - 25	Poster to raise awareness of meningitis and septicaemia and their symptoms. Poster and A6 flyer	MRF	General awareness Signs and symptoms
14 B	Symptoms alert!	Public	Poster to help identify the symptoms of meningitis and septicaemia in all age groups.	MRF	General awareness Signs and symptoms
14 C	Meningitis and septicaemia: Know the symptoms	Public	Poster to help identify the symptoms of meningitis and septicaemia in all age groups.	MRF	General awareness Signs and symptoms
14 D	Meningitis Baby Watch	Parents and other carers of babies and very small children	Illustrates symptoms to assist parents and other carers to recognise meningitis and septicaemia in babies and too young to explain how they are feeling Poster and A6 card. Also version printed for Red Book, which only covers half of all red books, due to local authorities' decision to include	MRF	General awareness Signs and symptoms
14 E	Symptoms card	All	Straight forward list of meningitis and septicaemia symptoms to fit into a wallet or purse	MRF	General awareness Signs and symptoms
14 F	Race against time	All	A symptoms leaflet addressing	MRF	General awareness

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			myths about meningitis and septicaemia.		Signs and symptoms
14 G	Tot watch	Parents and other carers of toddlers and young children under five	Leaflet to explain the early symptoms: limb pain, cold hands and feet, and pallor as well as more severe	MRF	General awareness Signs and symptoms
14 H	Am I At Risk	Areas with cases of meningitis		MRF	Public Health Management
14 I	Fact sheet: Hib influenza B vaccine	Public	MRF has 24 factsheets. These cover a range of FAQs on different disease types, vaccines, and other issues, such as travel.	MRF	General awareness Signs and symptoms Prevention Diagnosis & treatment Post-illness support and guidance
14 J	Fact sheet: MenACWY	Public		MRF	General awareness Signs and symptoms Prevention Diagnosis & treatment Post-illness support and guidance
14 K	Fact sheet: Men C	Public		MRF	General awareness Signs and symptoms Prevention Diagnosis & treatment
14 L	Fact sheet: Meningitis information for Nurseries and Crèches	Public		MRF	General awareness Signs and symptoms Prevention
14M	Fact sheet: Pneumococcal Meningitis – Vaccinations	Public		MRF	General awareness Signs and symptoms

					Prevention Diagnosis & treatment
14 N	Fact sheet: Information for schools	Public		MRF	General awareness Signs and symptoms Prevention
14 O	Fact sheet: Travellers and pilgrims	Public		MRF	General awareness Signs & symptoms Prevention
14 P	Fact sheet: UK Vaccines	Public		MRF	General awareness Prevention
14 Q	Fact sheet: Group A Streptococcus (GAS)	Public		MRF	General awareness Signs and symptoms Prevention Diagnosis & treatment
14 R	Fact sheet: Group B Streptococcal meningitis	Public		MRF	General awareness Signs and symptoms Prevention Diagnosis & treatment
14 S	Fact sheet: Men W	Public		MRF	General awareness Signs and symptoms Prevention Diagnosis & treatment
14 T	Fact sheet: Men B	Public		MRF	General awareness Signs and symptoms Prevention Diagnosis & treatment
14 U	Fact sheet: MMR	Public		MRF	General awareness Signs and symptoms Prevention

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14 V	Fact sheet: Viral meningitis	Public		MRF	General awareness Signs and symptoms Diagnosis & treatment Post-illness support and guidance
14 W	Lessons from research for doctors in training: recognition and early management of meningococcal disease in children and young people	Junior Doctors	A booklet to help doctors in the diagnosis and treatment of and treatment of meningitis and septicaemia.	MRF	Diagnosis and treatment
14 X	Clinician's Guide to Recognition and Early Management of Meningococcal Disease in Children	Doctors in A&E, PICU, Paediatrics and General Medicine	An interactive e-learning tool for doctors in training http://www.mrfpaediatricguide.info/	MRF	Diagnosis and treatment
14 Y	Management of meningococcal disease and management of bacterial meningitis in children and young people	Doctors in A&E, PICU, Paediatrics and General Medicine in the UK	Two posters updating the original St Mary's/MRF protocol 'Early Management of Meningococcal Disease' in line with NICE guideline CG102.	MRF	Diagnosis and treatment
14 Z	Early management of suspected bacterial meningitis and meningococcal sepsis in immunocompetent adults	Doctors in A&E, Critical Care, Infectious Diseases and General Medicine	Algorithm focused on minimising delays in diagnosis and administration of antibiotics, appropriate use of monitoring, investigations, critical care facilities and management of the complications of the disease See also ref 06	MRF	Diagnosis and treatment

14 AA	Vital signs for frontline Nurses – Early recognition of meningitis and septicaemia - UK	Doctors in A&E, Critical Care, Infectious Diseases and General Medicine	Algorithm focused on minimising delays in diagnosis and administration of antibiotics, appropriate use of monitoring, investigations, critical care facilities and management of the complications of the disease	MRF	Diagnosis and treatment
14 AB	Bacterial meningitis and septicaemia in children: A discharge checklist - England, Wales and Northern Ireland	Doctors in A&E, PICU, Paediatrics and General Medicine	Separate resource for Scotland - https://www.meningitis.org/getmedia/32c6d4cb-f327-4393-92a2-e76309d5150c/hospital-discharge-checklist-scotland-may-2016	MRF	Diagnosis and treatment
14 AC	Meningococcal meningitis and septicaemia – Identification and management for ambulance personnel	Ambulance Personnel	Card to help ambulance personnel identify and manage meningococcal septicaemia in patients they are transporting to hospital Poster and card. Currently out of date but due to be updated soon.	MRF	Diagnosis and treatment
14 AD	eTool: Improving the recognition, diagnosis and management of bacterial meningitis in young infants	Doctors in A&E, PICU, Paediatrics and General Medicine	Distance learning product	MRF	Diagnosis and treatment
14 AE	Management of bacterial meningitis in infants under three months of age	Doctors in A&E, PICU, Paediatrics and General Medicine	algorithm poster for clinicians can aid rapid identification and appropriate management of bacterial meningitis in infants under three months of age Published by MRF	MRF	Diagnosis and treatment

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14 AF	Lumbar Puncture in infants - Patient information sheet	Doctors in A&E, PICU, Paediatrics and General Medicine	An information sheet which clinicians can give to parents of young infants presenting with possible bacterial meningitis, to explain why the lumbar puncture procedure is necessary and to help reassure about the safety of the procedure RCPCH e-learning tool in collaboration with MRF https://www.rcpch.ac.uk/e-learning	RCPCH e-learning tool in collaboration with MRF	Diagnosis and treatment
14 AG	Meningococcal meningitis and septicaemia guidance notes: Diagnosis and treatment in General Practice - UK	General Practitioners in the UK	A booklet to help in the recognition of meningococcal disease, particularly in the early stage, emphasising key factors to identify severely ill patients. Booklet and wallchart	MRF	Diagnosis and treatment
14 AH	Vital signs, vital issues - UK	Community practitioners in the UK	A booklet to assist with early recognition of meningitis and septicaemia; to inform about meningitis vaccines and the diseases they prevent, and to help practitioners reassure parents about vaccine safety No longer available but due to be updated in near future.	MRF	Diagnosis and treatment Prevention

Meningitis Now					
15 A	George Z's Story	Public		Men. Now	General awareness
15 B	Meningitis explained	Public		Men. Now	General awareness Signs and symptoms Diagnosis & treatment Post-illness support and guidance
15 C	Meningitis signs and symptoms	Public		Men. Now	General awareness Signs and symptoms
15 D	Posters, Signs and symptoms card	Public		Men. Now	General awareness Signs and symptoms Diagnosis & treatment Post-illness support and guidance
15 E	Meningitis can affect anyone: knowing the signs and symptoms can save lives	Public		Men. Now	General awareness Signs and symptoms Diagnosis & treatment Post-illness support and guidance
15 F	Viral meningitis, the facts	Public		Men. Now	General awareness Signs and symptoms Diagnosis & treatment Post-illness support & guidance
15 G	Meningococcal disease, the facts	Public		Men. Now	General awareness Signs and symptoms Diagnosis & treatment Post-illness support and guidance
15 H	Pneumococcal meningitis, the facts	Public		Men. Now	General awareness Signs and symptoms Diagnosis & treatment

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					Post-illness support and guidance
15 I	Tuberculous (TB) meningitis, The facts	Public		Men. Now	General awareness Signs and symptoms Diagnosis & treatment Post-illness support and guidance
15 J	Neonatal meningitis, the facts	Public		Men. Now	General awareness Signs and symptoms Diagnosis & treatment Post-illness support and guidance
15 K	Meningitis vaccines, the facts	Public		Men. Now	General awareness Signs and symptoms Diagnosis & treatment Post-illness support and guidance
15 L	Be vocal about viral meningitis: Guide for employers	Employers		Men. Now	General awareness Signs and symptoms Diagnosis & treatment Post-illness support and guidance
15 M	Fact sheet – Our support services	Public		Men Now	• Post-illness support and guidance
15 N	Fact sheet – Structure and function of the brain	Public		Men Now MRF	General Awareness
15 O	Fact sheet – Kidney damage during and after septicaemia	Public		Men Now MRF	Diagnosis and treatment Post-illness support and guidance
15 P	Fact sheet – Useful and relevant research	Public		Men Now MRF	• Post-illness support and guidance
15 Q	Fact sheet – Difficulty	Public		Men Now	• Post-illness support and

	accessing NHS services			MRF	guidance
15 R	References and evidence	Clinicians Public	Includes links to some documents already listed		<ul style="list-style-type: none"> • General awareness • Signs and symptoms • Diagnosis & treatment
15 S	Be vocal about meningitis: information for health professionals	Health Professionals		Published by Men. Now	<ul style="list-style-type: none"> • General awareness • Signs and symptoms • Diagnosis & treatment

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Post-illness support and guidance

Ref	Publication title	Audience	Additional information	Source	Stage
16	Support for you	Patients		Published by MRF	Post-illness support & guidance
17	Meningitis and septicaemia: What happens next?	Patients		Published by MRF	Post-illness support and guidance
18	Your guide - Recovering from childhood meningitis and septicaemia UK	Parents/carers	Also a Journal available with this resource. Plus additional factsheets available online re: after effects.	MRF and Men Now.	Post-illness support and guidance
19	Living with bereavement	Public		Published by MRF	Post-illness support and guidance
20	After meningitis: recovery following meningitis or meningococcal septicaemia	Public		Men Now	Post-illness support and guidance
21	Bereavement following meningitis: how we can support you	Public		Men Now	Post-illness support and guidance
22	Information for families: Meningitis and childhood deafness	Public		Men Now MRF	Post-illness support and guidance
23	Fact sheet - Hearing loss and tinnitus after meningitis	Public		Men Now MRF	Post-illness support and guidance
24	Fact sheet - Problems with balance after	Public		Men Now	Post-illness support

	meningitis			MRF	and guidance
25	Fact sheet – Physical effects of ABI	Public		Men Now MRF	Post-illness support and guidance
26	Fact sheet – Sensory effects of ABI	Public		Men Now MRF	Post-illness support and guidance
27	Fact sheet – Learning and cognitive effect of ABI	Public		Men Now MRF	Post-illness support and guidance
28	Fact sheet – Emotional and behavioural effects of ABI	Public		Men Now MRF	Post-illness support and guidance
29	Fact sheet – Speech, language and communication problems after ABI	Public		Men Now MRF	Post-illness support and guidance
30	Fact sheet – bone growth problems after septicaemia	Public		Men Now MRF	Post-illness support and guidance
31	Fact sheet – Skin scarring after septicaemia	Public		Men Now MRF	Post-illness support and guidance
32	Fact sheet – The use of external fixators for limb correction	Public		Men Now MRF	Post-illness support and guidance
33	Fact sheet – Amputation including loss of finger, toes and limbs	Public		Men Now MRF	Post-illness support and guidance

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34	Fact sheet – Amputee rehabilitation	Public		Men Now MRF	Post-illness support and guidance
35	Fact sheet – Benefits	Public		Men Now	Post-illness support and guidance
36	Fact sheet – Complementary therapies	Public		Men Now	Post-illness support and guidance
37	Fact sheet – Educational rights	Public		Men Now MRF	Post-illness support and guidance
38	Fact sheet – Social work and community support	Public		Men Now MRF	Post-illness support and guidance
39	Fact sheet - Learning and development	Public		Men Now	Post-illness support and guidance

Example of e-learning/interactive training packages available to support continuing professional development for healthcare professionals

Royal College of Paediatrics & Child Health (RCPCH)

- **Bacterial Meningitis and Meningococcal Septicaemia in Children** – aimed at those who want to improve their ability to assess and manage those children who present with possible bacterial meningitis and/or meningococcal septicaemia
- **Spotting the Sick Child** - to support health professionals in the assessment of the acutely sick child.

<https://www.rcch.ac.uk/training-examinations-professional-development/continuing-professional-development-cpd/education-p-7>

Health Education England (HEE)

- eLearning for Healthcare (eLfh) 'THINK SEPSIS':
- Primary Care e-learning for sepsis identification and management (including children).
- Paediatrics - an introductory film linked to associated educational and safety-netting materials
- Paediatrics - an extended case based guide involving the stories of three children, their assessment, experiences and treatment to support clinicians in the recognition and treatment of sepsis in children.

AMR Training Guide - signposts prescribers and other staff to educational sessions on infections that will help support their learning (includes paediatrics, meningitis and sepsis).

Primary Care: RCGP sepsis spotlight - Online toolkit linked to all learning resources available through a designated RCGP portal & educational interventions such as workshops, e-learning, webinar and podcasts

References

ⁱ Mayr FB, Yende S, Angus DC. Epidemiology of severe sepsis. *Virulence* 2014; **5**(1): 4-11.
<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3916382/pdf/viru-5-4.pdf>

ⁱⁱ Fever in under 5s: Assessment and initial management, NICE, Clinical Guideline [CG160] <https://www.nice.org.uk/guidance/cg160>

ⁱⁱⁱ The validation studies are:

- Verbakel JY, Van den Bruel A, Thompson M, Stevens R, Aertgeerts B, Oostenbrink R, Moll HA, Berger MY, Lakhanpaul M, Mant D, Buntinx F; European Research Network on Recognising Serious Infection (ERNIE). How well do clinical prediction rules perform in identifying serious infections in acutely ill children across an international network of ambulatory care datasets? *BMC Med.* 2013 Jan 15;11:10. doi: 10.1186/1741-7015-11-10.
- Kerkhof E, Lakhanpaul M, Ray S, Verbakel JY, Van den Bruel A, Thompson M, Berger MY, Moll HA, Oostenbrink R; European Research Network on recognising serious InfEctions (ERNIE) members. The predictive value of the NICE "red traffic lights" in acutely ill children. *PLoS One.* 2014 Mar 14;9(3):e90847. doi: 10.1371/journal.pone.0090847
- De S, Williams GJ, Hayen A, Macaskill P, McCaskill M, Isaacs D, Craig JC. Accuracy of the "traffic light" clinical decision rule for serious bacterial infections in young children with fever: a retrospective cohort study. *BMJ.* 2013 Feb 13;346:f866. doi: 10.1136/bmj.f866.

^{iv} Campbell H et al, Changing attitudes to childhood immunisation in English parents, *Vaccine* 35 (2017) 2979–2985

^v An online survey carried out by Opinium Research on behalf of Meningitis Trust (Meningitis Now) of 1002 adults aged 18 – 24 years from 21 – 24 July 2013. (Unpublished) For more detail, please contact Meningitis Now research@meningitisnow.org

^{vi} Same as v

^{vii} Thompson MJ, Ninis N, Perera R, et al. Clinical recognition of meningococcal disease in children and adolescents. *Lancet* 2006; **367** (9508): 397-403

^{viii} Same as vii

^{ix} References on children seen by a doctor but not admitted to hospital in early phases of illness:

Thompson MJ, Ninis N, Perera R, Mayon-White R, Phillips C, Bailey L, Harnden A, Mant D, Levin M. Clinical recognition of meningococcal disease in children and adolescents. Lancet. 2006 Feb 4;367(9508):397-403.

Riordan FA, Thomson AP, Sills JA, Hart CA. Who spots the spots? Diagnosis and treatment of early meningococcal disease in children. BMJ. 1996 Nov 16;313(7067):1255-6.

^x Hard Truths: The Journey to Putting Patients First:

Volume One of the Government Response to the Mid Staffordshire NHS Foundation Trust Public Inquiry

Volume Two of the Government Response to the Mid Staffordshire NHS Foundation Trust Public Inquiry: Response to the Inquiry's Recommendations

<https://www.gov.uk/government/publications/mid-staffordshire-nhs-ft-public-inquiry-government-response>

^{xi} The Purple Guide to Health, Safety and Welfare at Music and other Events

<https://www.thepurpleguide.co.uk/>

^{xii} HEE's sepsis programme on eLearning for Healthcare incl. new training material to tackle the treatment and diagnosis of sepsis in children is available at <https://www.e-lfh.org.uk/programmes/sepsis/>