

Child Death Review Programme

Rapid response on deaths of children from meningitis and meningococcal disease in Wales

This rapid response on deaths of children from meningitis and meningococcal disease in Wales is undertaken for, and at the request of, Welsh Government. It seeks to describe the numbers of cases known to the Child Death Review Programme and identify key guidance/recommendations in existence for the UK that could contribute to reducing child deaths from meningitis.

Due to the overlap between meningococcal sepsis and meningococcal meningitis both in clinical terms and within the data identified, deaths from meningococcal disease were included irrespective of whether there was a mention of meningitis. The response focuses on acute meningitis and meningococcal disease; although we recognise that there may, on occasion, be later effects from meningitis that can contribute to death.

The Observatory Evidence Service undertook a scoping searchⁱ to inform this response. The search was focused on guidance and recommendations on diagnosis and treatment of meningitis in children and young people under 18 years of age from the websites of the National Institute for Health and Care Excellence (NICE), health protection within Public Health England (formerly the Health Protection Agency), Meningitis Research Foundation, Royal College of Paediatrics and Child Health, Royal College of General Practice, and the College of Emergency Medicine.

Notification and laboratory reports of meningitis and meningococcal disease

In the ten years between 2003 and 2012, there were 930 clinical notifications of meningitis and

710 clinical notifications of meningococcal septicaemia among all ages in Wales. Fifty five percent of meningitis notifications and 86% of meningococcal septicaemia notifications were in children and young people under 18 years of age. Amongst those under 18 years of age, meningitis and meningococcal septicaemia rates were highest in those under one year of age.

During the ten years between 2003 and 2012, there were 89 laboratory reports of patients under 18 years of age with a cerebrospinal fluid (CSF) specimen positive for *Neisseria meningitidis*. Of these, 48 were known to be *Neisseria meningitidis* group B and none were group C. In addition, between 2003 and 2012, there were 21 laboratory reports of patients under 18 years of age with CSF specimens positive for *Streptococcus pneumoniae*. There were no laboratory reports of patients under 18 years of age with a CSF specimen positive for *Haemophilus influenzae* type b. Rates of CSF specimens positive for *Neisseria meningitidis* were highest in those under one year of age.

Positive blood specimens represent cases of septicaemia. In the ten years between 2003 and 2012, there were 507 laboratory reports of patients under 18 years of age with blood specimens positive for *Neisseria meningitidis*. Of these, 306 were known to be *Neisseria meningitidis* group B and one group C.

ⁱ A scoping search uses easily accessible sources of information and is not intended to be a comprehensive search for all available material. It can therefore potentially miss important sources of information. There is no critical appraisal of the identified sources nor any attempt at synthesis of findings.



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This contextual information was provided by Public Health Wales.

Deaths in Wales 2009-present

Between 1 October 2009 and 1 July 2014 there were 18 deaths of children and young people under 18 years of age, who were either normally resident in Wales or who died in Wales, where acute meningitis or meningococcal disease was a contributory factor identified from the Child Death Review Databaseⁱⁱ. Twelve of these involved meningococcal disease and the remaining deaths involved bacterial meningitis, including pneumococcal and streptococcus Group A infection. Ten of these were children under two years of age, four of whom were under one year of age. No deaths from viral meningitis were identified during this period. Some of those who died from pneumococcal meningitis were born before the cohort who would have received universal vaccination for pneumococcal disease (born before 2004).

Existing recommendations

The following recommendations for the UK were identified

Population prevention:

- [Immunisations against infectious disease](#) (the Green Book) recommends children are vaccinated to provide protection against:
 - Pneumococcal disease
 - Conjugate vaccine at two and four months, and within a month of the first birthday
 - Polysaccharide vaccine for those over the age of two in clinical risk groups
 - Meningococcal group C disease at three months, within a month of the first birthday and at 14 years
 - *Haemophilus influenzae* type b at two, three and four months, and within a month of the first birthday

ⁱⁱInternational Statistical Classification of Diseases and Related Health Problems 10th Revision, codes G00, G03, A39 or text provided directly by a clinician.

- Other infections that may cause meningitis, including mumps and measles

Identification, management and treatment:

- [NICE clinical guideline 102](#) *Bacterial meningitis and meningococcal septicaemia in children. Management of bacterial meningitis and meningococcal septicaemia in children and young people younger than 16 years in primary and secondary care*
 - This covers
 - Symptoms and signs and initial assessment
 - Pre hospital management
 - Diagnosis in secondary care
 - Management in secondary care
 - Long term management
 - It is supported by algorithms and resources including a baseline assessment
- [NICE clinical guideline 160](#) *Feverish illness in children. Assessment and initial management in children younger than 5 years*
- The College of Emergency Medicine [Clinical standards for Emergency Departments](#) including
 - Sepsis and meningitis for children derived from the NICE guidelines 102 (bacterial meningitis and meningococcal septicaemia in children and young people younger than 16 years) and NICE guideline 160 (feverish illness in children younger than 5 years)
 - Feverish children derived from the NICE guideline 160 (feverish illness in children younger than 5 years)
- Algorithms, guidelines, wall charts and other resources from the [Meningitis Research Foundation](#) for the identification and management of meningococcal septicaemia and/or meningitis aimed at particular professionals including:
 - Ambulance personnel
 - General practice
 - Frontline nurses
 - Hospital doctors – paediatrics
 - Hospital doctors – adults
 - Community practitioners

- Paediatric Accident and Emergency Research Group [Management of the child with a decreased level of consciousness](#) University of Nottingham/National Reyes Syndrome Foundation UK, and endorsed by the Royal College of Paediatrics and Child Health
- Public Health England *UK Standards for microbiology investigation: investigation of viral encephalitis and meningitis*

Prevention of secondary cases:

- Public Health England [guidance](#) on the public health management of meningococcal disease (issued by the then Health Protection Agency).

Other resources available include:

- [Spotting the sick child](#), a website commissioned by the Department of Health. This incorporates guidance from eight NICE clinical guidelines, with supplementary practical information, reflecting the guidance and facilitating implementation
- [Lessons from research for doctors in training](#) on recognition and early management of meningococcal disease in children and young people is available from the Meningitis Research Foundation and endorsed by the Royal College of Paediatrics and Child Health and the College of Emergency Medicine. It has been updated in line with NICE clinical guideline 102 and uses real-life case histories as a learning tool

Discussion

Vaccination has played a major role in preventing meningitis in the UK. Hib was once the leading cause of bacterial meningitis in children; however, since vaccination began in 1992, Hib meningitis has been virtually eradicated in England and Wales (Davison & Ramsay, 2003). Eighteen months after the introduction of Meningococcal C vaccination in 1999, the number of laboratory reports of serogroup C had fallen by over 80% in the targeted group; meanwhile, cases of serogroup B have remained high (Davison & Ramsay 2003). There was only one laboratory

confirmed blood or CSF specimen from meningococcal group C in the last decade, as compared with 354 group B. After the introduction of pneumococcal conjugate vaccination into the routine childhood immunisation programme in 2006 there has been a substantial decline in pneumococcal meningitis in children aged less than 5 years (Miller et al, 2011).

Prompt recognition of the signs and symptoms of bacterial meningitis and meningococcal disease is the key to preventing the deaths of children and young people who contract the diseases ([NICE clinical guideline 102](#)). Children frequently become unwell with symptoms such as fever, rash or headache; however, encountering meningitis or meningococcal disease remains a rare event for individual professionals. A GP working full time in Wales might expect, on average, to see a child with meningitis or meningococcal disease about once every seventeen years.ⁱⁱⁱ There is a substantial amount of guidance and educational material available which targets a wide range of professionals. There is also a range of materials aimed at the public and parents, including from NHS Direct Wales and from charities such as Meningitis Now and the Meningitis Research Foundation.

There is consistent advice that early identification and management of meningitis and meningococcal disease is essential to preventing child deaths. However, we do not know whether the following factors play a role in child deaths in Wales:

- Parental understanding of when to seek medical advice
- Availability of information for other carers, including nurseries or schools
- The ease with which public or professionals can find and use relevant guidance materials
- Consistency of guidance

ⁱⁱⁱ Based on typically 112 notifications of meningitis or meningococcal disease in people under 18 years per year in Wales, and approximately with about 1,900 whole time equivalent general practitioners in Wales.

- Appropriateness of response of healthcare professionals to sick children, particularly within general practice, out of hours services and emergency departments
- Use of case studies such as 'lessons from research for doctors in training' in the training of professionals

We identified a number of factors that may have potential to reduce the likelihood of deaths of children from meningitis or meningococcal disease, including:

- Universal meningitis B vaccination in early childhood, which has been subject to a recent position statement by the UK Joint Committee on Vaccination and Immunisation^{iv}
- Further uptake of pneumococcal polysaccharide vaccine among children over the age of two in clinical risk groups
- Assessing or auditing use of existing guidance among healthcare professionals
- Assessing or auditing training of healthcare professionals both undergraduate and postgraduate, across disciplines and in pre-hospital and hospital settings, e.g. medical students, general practitioners, and accident and emergency staff.

Following this rapid response, the Child Death Review Team plans to:

- Develop a specific record of child death form for deaths from infection, which will include relevant items for meningitis and meningococcal disease
- Propose to the Child Death Review Steering Group that a thematic review of deaths of children from meningitis and meningococcal disease is scheduled into the Child Death Review Programme work plan.

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References:

Davison KL and Ramsay ME. (2003). The epidemiology of acute meningitis in children in England and Wales. *Arch Dis Child* 88:662-64.

Miller E et al. (2011). Herd immunity and serotype replacement 4 years after seven-valent pneumococcal conjugate vaccination in England and Wales: an observational cohort study. *Lancet Infect Dis* 11:760-68.

Hyperlinks provided to guidelines and recommendations within text, accessed 12 August 2014.

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^{iv} Among the conclusions were that the Joint Committee on Vaccination and Immunisation "recommended a programme for use of the Men B vaccine with the NHS immunisation schedule at 2, 4, 12 months of age (2+1) in a carefully planned programme. Given the vaccine only demonstrated cost-effectiveness at a low price, plans for implementation should anticipate a sustainable and cost-effective programme."



For more information:

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