



Spotting a seriously ill child

The need for safety netting advice for parents when a sick child is sent home by a health professional.

Executive summary

A major difficulty in recognising the early signs of meningitis and sepsis is that they are often very similar to other common, less serious childhood illnesses, such as flu or mild viral illness.

One study found that around half of children who had the most common type of bacterial meningitis were sent home after their first visit to a GP or health professional and not admitted to hospital.

National clinical recommendations suggest that parents and carers of children and young people presenting with early non-specific symptoms should be given 'safety netting' information before they are sent home that includes information on bacterial meningitis and sepsis. There is also evidence that providing good quality safety netting information could decrease demand for antibiotics from patients and improve antimicrobial stewardship.

In reality, safety netting advice and disease information is not always given to parents.

In addition, existing safety netting resources contain variable information, may not pick up both sepsis and meningitis, and are not monitored or evaluated to ensure they are delivered to parents by health professionals.

This leads to inappropriate advice and management, can delay life-saving treatment, and costs lives.

Recommendations

1. Audit of National Institute for Health and Care Excellence (NICE) Clinical Guideline CG102 'Meningitis (bacterial) and meningococcal septicaemia in under 16s: recognition, diagnosis and management' and accompanying Quality Standard QS19 'Meningitis (Bacterial) and Meningococcal Septicaemia in Children and Young People' [appendix 1.4] to determine the true level and quality of safety netting information being delivered to parents.
2. Varied, local sepsis and meningitis safety netting resources [appendix 1.3] to be combined and a national standard template agreed for healthcare professionals to use.
3. A national campaign and central resource hub for parents to enable them to access safety netting information easily.
4. Existing national Quality Measures for safety netting [appendix 1.4] to be developed into metrics used by the Care Quality Commission during inspection to ensure safety netting advice is delivered to parents.
5. Education and training materials for health professionals should include consideration of safety netting information in the context of infection prevention and control and antimicrobial resistance and stewardship.

Meningitis, septicaemia and sepsis

Bacterial infections are not always serious. However, bacteria can sometimes invade the body causing life-threatening illness. Septicaemia is a high level of bacteria in the blood causing blood poisoning which triggers sepsis. Sepsis is the body's overwhelming response to infection that can lead to tissue damage, organ failure and death (the terms septicaemia and sepsis are sometimes used interchangeably). If the bacteria reach the fluid surrounding the brain this causes meningitis – the swelling of the meninges (the lining around the brain and spinal cord). Both meningitis and sepsis can kill within hours. Severe cases of sepsis and meningitis are most often associated with bacterial infection, but they can also be caused by viral and fungal infections.

Encouraging parents to seek medical attention for a child early therefore risks overburdening GPs and emergency departments with large numbers of worried parents whose children have less serious illnesses.

However, the fast action of meningitis and sepsis means that leaving symptoms to deteriorate unchecked could cost a child's life.

Most children with meningitis and sepsis from meningococcal disease display only non-specific symptoms in the first 4-6 hours of illness but are close to death in 24 hours

Difficulties spotting meningitis or sepsis

Meningitis and sepsis can occur together or separately and share many early symptoms. A major difficulty in recognising these early signs is that they are often very similar to other common, less serious childhood illnesses.

Recognising meningitis and sepsis in young infants is even more challenging because symptoms are non-specific and show little progression over time. Additionally, 50% of young infants with meningitis do not present with the classic sign of fever.¹

As a result, spotting a child with life-threatening meningitis has been described as finding 'a needle in a haystack'.²

One of the major causes of meningitis and sepsis in childhood is infection by meningococcal bacteria (meningococcal disease).

Most children with meningitis or sepsis from meningococcal disease display only non-specific symptoms in the first 4-6 hours of illness but are close to death by 24 hours.³ When seen by a doctor, these early non-specific signs make the diagnosis extremely difficult.⁴

Seeking help

On average, parents whose children have meningococcal disease seek help around 5 hours after the first symptoms appear and 76% attend hospital within 24 hours - of these 53% attend their GP surgery before going to hospital.³

In one study, the average time to hospital admission was around 19 hours.³ While the rash and impaired consciousness commonly associated with meningococcal disease developed late in the children in this study (at around 13-22 hours after first symptoms), 72% of cases show early symptoms of sepsis that could have been picked up well before they went to hospital (leg pains, cold hands and feet, abnormal skin colour that first developed at around 8 hours).

Enabling parents to understand symptoms which can help distinguish meningitis and sepsis from other milder illness is therefore key.

Equally, healthcare professionals need to encourage parents to look for these symptoms if they send a child home at first visit [*appendix 1.1 – patient pathway*].

1. Okike, Ifeanyichukwu O., et al. "Clinical Characteristics and Risk Factors for Poor Outcome in Infants Less Than 90 Days of Age with Bacterial Meningitis in the United Kingdom and Ireland." *Pediatric infectious disease journal* (2018).

2. Davis, Tessa, et al. "Needle in a haystack: How to identify the sick febrile child." *Emergency Medicine Australasia* 27.4 (2015): 284-286.

3. 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.

4. 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.

Sending a child home

Studies spanning the last two decades have shown difficulties with meningitis diagnosis. One study found that around half (49%) of children who had the most common type of bacterial meningitis were sent home after their first visit to a GP or health professional and not admitted to hospital.³

49% of children who had the most common type of bacterial meningitis were sent home after their first visit to a GP

A recent (2017) study in very young infants showed that the problem persists. Only 30% of parents of very young infants with bacterial meningitis took the child straight to the hospital: 70% sought help by phoning the GP, calling the 24-hour NHS telephone service or contacting the community midwife, and 28% were advised to stay at home.⁵

Safety netting

The NICE bacterial meningitis and meningococcal disease quality standard recommends that parents and carers of children and young people presenting with early non-specific symptoms and signs should be given 'safety netting' information before they are sent home that includes information on bacterial meningitis and sepsis.⁶ 'Safety netting' information comprises oral and/or written information on what symptoms to look out for, how to access further care, likely time course of expected illness and, if appropriate, the uncertainty of the diagnosis.⁷

In reality, safety netting advice and disease information is not always given to parents [see appendix 1.2 – accounts from parents].

Inappropriate action

Research into young infants with bacterial meningitis found 30% were assessed to have received inappropriate pre-hospital management which resulted in delays in seeking help despite the presence of worrying clinical features.⁵

Examples of inappropriate advice given to parents includes being told that their child's fever was due to a change in milk formula, or where prune juice was recommended for fever and irritability.

Inappropriate advice can delay life-saving treatment. If medical advice, either in person or over the telephone, reassures that the child was suffering from a 'trivial infection', parents may hesitate to question their doctor's initial diagnosis and delay seeking further advice when the child's condition subsequently deteriorates.⁸

In one study, while 35 children had signs of meningococcal infection, parents of 4 of them were inappropriately reassured by advice given over the telephone by GPs or health professionals, without the child being properly assessed.⁸

30% were assessed to have received inappropriate pre-hospital management

Even once a diagnosis has been made, advice and information may not be given to parents. An audit of national guidance on sepsis management found that only 5.6% of sepsis patients are given any printed information about the illness.⁹ This is despite recommendations that are supposed to ensure a care team member is nominated to give information to families and carers.

5. Okike, Ifeanyichukwu O., et al. "Assessment of healthcare delivery in the early management of bacterial meningitis in UK young infants: an observational study." *BMJ open* 7.8 (2017): e015700.

6. Meningitis (bacterial) and meningococcal septicaemia in children and young people. Quality standard [QS19] Published date: June 2012

7. Roland D et al. Safety netting in healthcare settings: what it means, and for whom? *Arch Dis Child Educ Pract Ed* 2014;99:48–53. doi:10.1136/archdischild-2012-303056.

8. Nadel, S et al. Avoidable deficiencies in the delivery of health care to children with meningococcal disease. *Journal of Accident & Emergency Medicine*, 1998;15:298-303

9. APL Goodwin FRCA FFICM et al. Just Say Sepsis! A review of the process of care received by patients with sepsis. A report by the National Confidential Enquiry into Patient Outcome and Death (2015)

Spotting the seriously ill child

Because of the non-specific early symptoms of meningitis and sepsis, parental concern should always be seriously considered as a reason for admitting a feverish or deteriorating child for further observation.²

National guidance, standards and recommendations for meningitis and sepsis recognition frequently point towards a mix of medical knowledge, clinical experience and the gut feeling of clinicians and parents. An influential review of prediction rules for identifying children with serious infection found that the most useful clinical features for ruling in serious infection was parental or clinician overall concern that the illness was different from previous illnesses or that something was wrong.¹⁰ The NICE clinical meningitis guideline, in its advice to parents, states, 'Not everyone gets all of these symptoms. If you think your child is ill enough to need medical help, then trust your instincts.'¹¹ It also encourages clinicians to take parents' concerns seriously.

Parents and carers know their children best 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 concerns should be encouraged and healthcare professionals should respect those concerns.¹²

In addition, when faced with often confusing early symptoms of sepsis and meningitis, research shows that parents need information to contain permission-giving lines, in order to seek help, such as 'don't be afraid to ask a health professional'.¹³

If a child is sent home after a first visit to a health professional, parents should therefore not only be given medical information about symptoms, but also need reassurance that they are being listened to and permission to return if they believe their child's illness is getting worse.

Existing safety netting advice

Safety netting advice and information does exist for both sepsis and meningitis [*appendix 1.3 – current safety netting advice*] but there is no audit or check to ensure it is delivered to parents. The information also varies in its advice.

Furthermore, while the early symptoms of both sepsis and meningitis overlap, national, standardised safety netting advice does not exist that covers both sepsis and meningitis. This could mean parents are given safety netting advice for sepsis and miss meningitis, or vice versa.



Izzy Gentry's death, was linked to 'neglect and gross failures in care'. She presented with gastrointestinal symptoms, headache, and neck stiffness that are more typical of meningitis compared to sepsis. Paramedics considered sepsis but secondary care dismissed it as gastroenteritis. Safety netting advice needs to capture both sepsis and meningitis.

10. Thompson M et al. Systematic review and validation of prediction rules for identifying children with serious infections in emergency departments and urgent-access primary care. *Health Technology Assessment* 2012; 16: ISSN 1366-5278.

11. Meningitis (bacterial) and meningococcal septicaemia in under 16s: recognition, diagnosis and management. NICE Clinical guideline [CG102] Published date: June 2010. Last updated: February 2015.

12. Meningococcal Working Group report. 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 Department of Health and Social Care. April 2018.

13. Sepsis Campaign Development Research. Qualitative Research Findings. Market research for Public Health England by Define Research & Insight Ltd. September 2016

Positive impact of safety-netting

GP's are often the first point of call for parents with a sick child. However, without safety-netting advice being given if a child is sent home, multiple appointments or contacts can be made for a relatively well child. Safety netting advice reduces re-attendances and parents want and need explicit and consistent advice for appropriate home management of their unwell child.^{14,15}

Additionally, the provision of safety netting information may improve antimicrobial stewardship.¹⁶ A survey of healthcare educators identified a perception amongst clinicians that parents want antibiotics for their child but in reality parents may be satisfied with information about how to manage symptoms and how to identify signs of deterioration.

Monitoring safety netting

National quality standards for safety netting advice already exist for meningitis [appendix 1.4] management but these have not been audited or measured.⁶

An expert Meningococcal Working Group was established in 2018 at the request of the Secretary of State for Health and Social Care with a view to improved assurance of early diagnosis and of meningitis. The group recommended that patients and carers should be empowered with appropriate knowledge so they can seek further advice and assessment if concerned. The recommendation stated that 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. They suggested, as an example, that the Care Quality Commission could consider this metric during inspections of acute trusts and primary care.¹²

Recommendations

Based on the evidence in this report, Meningitis Research Foundation has made the following recommendations:

1. Audit of National Institute for Health and Care Excellence Clinical Guideline nCG102 '*Meningitis (bacterial) and meningococcal septicaemia in under 16s: recognition, diagnosis and management*' and accompanying Quality Standard QS19 '*Meningitis (Bacterial) and Meningococcal Septicaemia in Children and Young People*' [see appendix 1.4] to determine the true level and quality of safety netting information being delivered to parents.
2. Varied, local sepsis and meningitis safety netting resources [appendix 1.3] to be combined and a national standard template agreed for health professionals to use.
3. A national campaign and central resource hub for parents to enable them to access safety netting information easily.
4. Quality measures from existing safety netting quality standards [appendix 1.4] to be developed into metrics used by the Care Quality Commission during inspection to ensure safety netting advice is delivered to parents.
5. Education and training materials for health professionals should include consideration of safety netting information in the context of infection prevention and control and antimicrobial resistance and stewardship.

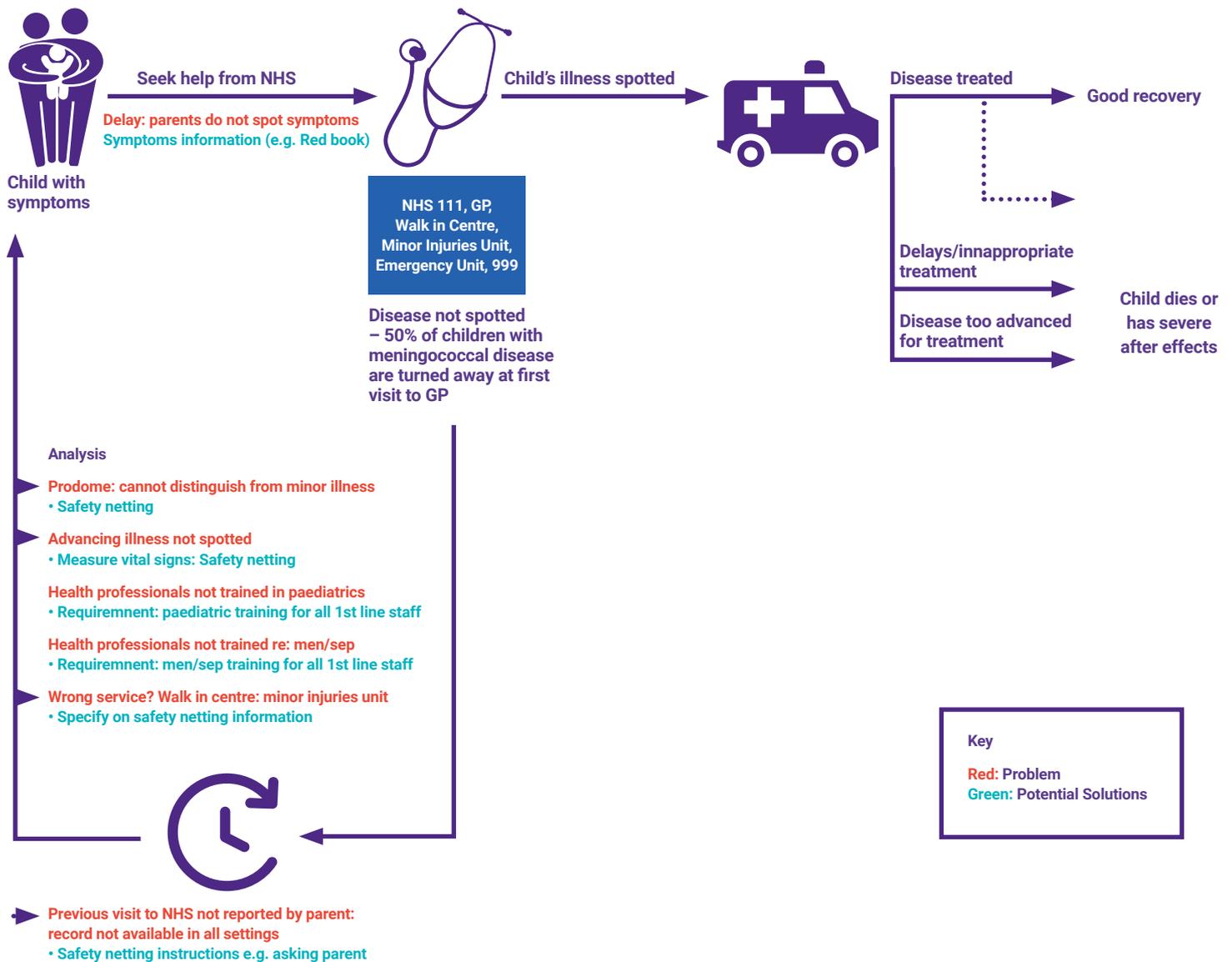
14. Maguire S, Ranmal R, Komulainen S, Pearse S, Maconochie I, Lakhnypaul M, Davies F, Kai J, Stephenson T. On behalf of the RCPCH Fever Project Board (2011) Which urgent care services do febrile children use and why? Archives of Disease in Childhood 2011 (online June 3)

15. Royal College of Paediatrics and Child Health et al. To understand and improve the experience of parents and carers who need advice when a child has a fever (high temperature). RESEARCH REPORT March 2010.

16. NHS Health Education England (2018). Tackling antimicrobial resistance: educational priorities. Available from <https://hee.nhs.uk/sites/default/files/documents/Tackling%20antimicrobial%20resistance%20-%20educational%20priorities%20report.pdf> (Accessed September 2018)

Appendix 1.1

Patient pathway and analysis of problems and solutions that could be addressed to improve health outcomes for children with meningitis and sepsis



Appendix 1.2

We asked parents of children who had meningitis to give us an account of their experience if they had been sent home after a first visit to a health professional.

We received 134 accounts from people who had been sent home after the first visit to a GP via our facebook page. While most cases of meningitis are dealt with appropriately, these accounts highlight some of the difficulties of diagnosis at the early stages of meningitis and sepsis and the need to provide safety netting advice so that parents feel empowered and able to return for help if things get worse.

This is a summary of the 134 accounts we received. Parents were simply asked to share their story and so all of the information pertaining to their experience may not have been captured. The exercise was intended to help recognise some common themes.

Of the 134 stories we received:

23 were from parents whose child had died, the remainder were survivors although many had after affects, such as amputations or brain injury.

28 specifically mentioned feeling lucky that things hadn't turned out worse. Safety netting information removes reliance on 'luck' by giving structured advice that empowers parents to monitor their child frequently and take action if they are concerned.

103 were inappropriately reassured, due to early signs being similar to milder illness. Safety netting information would help to combat inappropriate reassurance.

“He didn’t give me a full examination, despite me saying I had a horrendous headache and neck stiffness, he just prescribed some Codeine and rest.”

“I was even told ‘if it were meningitis u would be dead by now’.”

“I was told it was just a tension headache.”

“The paramedics tried to put me back to bed saying I was drunk and needed to sleep it off. Being in my mid-twenties and being Xmas eve I guess it made sense to them. It was only when they were told that I was breastfeeding my 9-week-old baby, and therefore not drinking, that they took me seriously. But my family had to argue with them even after they knew.”

“Luckily someone had taken blood cultures and we were telephoned approx. 27 hours later.”

“I was incredibly lucky.”

“I was just very lucky that my Nan checked on me.”

40 felt that they knew the illness was serious, even if they were told it wasn't. National clinical guidance recommend that doctors trust parent's instincts and safety netting advice that included this would help to empower parents to suggest mention meningitis and sepsis to a healthcare professional.

"I argued it but I believed as they were medically minded they knew more than me. Took the calpol they gave me and left the hospital under their instruction. I beat myself up every day for not listening to my motherly instinct. [He] died of meningococcal septicaemia early hours New Year's morning."

"I just had a feeling."

"We took her to the GP on Thursday morning because she was not getting any better. The GP said he has two children and that it's just normal baby behaviour. We weren't satisfied with this and went straight to emergency."

"I was convinced there was something wrong and managed to get an appointment with a doctor who had also just had a baby and had read up on infant diagnoses. We caught it early and he survived with no health issues. However, if I had followed the first doctors' advice things would have been very different."

"I can't help thinking that it could have been prevented if my concerns had been taken seriously in the first place."

"I was told to nurse him through it, the GP being satisfied that he'd already been seen that day - despite my own alarm bells going bananas!"

"GP's need to listen to parents we know our children better than anyone."

"...had to rush her back in 24 hours later despite me constantly contacting them telling them something wasn't right."

10 didn't feel they could go back to their initial GP/health professional when their child got worse after a first visit. Safety netting advice should encourage parents to return if the child get worse.

"Luckily I took him to a different Doctor the next day."

"It was the 3rd GP that made arrangement for an instant hospital admission. We have been very lucky, it could very easily have been a different outcome."

"Mummy instincts kicked in again and we took her to another local hospital where she got worse and they rushed her off."

"Luckily my instincts kicked in and 30 mins later I rang an ambulance."

"We took her to the GP on the Monday, got the usual viral diagnosis and eye infection (because she couldn't open her eyes) so I wasn't happy and took her to A&E."

"As a family [we] are so glad I went with a mother's instinct and I knew our baby was seriously ill and was not getting better. I urge any parent Guardian to not give up we know our children. I believe to this day if I did not act how I did my little lad would not be here today."

5 parents mentioned being given advice to come back if things got worse. Even this limited safety netting advice still helped to ensure children with meningitis and sepsis were treated quickly.

64 mentioned being persistent or needed to go back to a healthcare professional several times. Safety netting advice should encourage parents to return if their child gets worse.

“I telephoned my own GP as she was worse and was told to call back two hours later if no improvement.”

“My paediatrician did give us his cell number and followed up with us throughout the day.”

“Saw GP who said to see how she went and may need to be admitted to hospital for a drip if she didn’t feed, and to call her if she got worse.”

“Will always be grateful to them for being a phone call away when I didn’t know how to deal with the change in my boy.”

“I was initially referred to the hospital by a go where a doctor saw him but sent us home again with a card giving us direct access to paediatric a & e if we needed it.”

“We insisted he should go to hospital.”

“I took him to the doctor’s 3 or 4 times seeing different people and was told a few different things including that it was a virus.”

“My advice to parents is always trust your instincts fight for them second 3rd 4th 5th opinions if your instincts are telling you it is serious.”

“I called the doctor out not once, twice but 3 times to be told ear/throat infection then that I was an over anxious mother and put him to bed. Unfortunately my baby was dead by morning, 24hrs before he was running around a happy lad.”

A word cloud of the most common words in their responses.



Appendix 1.3

Safety netting advice exists but there is no national standard that combines information to improve both meningitis and sepsis recognition.

A. Safety netting resource supplied with [NICE Guideline CG160](#)

Issues include:

- Only useful for children with fever, despite only around half of babies under three months of age who have bacterial meningitis presenting with fever.¹

B. NHS England Primary Care [Resource Pack](#)

Issues include:

- Provides safety netting advice for sepsis but some classic features of meningitis are missed which may be the only symptoms present. Gastrointestinal symptoms, vomiting and headache are often early and more typical signs of meningitis compared to sepsis.

C. Royal College of General Practitioners information for unwell children

Issues include:

- Not easily available directly to patients. Does not contain all meningitis and sepsis safety netting information in one resource.

Appendix 1.4

Meningitis (bacterial) and meningococcal septicaemia in children and young people. Quality standard QS19. Published date: June 2012

Quality statement 1: 'Safety netting' information

Parents and carers of children and young people presenting with non-specific symptoms and signs are given 'safety netting' information that includes information on bacterial meningitis and meningococcal septicaemia.

'Safety netting' information comprises oral and/or written information on what symptoms to look out for, how to access further care, likely time course of expected illness and, if appropriate, the uncertainty of the diagnosis.

Information on warning symptoms should include a specific instruction for parents and carers looking after a feverish child to seek further advice if any of the following occur:

- The child develops a non-blanching rash.
- The parent or carer feels that the child is less well than when they previously sought advice.
- The parent or carer is more worried than when they previously sought advice.
- The fever lasts longer than 5 days.
- The parent or carer is distressed, or concerned that they are unable to look after the child.
- The child is lethargic or irritable.
- The child stops feeding (infants only).
- The child has a fit.