

Meningitis (bacterial) and meningococcal disease: recognition, diagnosis and management

[K3] Evidence review on information for confirmed bacterial meningitis or meningococcal disease

NICE guideline NG240

Evidence review underpinning recommendations 1.11.1 to 1.11.2, 1.11.5 and 1.12.11 to 1.12.13 in the NICE guideline

March 2024

Final

This evidence review was developed by NICE

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Information for confirmed bacterial meningitis or meningococcal disease

Review question

What information is valued by patients with confirmed bacterial meningitis or meningococcal disease, and their families or carers?

Introduction

Bacterial meningitis and meningococcal disease (meningococcal sepsis with or without an associated meningitis) are rare but serious infections, which can occur in any age group.

When a diagnosis of bacterial meningitis or meningococcal disease is confirmed, patients and their families or carers will naturally have many concerns and questions.

The aim of this review is to determine what information patients, and their families or carers value, when a diagnosis of bacterial meningitis or meningococcal disease is confirmed.

Summary of the protocol

See Table 1 for a summary of the Population, Phenomenon of Interest and Context (PPC) characteristics of this review.

Table 1: Summary of the protocol (PPC table)

Population	<ul style="list-style-type: none"> • People with confirmed bacterial meningitis or meningococcal disease. • Parents or carers of babies, children, and young people with confirmed bacterial meningitis or meningococcal disease. • Families or carers of adults with confirmed bacterial meningitis or meningococcal disease.
Phenomenon of interest	<p>Views and experiences of the information provided when bacterial meningitis and/or meningococcal disease is confirmed.</p> <p>Themes will be identified from the literature. The committee identified the following potential themes (however, not all of these themes may be found in the literature, and additional themes may be identified):</p> <ul style="list-style-type: none"> • Information content (including prognosis) • Information format • Information sources • Decision making • Timing of information provision • Information about follow-up • Language • Communication
Context	<p>Studies sought will be those published in the English language from OECD high income European countries, Australia, Canada and New Zealand, from 2000 until the date the searches are run.</p> <p>The search cut-off date of 2000 was selected as microbiology has not changed much since 2000 and most relevant interventions were available by then. Including studies prior to this may not capture experiences reflective of current practice.</p>

OECD: Organisation for Economic Co-operation and Development

For further details see the review protocol in appendix A.

Methods and process

This evidence review was developed using the methods and process described in [Developing NICE guidelines: the manual](#). Methods specific to this review question are described in the review protocol in appendix A and the methods document (supplementary document 1).

Declarations of interest were recorded according to [NICE's conflicts of interest policy](#).

Qualitative evidence

Included studies

Four studies were included in this review, 2 mixed-methods studies (Clark 2013, Wisemantel 2018), and 2 qualitative studies (Haines 2005, Sweeney 2013).

The included studies are summarised in Table 2.

All studies reported the views and experiences of parents or carers of babies, children, and young people with confirmed bacterial meningitis or meningococcal disease.

The data from the included studies were synthesised and a number of central themes and sub-themes emerged (as shown in Figure 1).

One study was from the UK and Ireland (Clark 2013), 1 study was from England (Haines 2005), 1 study was from the UK (Sweeney 2013), and 1 study was from Australia (Wisemantel 2018).

See the literature search strategy in appendix B and study selection flow chart in appendix C.

Excluded studies

Studies not included in this review are listed, and reasons for their exclusion are provided in appendix J.

Summary of included studies

Summaries of the studies that were included in this review are presented in Table 2.

Table 2: Summary of included studies

Study	Population	Methods	Themes applied after thematic synthesis
Clark 2013	N=194; n=18 invited for interview	Setting: Purposive sampling from Meningitis Research Foundation members in the UK & Ireland	<ul style="list-style-type: none"> Information on discharge from hospital Communication
Grounded theory	Parent/legal guardian of children who survived meningitis and/or septicaemia.	Data collection and analysis: Semi-structured interviews (face-to-face or over the phone), analysed	

Study	Population	Methods	Themes applied after thematic synthesis
	<p>Only, those parents reporting permanent after-effects, and who had accessed aftercare and support, were invited for interview.</p> <p>Age of children in years at the time of illness (mean): 3.83</p>	using the constant comparison method from grounded theory	
Haines 2005 Phenomenological England	<p>N=7</p> <p>Parents of children admitted to PICU who survived severe meningococcal disease.</p> <p>Age: NR</p>	<p>Setting: Purposive sampling from a PICU in England</p> <p>Data collection and analysis: Semi-structured interviews (face-to-face), analysed using Colaizzi's Interpretation Process</p>	<ul style="list-style-type: none"> • Information during hospitalisation • Information sources • Communication
Sweeney 2013 General qualitative enquiry UK	<p>N=244</p> <p>Parents/carers of survivors of serogroup B meningococcal Disease in childhood</p> <p>Age: NR</p>	<p>Setting: Purposive sampling as part of a UK population-based study (MOSAIC)</p> <p>Data collection and analysis: Structured interviews (over the phone), analysed using qualitative content analysis</p>	<ul style="list-style-type: none"> • Information at diagnosis • Information during hospitalisation • Information on discharge from hospital • Information format • Communication
Wisemantel 2018 General qualitative enquiry Australia	<p>N=6</p> <p>Parents who had experienced a child or young person with an invasive meningococcal disease.</p> <p>Age: NR</p>	<p>Setting: Convenience sampling from a regional area of New South Wales that includes a large city, regional centres, and rural and remote areas.</p> <p>Data collection and analysis: Semi-structured interviews (face-to-face), analysed using thematic analysis with inductive and deductive techniques</p>	<ul style="list-style-type: none"> • Information at diagnosis • Information format • Information sources • Communication

MOSAIC: Meningococcal outcomes in adolescents and in children; NR: not reported; PICU: paediatric intensive care unit

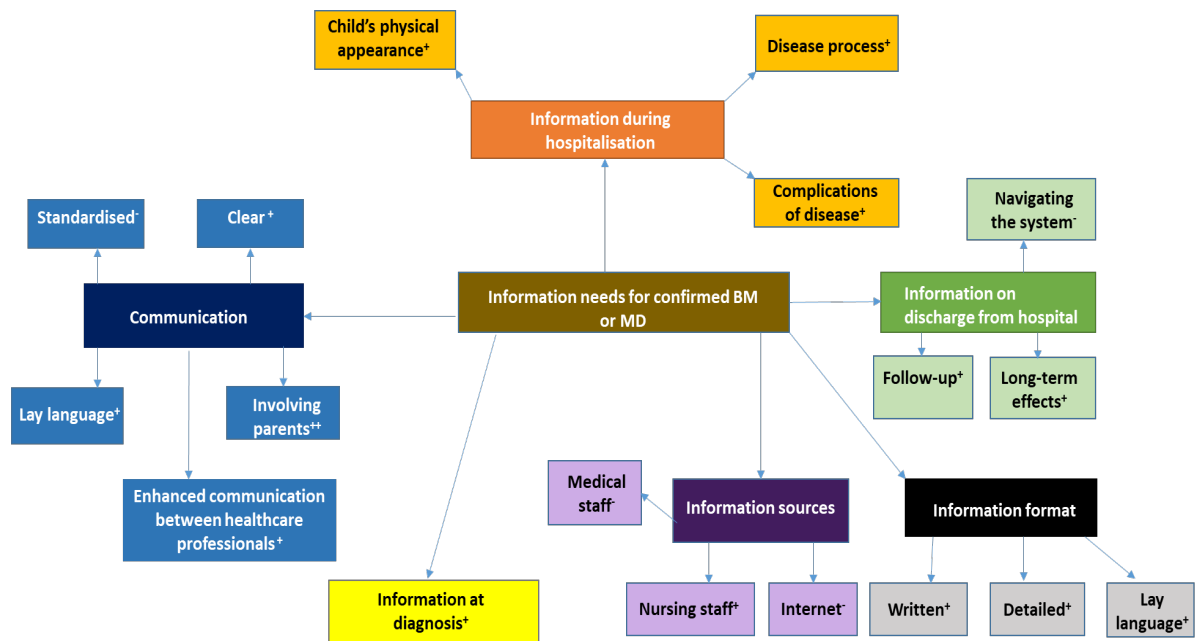
See the full evidence tables in appendix D.

This was a qualitative meta-synthesis, so no quantitative meta-analysis was conducted (and there are no forest plots in appendix E).

Summary of the evidence

The evidence generated 6 main themes in relation to the information valued by parents, their families, and carers when bacterial meningitis or meningococcal disease is confirmed. Two studies provided the evidence relating to information at diagnosis, which had no subthemes. Two studies provided the evidence relating to information during hospitalisation, which had 3 subthemes (child's physical appearance, disease process and complications of the disease). Two studies provided the evidence relating to information on discharge from hospital, which had 3 subthemes (navigating the system, long-term effects and follow-up). Two studies provided the evidence relating to information format, which had 3 subthemes (written, detailed and lay language). Two studies provided the evidence relating to information sources, which had 3 subthemes (medical staff, nursing staff and internet). Four studies provided the evidence relating to communication, which had 5 subthemes (standardised, clear, lay language, involving parents and enhanced communication between healthcare professionals). The overarching themes and subthemes were developed to allow subthemes on a common topic to be grouped to aid presentation of results, without obscuring the detail included within the individual subthemes. For example, the subthemes on information sources all related to different sources of information that parents and carers had reported using and what their views about these different sources were. The theme map (Figure 1) illustrates these overarching themes and related subthemes.

Figure 1: Theme map



BM: Bacterial Meningitis; MD: Meningococcal disease

++ = high quality evidence; + = moderate quality evidence; - = low quality evidence

No evidence relevant to the themes of information content, decision making, or timing of information provision, that were included as phenomenon of interest in the protocol were identified.

A summary of the strength of evidence, assessed using GRADE-CERQual, is presented for each of the sub-themes in the theme map above. The main reasons for downgrading were due to concerns about the methodological limitations of the primary studies (for example, because of a lack of consideration of the relationship between researcher and participants, no justification for data collection methods as it relates to data saturation and potential for recruitment bias), concerns about relevance (for example, because studies restricted the population to meningococcal disease, thereby under-representing less severe forms of the

disease), and concerns about adequacy (for example, for review findings when evidence offered no or only some or moderately rich data).

Findings from the studies are summarised in GRADE-CERQual tables. See the evidence profiles in appendix F for details.

Economic evidence

Included studies

A single economic search was undertaken for all topics included in the scope of this guideline, but no economic studies were identified which were applicable to this review question.

Economic model

No economic modelling was undertaken for this review because the committee agreed that other topics were higher priorities for economic evaluation. This was because this review does not involve a comparison of competing courses of action.

The committee's discussion and interpretation of the evidence

The outcomes that matter most

The review focused on the views and experiences of the information provided when bacterial meningitis and/or meningococcal disease is confirmed. The committee identified a number of potential themes as illustrative of the main themes to guide the review. These themes were information content (including prognosis), information format, information sources, decision making, timing of information provision, information about follow-up, language, and communication. However, the potential themes were not exhaustive, as the committee did not want to constrain the evidence, and an emergent approach was taken to the thematic synthesis.

The quality of the evidence

The evidence was assessed using GRADE-CERQual methodology, and the overall confidence in the findings ranged from low to high. Assessments of the potential methodological limitations of the primary studies were undertaken using the CASP checklist; overall concerns about methodological limitations were rated as "minor concerns for all the review findings". The most common issues were lack of consideration of the relationship between researcher and participants, no justification for data collection methods as it relates to data saturation and potential for recruitment bias. Concerns about relevance was "minor" for all review findings, which was due to studies restricting population to meningococcal disease with the potential to under-represent less severe forms of the disease. Concerns about coherence were "no or very minor" for all the review findings, as there was no data that contradicted the findings nor was there ambiguous data. Concerns about adequacy ranged from "no or very minor" to "serious". There were serious concerns for review findings when evidence offered no rich data, moderate concerns for review findings when evidence offered some rich data and minor concerns for review findings that were based on evidence offering moderately rich data. The number of studies contributing to each subtheme ranged from 1 to 3.

No evidence was identified for the following outcomes: theme of information content, decision making, or timing of information provision.

Benefits and harms

All the evidence identified for this review focused on the views of parents or carers. However, the committee agreed that the recommendations made should apply equally to people with confirmed bacterial meningitis or meningococcal disease themselves. However, they acknowledged that there may be differences in the types and delivery of information provided to people with confirmed bacterial meningitis or meningococcal disease and their parents or carers due to factors such as the developmental age of the individual and the impact of the illness on the person's ability to communicate. The committee noted that there were no differences in the emergent themes based on whether the diagnosis was bacterial meningitis or meningococcal disease.

The protocol for this evidence review did not include neonates because the NICE guidance on [Neonatal infection](#) includes recommendations on information. However, the committee highlighted that the information needs covered in this review are very specific to bacterial meningitis and overlap significantly with recommendations about responding to potential long-term complications (which include neonates) and agreed that the recommendations about information post diagnosis that applied to babies (28 days to 1 year) should be extended to neonates.

The committee were aware of existing NICE guidance on [patient experience in adult NHS services](#) and [babies, children and young people's experience of healthcare](#), and focused recommendations on information needs that were specific to bacterial meningitis and meningococcal disease.

There was moderate quality evidence from theme 1 (information at diagnosis) that parents would like more information about meningitis, diagnosis and treatment, and better communication regarding this. Based on this evidence, and their clinical knowledge and experience, the committee recommended that people with bacterial meningitis or meningococcal disease, their families and carers should be provided with information about what might happen during the course of the disease. The committee also agreed that information should include uncertainty around prognosis as the potential for long-term complications may not be apparent at this stage. However, the committee highlighted that, in their experience, fear often originates from a lack of information and, therefore, agreed that keeping people with bacterial meningitis or meningococcal disease and their parents or carers informed on when they can expect to know more is important to reduce anxiety. The committee acknowledged the importance of tailoring the information that is given to individual circumstances as providing people with information about all the possible short and long-term outcomes of bacterial meningitis and meningococcal disease and potential requirement of critical care in circumstances where people are alert and responding well to treatment may cause unnecessary alarm. Based on their knowledge and experience, the committee agreed people should be told about the risk of passing on the infection as this is something that is frequently asked about. They noted this may be particularly important for meningitis in neonates caused by group B streptococcus as antibiotic prophylaxis may be required during labour in subsequent pregnancies. The committee acknowledged that meningococcal and Hib (Haemophilus influenzae type b) infections are notifiable diseases and recommended that people with meningococcal or Hib infection and their parents, family members and carers should be made aware that preventative measures (for example, isolation) may be needed for close contacts.

Moderate quality evidence from theme 2 (information during hospitalisation) highlighted the need for more information during this phase of illness. Specifically, subtheme 2.1 (child's physical appearance) showed that parents did not feel prepared for how different their child looked, or how they would act when withdrawing from sedative treatment and found this distressing. Therefore, the committee recommended that people are informed about how the illness, or its treatment, may affect appearance or behaviour. The committee highlighted some examples of how appearance may be affected based on their experience, including the

presence of drips or other invasive devices, the potential for swelling associated with fluid resuscitation in people with septic shock, and the spreading of rashes or changes in skin colour associated with meningococcal disease. The recommendation also included the provision of information about the effects of sedative withdrawal (such as agitation or abnormal neurological behaviour). As discussed above, the committee discussed and agreed the importance of tailoring information so that it is relevant to the individual circumstances.

Sub-theme 2.2 (disease process) indicated that parents would like more information on the disease process and the opportunity to ask questions, particularly when their child was in an intensive care unit. The committee agreed that the opportunity to ask questions was important and recommended, based on their experience, that information should be repeated, people should be given multiple opportunities to ask questions and understanding should be checked, as people may be very distressed or fearful initially which may impact their ability to process or understand the information provided and they may need time to digest the information before asking questions.

Theme 3 (information on discharge from hospital) provided low to moderate quality evidence about areas where people wanted more information at the point of discharge from hospital. Specially, sub-theme 3.1 (navigating the system) provided evidence that people had to learn how to navigate the system themselves and didn't know what to do next to access support, sub-theme 3.2 (long-term effects) further highlighted that people wanted more information about potential complications and long-term effects of illness, and sub-theme 3.3 (follow-up) indicated that there was a lack of clarity about the follow-up plan following discharge and again, some parents reported being told to 'wait and see'. The committee agreed that information about these areas was important and therefore, recommended that people are provided with information about how they can access support (for example, contact details of meningitis charities) and what follow-up can be expected now and in the longer term in terms of assessments and aftercare. There was moderate quality evidence from sub-theme 2.3 (complications of disease) that parents were unaware of potential complications associated with bacterial meningitis or meningococcal disease and that they would have felt more prepared had information provision been better. The committee were aware that, based on their knowledge and experience as well as evidence from the reviews on long term complications (see evidence reviews I1 and I2), that there is a wide range of potential long-term complications that can occur, many of which may not be evident for several months, or potentially years in the case of neurodevelopmental outcomes in children. Therefore, the committee recommended that people should be made aware of potential long-term complications and uncertainties about what long-term complications they might experience. The committee also recommended that the follow-up plan is documented in a discharge summary so that people have detailed written information that they can refer to.

Based on their clinical experience of frequently asked questions, the committee recommended that people are provided with information on when they can likely resume normal activities, such as driving or travel, work or education, and exercise or sports, and the follow-up considerations which may affect these things.

There was moderate quality evidence from sub-theme 6.5 (enhanced communication between healthcare professionals) that parents reported poor communication between different specialists which results in support that was unresponsive to needs; however, when different professionals did communicate, they felt there were shared plans and goals that helped to meet their child's needs. Therefore, the committee recommended that the hospital team should coordinate with tertiary and primary care and other specialists, and allied professionals and community teams (for example, audiology, and speech and language therapy departments) that will be involved in follow-up. The committee agreed this was important for ensuring that needs are effectively met and to avoid gaps in the provision of care.

There was moderate quality evidence from sub-theme 6.3 (lay-language) that the use of lay language was important so that parents could understand everything that was going on. The committee agreed that they did not need to make a specific recommendation about this as the use of simple, clear language that avoids jargon is covered by the guidelines cross-referenced above.

Cost effectiveness and resource use

This qualitative review question did not consider decisions between competing alternatives and therefore is not directly relevant to the tools of economic evaluation. Whilst communication and information provision do consume resources, they are also a vital and routine part of healthcare provision. The committee felt their recommendations reflected good practice which would not entail a significant resource impact to the NHS and would help promote the provision of information that is valued by patients and carers when bacterial meningitis or meningococcal disease has been confirmed.

Recommendations supported by this evidence review

This evidence review supports recommendations 1.11.1 to 1.11.2, 1.11.5 and 1.12.11 to 1.12.13. Other evidence supporting these recommendations can be found in the evidence review on support for confirmed bacterial meningitis or meningococcal disease (see evidence review K4).

References – included studies

Qualitative

Clark 2013

Clark, L. J., Glennie, L., Audrey, S., Hickman, M., Trotter, C. L. The health, social and educational needs of children who have survived meningitis and septicaemia: the parents' perspective. *BMC public health*, 13, 954, 2013

Haines 2005

Haines, C. Parents' experiences of living through their child's suffering from and surviving severe meningococcal disease. *Nursing in critical care*, 10, 78-89, 2005

Sweeney 2013

Sweeney, F., Viner, R. M., Booy, R., Christie, D. Parents' experiences of support during and after their child's diagnosis of meningococcal disease. *Acta Paediatrica*, 102, e126-30, 2013

Wisemantel 2018

Wisemantel, M., Maple, M., Massey, P. D., Osbourn, M., Kohlhagen, J. Psychosocial challenges of invasive meningococcal disease for children and their families. *Australian Social Work*, 71, 478-490, 2018.

Economic

No studies were identified which were applicable to this review question.

Appendices

Appendix A Review protocols

Review protocol for review question: What information is valued by patients with confirmed bacterial meningitis or meningococcal disease, and their families or carers?

Table 3: Review protocol

Field	Content
PROSPERO registration number	CRD42020221149
Review title	Information for confirmed bacterial meningitis or meningococcal disease
Review question	What information is valued by patients with confirmed bacterial meningitis or meningococcal disease, and their families or carers?
Objective	To determine what information is valued by patients with confirmed bacterial meningitis or meningococcal disease, and their families or carers.
Searches	<p>The following databases will be searched:</p> <ul style="list-style-type: none"> Cochrane Central Register of Controlled Trials (CENTRAL) Cochrane Database of Systematic Reviews (CDSR) Embase MEDLINE PsycInfo Emcare or Cinahl <p>Searches will be restricted by:</p> <ul style="list-style-type: none"> Date limitations: studies after 2000 English language Human studies <p>The full search strategies for MEDLINE database will be published in the final review.</p>

Field	Content
Condition or domain being studied	People with confirmed bacterial meningitis or meningococcal disease
Population	<p>Inclusion:</p> <ul style="list-style-type: none"> • People with confirmed bacterial meningitis or meningococcal disease. • Parents or carers of babies, children, and young people with confirmed bacterial meningitis or meningococcal disease. • Families or carers of adults with confirmed bacterial meningitis or meningococcal disease. <p>Exclusion:</p> <ul style="list-style-type: none"> • People and parents or carers of people: <ul style="list-style-type: none"> ○ with known immunodeficiency. ○ who have brain tumours, pre-existing hydrocephalus, intracranial shunts, previous neurosurgical procedures, or known cranial or spinal anomalies that increase the risk of bacterial meningitis. ○ with confirmed viral meningitis or viral encephalitis. ○ with confirmed tuberculous meningitis. ○ with confirmed fungal meningitis ○ suspected bacterial meningitis or meningococcal disease • The views of staff caring for people with suspected or confirmed bacterial meningitis or meningococcal disease.
Phenomenon of interest	Views and experiences of the information provided when bacterial meningitis and/or meningococcal disease is confirmed.
Comparator/Reference standard/Confounding factors	Not applicable
Types of study to be included	<p>Qualitative methods: systematic reviews of qualitative studies and primary qualitative studies, including semi-structured and structured interviews, focus groups, observations and surveys with open-ended questions.</p> <p>Exclusions:</p> <ul style="list-style-type: none"> • Quantitative studies (including surveys reporting only quantitative data) • Surveys which quantify open-ended answers for analysis • Conference abstracts

Field	Content
Other exclusion criteria	<ul style="list-style-type: none"> • Countries other than OECD high income European countries, Australia, New Zealand and Canada. • Studies conducted prior to 2000 as microbiology has not changed much since 2000 and most relevant interventions (for example, steroids) were available by then. • Studies published not in English-language
Context	This guidance will fully update the following: Meningitis (bacterial) and meningococcal septicaemia in under 16s: recognition, diagnosis and management (CG102)
Primary outcomes (critical outcomes)	<p>Themes will be identified from the literature. The committee identified the following potential themes (however, not all of these themes may be found in the literature, and additional themes may be identified):</p> <ul style="list-style-type: none"> • Information content (including prognosis) • Information format • Information sources • Decision making • Timing of information provision • Information about follow-up • Language • Communication
Secondary outcomes (important outcomes)	Not applicable
Data extraction (selection and coding)	All references identified by the searches and from other sources will be uploaded into STAR and de-duplicated. Titles and abstracts of the retrieved citations will be screened to identify studies that potentially meet the inclusion criteria outlined in the review protocol. Dual sifting will not be undertaken for this question. Full versions of the selected studies will be obtained for assessment. Studies that fail to meet the inclusion criteria once the full version has been checked will be excluded at this stage. Each study excluded after checking the full version will be listed, along with the reason for its exclusion. A standardised form will be used to extract data from studies. The following data will be extracted: study details (reference, country where study was carried out, type and dates), recruitment strategy, participant characteristics, setting, methods of data collection and analysis, relevant findings and source of funding. One reviewer will extract relevant data into a standardised form, and this will be quality assessed by a senior reviewer.
Risk of bias (quality) assessment	<p>Quality assessment of individual studies will be performed using the following checklists:</p> <ul style="list-style-type: none"> • ROBIS tool for systematic reviews • CASP checklist for qualitative studies

Field	Content														
	The quality assessment will be performed by one reviewer and this will be quality assessed by a senior reviewer.														
Strategy for data synthesis	<p>Secondary thematic analysis will be used to synthesise the evidence from individual studies.</p> <p>The GRADE-CERQual (Confidence in the Evidence from Reviews of Qualitative research; Lewin 2015) approach will be used to summarise the confidence in qualitative evidence. The overall confidence in evidence about each theme or sub-theme will be rated on four dimensions: methodological limitations, applicability, coherence and adequacy of data.</p> <p>Methodological limitations refer to the extent to which there were problems in the design or conduct of the studies and will be assessed with the Critical Appraisal Skills Programme (CASP) checklist for qualitative studies. Applicability of evidence will be assessed by determining the extent to which the body of evidence from the primary studies are applicable to the context of the review question. Coherence of findings will be assessed by examining the clarity of the data and the consistency of the findings within each theme. Adequacy of data will be assessed by looking at the degree of richness and quantity of findings</p>														
Analysis of sub-groups	<p>Formal subgroup analyses are not appropriate for this question due to qualitative data, but the views and experiences of the following groups will be considered separately, where possible:</p> <p>Confirmed diagnosis (Bacterial meningitis or meningococcal disease).</p> <p>Population:</p> <ul style="list-style-type: none"> • Patients aged 18 years or over and their families or carers • Patients aged under 18 years • Parents or carers of patients under 18 years 														
Type and method of review	<table border="0"> <tr> <td><input type="checkbox"/></td> <td>Intervention</td> </tr> <tr> <td><input type="checkbox"/></td> <td>Diagnostic</td> </tr> <tr> <td><input type="checkbox"/></td> <td>Prognostic</td> </tr> <tr> <td><input checked="" type="checkbox"/></td> <td>Qualitative</td> </tr> <tr> <td><input type="checkbox"/></td> <td>Epidemiologic</td> </tr> <tr> <td><input type="checkbox"/></td> <td>Service Delivery</td> </tr> <tr> <td><input type="checkbox"/></td> <td>Other (please specify)</td> </tr> </table>	<input type="checkbox"/>	Intervention	<input type="checkbox"/>	Diagnostic	<input type="checkbox"/>	Prognostic	<input checked="" type="checkbox"/>	Qualitative	<input type="checkbox"/>	Epidemiologic	<input type="checkbox"/>	Service Delivery	<input type="checkbox"/>	Other (please specify)
<input type="checkbox"/>	Intervention														
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<input type="checkbox"/>	Service Delivery														
<input type="checkbox"/>	Other (please specify)														
Language	English														
Country	England														
Anticipated or actual start	24/11/2020														

Field	Content		
date			
Anticipated completion date	07/12/2023		
Stage of review at time of this submission	Review stage	Started	Completed
	Preliminary searches	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Piloting of the study selection process	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Formal screening of search results against eligibility criteria	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Data extraction	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Risk of bias (quality) assessment	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Data analysis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Named contact	Named contact: National Guidelines Alliance Named contact e-mail: meningitis&meningococcal@nice.org.uk Organisational affiliation of the review: National Institute for Health and Care Excellence (NICE) and National Guideline Alliance		
Review team members	National Guideline Alliance		
Funding sources/sponsor	This systematic review is being completed by the National Guideline Alliance which receives funding from NICE.		
Conflicts of interest	All guideline committee members and anyone who has direct input into NICE guidelines (including the evidence review team and expert witnesses) must declare any potential conflicts of interest in line with NICE's code of practice for declaring and dealing with conflicts of interest. Any relevant interests, or changes to interests, will also be declared publicly at the start of each guideline committee meeting. Before each meeting, any potential conflicts of interest will be considered by the guideline committee Chair and a senior member of the development team. Any decisions to exclude a person from all or part of a meeting will be documented. Any changes to a member's declaration of interests will be recorded in the minutes of the meeting. Declarations of interests will be published with the final guideline.		
Collaborators	Development of this systematic review will be overseen by an advisory committee who will use the review to inform the development of evidence-based recommendations in line with section 3 of Developing NICE guidelines: the manual . Members of the guideline committee are available on the NICE website: https://www.nice.org.uk/guidance/indevelopment/gid-ng10149 .		
Other registration details	None		
Reference/URL for published protocol	https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42020221149		

Field	Content
Dissemination plans	NICE may use a range of different methods to raise awareness of the guideline. These include standard approaches such as: notifying registered stakeholders of publication publicising the guideline through NICE's newsletter and alerts issuing a press release or briefing as appropriate, posting news articles on the NICE website, using social media channels, and publicising the guideline within NICE.
Keywords	Bacterial meningitis, meningococcal disease, information, qualitative
Details of existing review of same topic by same authors	None
Current review status	<input type="checkbox"/> Ongoing <input checked="" type="checkbox"/> Completed but not published <input type="checkbox"/> Completed and published <input type="checkbox"/> Completed, published and being updated <input type="checkbox"/> Discontinued
Additional information	None
Details of final publication	www.nice.org.uk

CASP: Critical Appraisal Skills Programme; CDSR: Cochrane Database of Systematic Reviews; CENTRAL: Cochrane Central Register of Controlled Trials; DARE: Database of Abstracts of Reviews of Effects; GRADE-CERQual: Grading of Recommendations Assessment, Development and Evaluation-Confidence in the Evidence from Reviews of Qualitative research; NGA: National Guideline Alliance; NHS: National health service; NICE: National Institute for Health and Care Excellence; OECD: Organisation for Economic Co-operation and Development; RoB: risk of bias; ROBIS: Risk of Bias in Systematic Reviews

Appendix B Literature search strategies

Literature search strategies for review question: What information is valued by patients with confirmed bacterial meningitis or meningococcal disease, and their families or carers?

Clinical Search

This was a combined search to cover this review (K3), evidence review K4 on support for confirmed bacterial meningitis and/or meningococcal disease, and the evidence reviews (K1 and K2) on information for suspected bacterial meningitis and/or meningococcal disease and support for suspected bacterial meningitis and/or meningococcal disease.

Database(s): Medline, Embase & PsycINFO (Multifile) – OVID interface

Embase Classic+Embase 1947 to 2021 July 13, **Ovid MEDLINE(R) ALL** 1946 to July 13, 2021, **APA PsycINFO** 1806 to July Week 1 2021

Date of last search: 14 July 2021

Multifile database codes: emczd = Embase Classic+Embase; ppez = MEDLINE(R) ALL; psych = PsycINFO

#	Searches
1	Meningitis/ or Meningitis, Bacterial/ or Meningitis, Escherichia Coli/ or Meningitis, Haemophilus/ or Meningitis, Listeria/ or Meningitis, Meningococcal/ or Meningitis, Pneumococcal/ or Meningoencephalitis/
2	1 use medall
3	meningitis/ or bacterial meningitis/ or haemophilus meningitis/ or hemophilus influenzae meningitis/ or listeria meningitis/ or meningococcal meningitis/ or pneumococcal meningitis/ or meningoencephalitis/
4	3 use emczd
5	exp Meningitis/ use psych
6	((bacter* or infect*) adj3 (meningit* or meninges* or leptomeninges* or subarachnoid space?)).ti,ab.
7	(meningit* adj3 (e coli or escherichia coli or h?emophilus or hib or h?emophilus influenz* or h influenz* or listeria* or meningococc* or pneumococc* or gram-negativ* bacill* or gram negativ* bacill* or streptococc* or group B streptococc* or GBS or streptococcus pneumon* or s pneumon* or septic* or sepsis* or bacter?emi?)).ti,ab.
8	((e coli or escherichia coli or h?emophilus or hib or h?emophilus influenz* or h influenz* or listeria* or meningococc* or pneumococc* or gram-negativ* bacill* or gram negativ* bacill* or streptococc* or group B streptococc* or GBS or streptococcus pneumon* or s pneumon*) adj3 (septic* or sepsis* or bacter?emi?)).ti,ab.
9	(meningit* or mening?encephalitis*).ti,ab.
10	or/2,4-9
11	Meningococcal Infections/ or exp Neisseria meningitidis/
12	11 use medall
13	Meningococcosis/ or Meningococcemia/ or Neisseria Meningitidis/
14	13 use emczd
15	(meningococc* adj3 (sepsis* or septic* or toxic* or endotoxic* or disease? or infection?)).ti,ab.
16	(meningococcus* or meningococci* or meningococc?emi?).ti,ab.
17	(Neisseria* mening* or n mening*).ti,ab.
18	or/12,14-17
19	Access to Information/ or Information Centers/ or Information Services/ or Information Dissemination/ or Information Seeking Behavior/ or Communication/ or exp Communications Media/ or Mass Media/ or Consumer Health Information/ or exp Health Information Management/ or Health Communication/ or Health Promotion/ or Health Education/ or Health Knowledge, Attitudes, Practice/ or Patient Education as Topic/ or Government Publications as Topic/ or Patient Education Handout/ or Pamphlets/ or exp Audiovisual Aids/ or exp Computers, Handheld/ or Decision Support Systems, Clinical/ or exp Internet/ or Internet-Based Intervention/ or Web Browser/ or Social Media/ or Social Networking/ or Mobile Applications/ or Blogging/ or Electronic Mail/ or Text Messaging/ or Hotlines/ or Telephone/ or exp Mobile Phone/ or Television/ or Radio/ or Bibliotherapy/ or Health Literacy/ or Therapy, Computer-Assisted/mt or Telemedicine/ or Patient Advocacy/ or Consumer Advocacy/ or exp Social Support/ or Self-Help Groups/ or Peer Group/ or exp Counseling/ or Patient Participation/ or Empowerment/
20	19 use medall
21	access to information/ or information/ or information center/ or information service/ or information dissemination/ or information seeking/ or help seeking behavior/ or exp interpersonal communication/ or exp mass communication/ or consumer health information/ or health promotion/ or health education/ or education program/ or attitude to health/ or patient education/ or patient information/ or medical information/ or publication/ or visual information/ or exp audiovisual aid/ or personal digital assistant/ or exp decision support system/ or patient decision making/ or exp internet/ or web-based intervention/ or web browser/ or social media/ or blogging/ or social network/ or smartphone/ or mobile application/ or e-mail/ or email support/ or text messaging/ or text messaging support/ or hotline/ or telephone/ or telephone support/ or exp mobile phone/ or teleconsultation/ or television/ or radio/ or bibliotherapy/ or health literacy/ or computer assisted therapy/ or telehealth/ or telemedicine/ or patient advocacy/ or consumer advocacy/ or psychosocial care/ or social support/ or exp self help/ or exp support group/ or peer group/ or exp counseling/ or exp patient participation/ or empowerment/
22	21 use emczd

#	Searches
23	exp Audiovisual Communications Media/ or exp Advocacy/ or exp Bibliotherapy/ or exp Blog/ or exp Client Attitudes/ or exp Client Education/ or exp Client Participation/ or exp Communication/ or exp Communications Media/ or exp Computer Assisted Therapy/ or exp Computer Mediated Communication/ or exp Counseling/ or exp Decision Support Systems/ or exp Digital Interventions/ or exp Educational Audiovisual Aids/ or exp Educational Programs/ or exp Electronic Communication/ or exp Empowerment/ or exp Health Attitudes/ or exp Health Education/ or exp Health Care Utilization/ or exp Information Seeking/ or exp Help Seeking Behavior/ or exp Health Care Seeking Behavior/ or exp Health Literacy/ or exp Health Promotion/ or exp Hot Line Services/ or exp Internet/ or exp Interpersonal Communication/ or exp Information/ or exp Information Dissemination/ or exp Information Services/ or exp Mass Media/ or exp Mobile Applications/ or exp Mobile Devices/ or exp Mobile Phones/ or exp Peers/ or exp Reading Materials/ or exp Support Groups/ or exp Self-Help Techniques/ or exp Smartphones/ or exp Social Support/ or exp Social Media/ or exp Social Networks/ or exp Telecommunications Media/ or exp Telephone Systems/ or exp Telemedicine/ or exp Text Messaging/ or exp Treatment Compliance/ or exp Verbal Communication/ or exp Websites/ or exp Written Communication/
24	23 use psyh
25	((group* or psychosocial*) adj2 support*).tw.
26	(blog* or "mobile* app*" or "mobile* phone* app*" or "mobile* health* app*" or "download* app*" or ipad app* or booklet* or brochure* or cellphone* or dvd* or handout* or ict or internet* or leaflet* or manual or manuals or media or mobile* or online app* or pamphlet* or phone* or publication* or smartphone* or telephone* or webpage* or web based or website* or web site* or web page* or video* or helpseek* or help-seek* or healthcareseek* or healthcare-seek* or healthseek* or health-seek* or care-seek* or careseek*).tw.
27	((discussion* or online* or on-line*) adj3 (forum* or fora)).tw.
28	messag* board*.tw.
29	(hotline* or helpline* or hot-line* or help-line*).tw.
30	(social adj (network* or media)).tw.
31	((user* or family or families or parent* or father* or mother* or carer* or caregive* or care giv*) adj3 (advice or inform* or support* or guidance)).tw.
32	(information* adj3 (model* or program* or need* or require* or seek* or access* or dissem* or shar* or provid* or provision)).tw.
33	((inform* or support*) adj3 (help* or support* or benefi* or hinder* or hindran* or barrier* or facilitate* or practical* or clear* or accurate)).tw.
34	((information* or support* or advice or guidance) adj3 (type* or content* or method* or quality or format)).tw.
35	information sheet.tw.
36	patient guidance.tw.
37	or/20,22,24-36
38	Qualitative Research/
39	interview/ use medall
40	exp interview/ use emczd
41	interviews/ use psyh
42	interview*.tw.
43	thematic analysis/ use emczd
44	(theme* or thematic).mp.
45	qualitative.af.
46	questionnaire\$.mp.
47	ethnological research.mp.
48	ethnograph*.mp.
49	ethnonursing.af.
50	phenomenol*.af.
51	(life stor* or women* stor*).mp.
52	(grounded adj (theor* or study or studies or research or analys?s)).af.
53	((data adj1 saturat\$) or participant observ\$).tw.
54	(field adj (study or studies or research)).tw.
55	biographical method.tw.
56	theoretical sampl\$.af.
57	((purpos\$ adj4 sampl\$) or (focus adj group\$)).af.
58	open ended questionnaire/ use emczd
59	((open end* or openend*) adj3 questionnaire*).tw.
60	(account or accounts or unstructured or openended or open ended or text\$ or narrative\$.mp.
61	(life world or life-world or conversation analys?s or personal experience\$ or theoretical saturation).mp.
62	((lived or life) adj experience\$.mp.
63	narrative analys?s.af.
64	or/38-63
65	(10 or 18) and 37 and 64
66	Patient Preference/ or exp Patient Satisfaction/
67	66 use medall
68	parental attitude/ or patient satisfaction/ or patient preference/ or personal experience/
69	68 use emczd
70	exp Parental Attitudes/ or exp Client Attitudes/ or exp Consumer Satisfaction/ or exp Client Satisfaction/ or exp Preferences/
71	70 use psyh
72	(dissatis* or expectation* or experienc* or opinion* or perceive* or perspective* or preferenc* or satisf* or view*).tw.
73	(or/67,69,71) or 72

#	Searches
74	(10 or 18) and 37 and 73
75	65 or 74
76	Letter/ use medall
77	letter.pt. or letter/ use emczd
78	note.pt.
79	editorial.pt.
80	Editorial/ use medall
81	News/ use medall
82	news media/ use psyh
83	exp Historical Article/ use medall
84	Anecdotes as Topic/ use medall
85	Comment/ use medall
86	Case Report/ use medall
87	case report/ use emczd
88	case study/ use emczd
89	Case report/ use psyh
90	(letter or comment*).ti.
91	or/76-90
92	randomized controlled trial/ use medall
93	randomized controlled trial/ use emczd
94	random*.ti,ab.
95	cohort studies/ use medall
96	cohort analysis/ use emczd
97	cohort analysis/ use psyh
98	case-control studies/ use medall
99	case control study/ use emczd
100	or/92-99
101	91 not 100
102	(animals/ not humans/) or exp animals, laboratory/ or exp animal experimentation/ or exp models, animal/ or exp rodentia/
103	102 use medall
104	(animal/ not human/) or nonhuman/ or exp animal experiment/ or exp experimental animal/ or animal model/ or exp rodent/
105	104 use emczd
106	"primates (nonhuman)"/ or animal research/ or animal models/ or rodents/
107	106 use psyh
108	(rat or rats or mouse or mice).ti.
109	or/101,103,105,107-108
110	75 not 109
111	*Acute Disease/ or *Fever/ or *Sepsis/ or *Bacterial Infections/
112	111 use medall
113	*acute disease/ or *fever/ or *sepsis/ or *bacterial infection/ or exp *bacteremia/
114	113 use emczd
115	Infectious Disorders/ or Bacterial Disorders/ or *Hyperthermia/
116	115 use psyh
117	((acute* adj2 (ill or illness)) or fever or sepsis or bacter?emia or (bacteria* adj infection*)).m_titl.
118	112 or 114 or 116 or 117
119	37 and (64 or 73) and 118
120	(appropriat* adj informat*).tw.
121	(10 or 18 or 118) and 120 and (64 or 73)
122	119 or 121
123	122 not 109
124	110 or 123
125	limit 124 to English language
126	limit 125 to yr="1980 -Current"
127	limit 126 to (conference abstract or conference paper or conference review or conference proceeding) [Limit not valid in Ovid MEDLINE(R),Ovid MEDLINE(R) Daily Update,Ovid MEDLINE(R) PubMed not MEDLINE,Ovid MEDLINE(R) In-Process,Ovid MEDLINE(R) Publisher; records were retained]
128	127 use emczd
129	126 not 128

Database(s): Cochrane Library – Wiley interface**Cochrane Database of Systematic Reviews**, Issue 7 of 12, July 2021, **Cochrane Central Register of Controlled Trials**, Issue 7 of 12, July 2021

Date of last search: 14 July 2021

#	Searches
#1	MeSH descriptor: [Meningitis] this term only
#2	MeSH descriptor: [Meningitis, Bacterial] this term only
#3	MeSH descriptor: [Meningitis, Escherichia coli] this term only
#4	MeSH descriptor: [Meningitis, Haemophilus] this term only
#5	MeSH descriptor: [Meningitis, Listeria] this term only
#6	MeSH descriptor: [Meningitis, Meningococcal] this term only
#7	MeSH descriptor: [Meningitis, Pneumococcal] this term only
#8	MeSH descriptor: [Meningoencephalitis] this term only
#9	((bacter* or infect*) NEAR/3 (meningit* or meninges* or leptomeninges* or "subarachnoid space*")):ti,ab,kw
#10	((((meningit* NEAR/3 ("e coli" or "escherichia coli" or haemophilus or hemophilus or hib or "haemophilus influenz*" or "hemophilus influenz*" or "h influenz*" or listeria* or meningococc* or pneumococc* or "gram-negativ* bacill*" or "gram negativ* bacill*" or streptococc* or "group B streptococc*" or GBS or "streptococcus pneumon*" or "s pneumon*" or septic* or sepsis* or bacteraemia* or bacteremia*))))):ti,ab,kw
#11	(((((("e coli" or "escherichia coli" or haemophilus or hemophilus or hib or "haemophilus influenz*" or "hemophilus influenz*" or "h influenz*" or listeria* or meningococc* or pneumococc* or "gram-negativ* bacill*" or "gram negativ* bacill*" or streptococc* or "group B streptococc*" or GBS or "streptococcus pneumon*" or "s pneumon*") NEAR/3 (septic* or sepsis* or bacteraemia* or bacteremia*))))):ti,ab,kw
#12	((((meningoencephalitis* or meningoencephalitis* or meningit*)))):ti,ab,kw
#13	MeSH descriptor: [Meningococcal Infections] this term only
#14	MeSH descriptor: [Neisseria meningitidis] this term only
#15	((((meningococc* NEAR/3 (sepsis* or septic* or toxic* or endotoxic* or disease or diseases or infection or infections))))):ti,ab,kw
#16	(((((meningococcus* or meningococci* or meningococcaemia* or meningococcemia*))))):ti,ab,kw
#17	((Neisseria* NEXT mening*)):ti,ab,kw
#18	#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17
#19	MeSH descriptor: [Access to Information] this term only
#20	MeSH descriptor: [Information Centers] this term only
#21	MeSH descriptor: [Information Services] this term only
#22	MeSH descriptor: [Information Dissemination] this term only
#23	MeSH descriptor: [Information Seeking Behavior] this term only
#24	MeSH descriptor: [Communication] this term only
#25	MeSH descriptor: [Communications Media] explode all trees
#26	MeSH descriptor: [Mass Media] this term only
#27	MeSH descriptor: [Consumer Health Information] this term only
#28	MeSH descriptor: [Health Information Management] explode all trees
#29	MeSH descriptor: [Health Communication] this term only
#30	MeSH descriptor: [Health Promotion] this term only
#31	MeSH descriptor: [Health Education] this term only
#32	MeSH descriptor: [Health Knowledge, Attitudes, Practice] this term only
#33	MeSH descriptor: [Patient Education as Topic] this term only
#34	MeSH descriptor: [Government Publications as Topic] this term only
#35	MeSH descriptor: [Patient Education Handout] this term only
#36	MeSH descriptor: [Pamphlets] this term only
#37	MeSH descriptor: [Audiovisual Aids] explode all trees
#38	MeSH descriptor: [Computers, Handheld] explode all trees
#39	MeSH descriptor: [Decision Support Systems, Clinical] this term only
#40	MeSH descriptor: [Internet] explode all trees
#41	MeSH descriptor: [Internet-Based Intervention] this term only
#42	MeSH descriptor: [Web Browser] this term only
#43	MeSH descriptor: [Social Media] this term only
#44	MeSH descriptor: [Social Networking] this term only
#45	MeSH descriptor: [Mobile Applications] explode all trees
#46	MeSH descriptor: [Blogging] this term only
#47	MeSH descriptor: [Electronic Mail] this term only
#48	MeSH descriptor: [Text Messaging] this term only
#49	MeSH descriptor: [Hotlines] this term only
#50	MeSH descriptor: [Telephone] this term only
#51	MeSH descriptor: [Cell Phone] this term only
#52	MeSH descriptor: [Television] this term only
#53	MeSH descriptor: [Radio] this term only
#54	MeSH descriptor: [Bibliotherapy] this term only
#55	MeSH descriptor: [Health Literacy] this term only
#56	MeSH descriptor: [Therapy, Computer-Assisted] this term only and with qualifier(s): [methods - MT]

#	Searches
#57	MeSH descriptor: [Telemedicine] this term only
#58	MeSH descriptor: [Patient Advocacy] this term only
#59	MeSH descriptor: [Consumer Advocacy] this term only
#60	MeSH descriptor: [Social Support] explode all trees
#61	MeSH descriptor: [Self-Help Groups] this term only
#62	MeSH descriptor: [Peer Group] this term only
#63	MeSH descriptor: [Counseling] explode all trees
#64	MeSH descriptor: [Patient Participation] this term only
#65	MeSH descriptor: [Empowerment] this term only
#66	((group* or psychosocial*) NEAR/2 support*):ti,ab,kw
#67	((blog* or "mobile* app*" or "mobile* phone* app*" or "mobile* health* app*" or "download* app*" or "ipad app*" or booklet* or brochure* or cellphone* or dvd* or handout* or ict or internet* or leaflet* or manual or manuals or media or mobile* or "online app*" or pamphlet* or phone* or publication* or smartphone* or telephone* or webpage* or "web based" or website* or "web site*" or "web page*" or video* or helpseek* or help-seek* or healthcareseek* or healthcare-look* or healthseek* or health-look* or care-look* or careseek*)):ti,ab,kw
#68	((discussion* or online* or on-line*) NEAR/3 (forum* or fora)):ti,ab,kw
#69	("messag* board*"):ti,ab,kw
#70	((hotline* or helpline* or hot-line* or help-line*)):ti,ab,kw
#71	((social NEXT (network* or media))):ti,ab,kw
#72	((user* or family or families or parent* or father* or mother* or carer* or caregiver* or "care giv*") NEAR/3 (advice or inform* or support* or guidance)):ti,ab,kw
#73	((information* NEAR/3 (model* or program* or need* or require* or seek* or access* or dissem* or shar* or provid* or provision))):ti,ab,kw
#74	((inform* or support*) NEAR/3 (help* or support* or benefi* or hinder* or hindran* or barrier* or facilitate* or practical* or clear* or accurate*)):ti,ab,kw
#75	((information* or support* or advice or guidance) NEAR/3 (type* or content* or method* or quality or format*)):ti,ab,kw
#76	("information sheet"):ti,ab,kw
#77	("patient guidance"):ti,ab,kw
#78	#19 OR #20 OR #21 OR #22 OR #23 OR #24 OR #25 OR #26 OR #27 OR #28 OR #29 OR #30 OR #31 OR #32 OR #33 OR #34 OR #35 OR #36 OR #37 OR #38 OR #39 OR #40 OR #41 OR #42 OR #43 OR #44 OR #45 OR #46 OR #47 OR #48 OR #49 OR #50 OR #51 OR #52 OR #53 OR #54 OR #55 OR #56 OR #57 OR #58 OR #59 OR #60 OR #61 OR #62 OR #63 OR #64 OR #65 OR #66 OR #67 OR #68 OR #69 OR #70 OR #71 OR #72 OR #73 OR #74 OR #75 OR #76 OR #77
#79	#18 AND #78
#80	MeSH descriptor: [Acute Disease] this term only
#81	MeSH descriptor: [Fever] this term only
#82	MeSH descriptor: [Sepsis] this term only
#83	MeSH descriptor: [Bacterial Infections] this term only
#84	((acute* NEAR/2 (ill or illness)) or fever or sepsis or bacter?emia or (bacteria* adj infection*)):ti
#85	#80 or #81 or #82 or #83 or #84
#86	#78 AND #85
#87	((appropriat* NEXT informat*)):ti,ab,kw
#88	(#18 OR #85) AND #87
#89	#79 OR #86 OR #88

Database(s): Emcare – OVID interface

Emcare 1995 to present

Date of last search: 14 July 2021

#	Searches
1	meningitis/ or bacterial meningitis/ or haemophilus meningitis/ or hemophilus influenzae meningitis/ or listeria meningitis/ or meningococcal meningitis/ or pneumococcal meningitis/ or meningoencephalitis/
2	((bacter* or infect*) adj3 (meningit* or meninges* or leptomeninges* or subarachnoid space?)).ti,ab.
3	(meningit* adj3 (e coli or escherichia coli or h?emophilus or hib or h?emophilus influenz* or h influenz* or listeria* or meningococc* or pneumococc* or gram-negativ* bacill* or gram negativ* bacill* or streptococc* or group B streptococc* or GBS or streptococcus pneumon* or s pneumon* or septic* or sepsis* or bacter?emi?)).ti,ab.
4	((e coli or escherichia coli or h?emophilus or hib or h?emophilus influenz* or h influenz* or listeria* or meningococc* or pneumococc* or gram-negativ* bacill* or gram negativ* bacill* or streptococc* or group B streptococc* or GBS or streptococcus pneumon* or s pneumon*) adj3 (septic* or sepsis* or bacter?emi?)).ti,ab.
5	(meningit* or mening?encephalitis*).ti,ab.
6	or/1-5
7	Meningococcosis/ or Meningococcemia/ or Neisseria Meningitidis/
8	(meningococc* adj3 (sepsis* or septic* or toxic* or endotoxic* or disease? or infection?)).ti,ab.
9	(meningococcus* or meningococci* or meningococc?emi?).ti,ab.
10	(Neisseria* mening* or n mening*).ti,ab.
11	or/7-10
12	access to information/ or information/ or information center/ or information service/ or information dissemination/ or information seeking/ or help seeking behavior/ or exp interpersonal communication/ or exp mass communication/ or consumer health information/ or health promotion/ or health education/ or education program/ or attitude to health/ or patient education/ or patient information/ or medical information/ or publication/ or visual information/ or exp audiovisual aid/ or personal digital assistant/ or exp decision support system/ or patient decision making/ or exp internet/ or web-

#	Searches
	based intervention/ or web browser/ or social media/ or blogging/ or social network/ or smartphone/ or mobile application/ or e-mail/ or email support/ or text messaging/ or text messaging support/ or hotline/ or telephone/ or telephone support/ or exp mobile phone/ or teleconsultation/ or television/ or radio/ or bibliotherapy/ or health literacy/ or computer assisted therapy/ or telehealth/ or telemedicine/ or patient advocacy/ or consumer advocacy/ or psychosocial care/ or social support/ or exp self help/ or exp support group/ or peer group/ or exp counseling/ or exp patient participation/ or empowerment/
13	((group* or psychosocial*) adj2 support*).tw.
14	(blog* or "mobile* app*" or "mobile* phone* app*" or "mobile* health* app*" or "download* app*" or ipad app* or booklet* or brochure* or cellphone* or dvd* or handout* or ict or internet* or leaflet* or manual or manuals or media or mobile* or online app* or pamphlet* or phone* or publication* or smartphone* or telephone* or webpage* or web based or website* or web site* or web page* or video* or helpseek* or help-seek* or healthcaresseek* or healthcare-seek* or healthseek* or health-seek* or care-seek* or careseek*).tw.
15	((discussion* or online* or on-line*) adj3 (forum* or fora)).tw.
16	messag* board*.tw.
17	(hotline* or helpline* or hot-line* or help-line*).tw.
18	(social adj (network* or media)).tw.
19	((user* or family or families or parent* or father* or mother* or carer* or caregiver* or care giv*) adj3 (advice or inform* or support* or guidance)).tw.
20	(information* adj3 (model* or program* or need* or require* or seek* or access* or dissem* or shar* or provid* or provision)).tw.
21	((inform* or support*) adj3 (help* or support* or benefi* or hinder* or hindran* or barrier* or facilitate* or practical* or clear* or accurate*).tw.
22	((information* or support* or advice or guidance) adj3 (type* or content* or method* or quality or format)).tw.
23	information sheet.tw.
24	patient guidance.tw.
25	or/12-24
26	Qualitative Research/ or exp interview/
27	interview*.tw.
28	thematic analysis/
29	(theme* or thematic).mp.
30	qualitative.af.
31	questionnaire\$.mp.
32	ethnological research.mp.
33	ethnograph*.mp.
34	ethnonursing.af.
35	phenomenol*.af.
36	(life stor* or women* stor*).mp.
37	(grounded adj (theor* or study or studies or research or analys?s)).af.
38	((data adj1 saturat\$) or participant observ\$).tw.
39	(field adj (study or studies or research)).tw.
40	biographical method.tw.
41	theoretical sampl\$.af.
42	((purpos\$ adj4 sampl\$) or (focus adj group\$)).af.
43	open ended questionnaire/
44	((open end* or openend*) adj3 questionnaire*).tw.
45	(account or accounts or unstructured or openended or open ended or text\$ or narrative\$).mp.
46	(life world or life-world or conversation analys?s or personal experience\$ or theoretical saturation).mp.
47	((lived or life) adj experience\$).mp.
48	narrative analys?s.af.
49	parental attitude/ or patient satisfaction/ or patient preference/ or personal experience/
50	(dissatis* or expectation* or experienc* or opinion* or perceive* or perspective* or preferenc* or satisf* or view*).tw.
51	or/26-50
52	(6 or 11) and 25 and 51
53	limit 52 to (English language and yr="2000 -Current")
54	*acute disease/ or *fever/ or *sepsis/ or *bacterial infection/ or exp *bacteremia/
55	((acute* adj2 (ill or illness)) or fever or sepsis or bacter?emia or (bacteria* adj infection*).m_titl.
56	54 or 55
57	25 and 51 and 56
58	(appropriat* adj informat*).tw.
59	(6 or 11 or 56) and 51 and 58
60	57 or 59
61	limit 60 to (English language and yr="1980 -Current")
62	letter.pt.
63	Letter/
64	letter\$/
65	editorial.pt.
66	historical article.pt.
67	anecdote.pt.
68	commentary.pt.
69	note.pt.
70	Case Report/

#	Searches
71	case report\$.pt.
72	Case Study/
73	case study.pt.
74	exp animal/ not human/
75	Nonhuman/
76	exp Experimental Animal/
77	exp animal experiment/
78	exp animal model/
79	exp rodentia/
80	exp rodent/
81	Animals, Laboratory/
82	exp Animal Studies/
83	exp RODENTS/
84	or/62-83
85	61 not 84

Economic Search

One global search was conducted for economic evidence across the guideline.

Database(s): NHS Economic Evaluation Database (NHS EED), HTA Database – CRD interface

Date of last search: 11 March 2021

#	Searches
1	MeSH DESCRIPTOR meningitis IN NHSEED,HTA
2	MeSH DESCRIPTOR Meningitis, Bacterial IN NHSEED,HTA
3	MeSH DESCRIPTOR Meningitis, Escherichia coli IN NHSEED,HTA
4	MeSH DESCRIPTOR Meningitis, Haemophilus EXPLODE ALL TREES IN NHSEED,HTA
5	MeSH DESCRIPTOR Meningitis, Listeria IN NHSEED,HTA
6	MeSH DESCRIPTOR Meningitis, Meningococcal IN NHSEED,HTA
7	MeSH DESCRIPTOR Meningitis, Pneumococcal IN NHSEED,HTA
8	MeSH DESCRIPTOR Meningoencephalitis IN NHSEED,HTA
9	((bacter* or infect*) NEAR3 (meningit* or meninges* or leptomeninges* or subarachnoid space*)) IN NHSEED, HTA
10	((meningit* NEAR3 (e coli or escherichia coli or h?emophilus or hib or h?emophilus influenz* or h influenz* or listeria* or meningococc* or pneumococc* or gram-negativ* bacill* or gram negativ* bacill* or streptococc* or group B streptococc* or GBS or streptococcus pneumon* or s pneumon* or septic* or sepsis* or bacter?emi?))) IN NHSEED, HTA
11	((e coli or escherichia coli or h?emophilus or hib or h?emophilus influenz* or h influenz* or listeria* or meningococc* or pneumococc* or gram-negativ* bacill* or gram negativ* bacill* or streptococc* or group B streptococc* or GBS or streptococcus pneumon* or s pneumon*) NEAR3 (septic* or sepsis* or bacter?emi?))) IN NHSEED, HTA
12	((meningencephalitis* or meningoencephalitis* or meningit*) IN NHSEED, HTA
13	MeSH DESCRIPTOR Meningococcal Infections IN NHSEED,HTA
14	MeSH DESCRIPTOR Neisseria meningitidis EXPLODE ALL TREES IN NHSEED,HTA
15	((meningococc* NEAR3 (sepsis* or septic* or toxic* or endotoxic* or disease* or infection*)) IN NHSEED, HTA
16	((meningococcus* or meningococci* or meningococcaemia* or meningococcemia*) IN NHSEED, HTA
17	((Neisseria* NEXT mening*) IN NHSEED, HTA
18	#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17

Database(s): Medline & Embase (Multifile) – OVID interface

Embase Classic+Embase 1947 to 2021 March 10, **Ovid MEDLINE(R) and Epub Ahead of Print, In-Process & Other Non-Indexed Citations and Daily** 1946 to March 09, 2021

Date of last search: 11 March 2021

Multifile database codes: emczd = Embase Classic+Embase; ppez= MEDLINE(R) and Epub Ahead of Print, In-Process & Other Non-Indexed Citations and Daily

#	Searches
1	Meningitis/ or Meningitis, Bacterial/ or Meningitis, Escherichia Coli/ or Meningitis, Haemophilus/ or Meningitis, Listeria/ or Meningitis, Meningococcal/ or Meningitis, Pneumococcal/ or Meningoencephalitis/
2	1 use ppez
3	meningitis/ or bacterial meningitis/ or haemophilus meningitis/ or listeria meningitis/ or pneumococcal meningitis/ or meningoencephalitis/
4	3 use emczd
5	((bacter* or infect*) adj3 (meningit* or meninges* or leptomeninges* or subarachnoid space?)).ti,ab.
6	(meningit* adj3 (e coli or escherichia coli or h?emophilus or hib or h?emophilus influenz* or h influenz* or listeria* or meningococc* or pneumococc* or gram-negativ* bacill* or gram negativ* bacill* or streptococc* or group B streptococc* or GBS or streptococcus pneumon* or s pneumon* or septic* or sepsis* or bacter?emi?)).ti,ab.

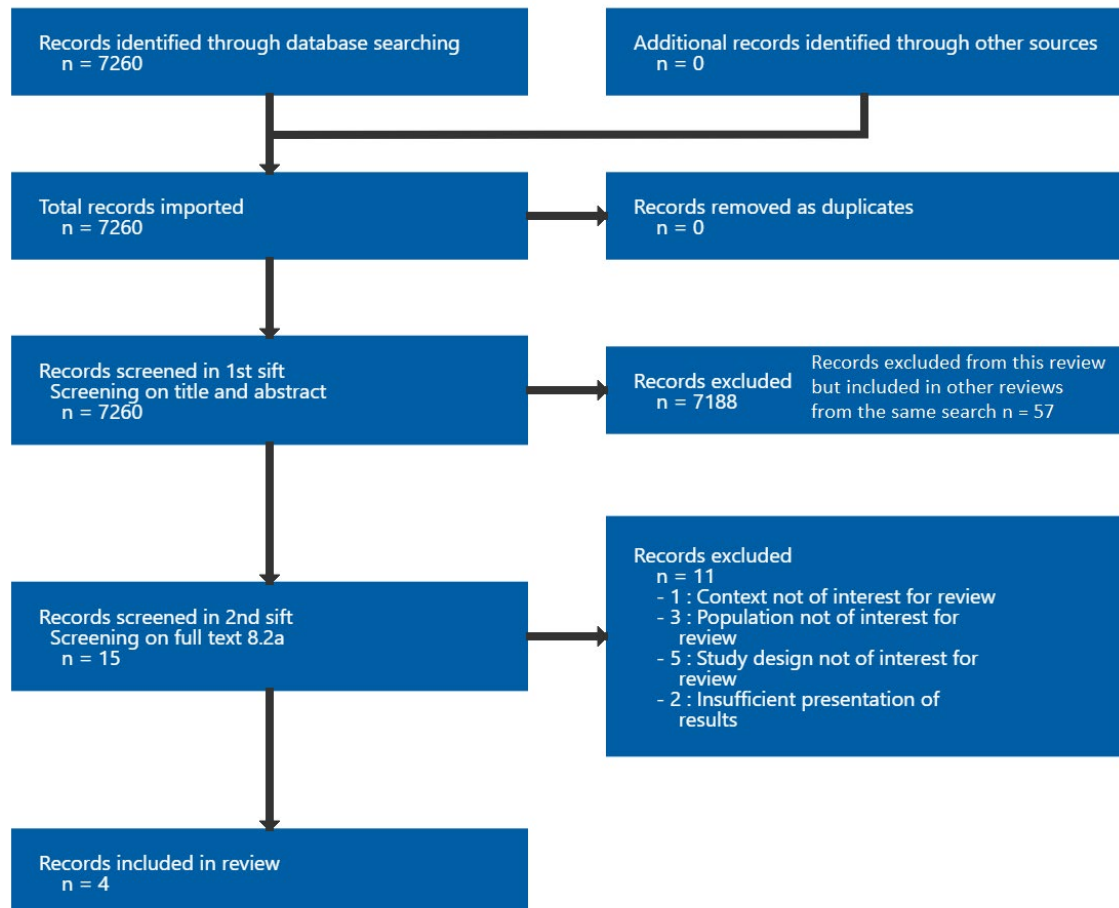
#	Searches
7	((e coli or escherichia coli or h?emophilus or hib or h?emophilus influenz* or h influenz* or listeria* or meningococc* or pneumococc* or gram-negativ* bacill* or gram negativ* bacill* or streptococc* or group B streptococc* or GBS or streptococcus pneumon* or s pneumon*) adj3 (septic* or sepsis* or bacter?emi?)).ti,ab.
8	(mening?encephalitis* or meningit*).ti,ab.
9	or/2,4-8
10	Meningococcal Infections/ or exp Neisseria meningitidis/
11	10 use ppez
12	Meningococcosis/ or Meningococcemia/ or Neisseria Meningitidis/
13	12 use emczd
14	(meningococc* adj3 (sepsis* or septic* or toxic* or endotoxic* or disease? or infection?)).ti,ab.
15	(meningococcus* or meningococci* or meningococc?emi?).ti,ab.
16	(Neisseria* mening* or n mening*).ti,ab.
17	or/11,13-16
18	Economics/ use ppez
19	Value of life/ use ppez
20	exp "Costs and Cost Analysis"/ use ppez
21	exp Economics, Hospital/ use ppez
22	exp Economics, Medical/ use ppez
23	Economics, Nursing/ use ppez
24	Economics, Pharmaceutical/ use ppez
25	exp "Fees and Charges"/ use ppez
26	exp Budgets/ use ppez
27	health economics/ use emczd
28	exp economic evaluation/ use emczd
29	exp health care cost/ use emczd
30	exp fee/ use emczd
31	budget/ use emczd
32	funding/ use emczd
33	budget*.ti,ab.
34	cost*.ti.
35	(economic* or pharmaco?economic*).ti.
36	(price* or pricing*).ti,ab.
37	(cost* adj2 (effective* or utilit* or benefit* or minimi* or unit* or estimat* or variable*)).ab.
38	(financ* or fee or fees).ti,ab.
39	(value adj2 (money or monetary)).ti,ab.
40	or/18-39
41	Quality-Adjusted Life Years/ use ppez
42	Sickness Impact Profile/
43	quality adjusted life year/ use emczd
44	"quality of life index"/ use emczd
45	(quality adjusted or quality adjusted life year*).tw.
46	(qaly* or qal or qald* or qale* or qtime* or qwb* or daly).tw.
47	(illness state* or health state*).tw.
48	(hui or hui2 or hui3).tw.
49	(multiattribute* or multi attribute*).tw.
50	(utilit* adj3 (score*1 or valu* or health* or cost* or measur* or disease* or mean or gain or gains or index*)).tw.
51	utilities.tw.
52	(eq-5d* or eq5d* or eq-5* or eq5* or euroqual* or euro qual* or euroqual 5d* or euro qual 5d* or euro qol* or euroqol* or euro quol* or euro quol* or euroquol5d* or euroquol5d* or eur qol* or eurqol* or eur qol5d* or eurqol5d* or eur?qul* or eur?qul5d* or euro* quality of life or european qol).tw.
53	(euro* adj3 (5 d* or 5d* or 5 dimension* or 5dimension* or 5 domain* or 5domain*)).tw.
54	(sf36 or sf 36 or sf thirty six or sf thirtysix).tw.
55	(time trade off*1 or time tradeoff*1 or tto or timetradeoff*1).tw.
56	Quality of Life/ and ((quality of life or qol) adj (score*1 or measure*1)).tw.
57	Quality of Life/ and ec.fs.
58	Quality of Life/ and (health adj3 status).tw.
59	(quality of life or qol).tw. and Cost-Benefit Analysis/ use ppez
60	(quality of life or qol).tw. and cost benefit analysis/ use emczd
61	((qol or hrqol or quality of life).tw. or *quality of life/) and ((qol or hrqol* or quality of life) adj2 (increas* or decreas* or improv* or declin* or reduc* or high* or low* or effect or effects or worse or score or scores or change*1 or impact*1 or impacted or deteriorat*)).ab.
62	Cost-Benefit Analysis/ use ppez and cost-effectiveness ratio*.tw. and (cost-effectiveness ratio* and (perspective* or life expectanc*)).tw.
63	cost benefit analysis/ use emczd and cost-effectiveness ratio*.tw. and (cost-effectiveness ratio* and (perspective* or life expectanc*)).tw.
64	*quality of life/ and (quality of life or qol).ti.
65	quality of life/ and ((quality of life or qol) adj3 (improv* or chang*)).tw.
66	quality of life/ and health-related quality of life.tw.
67	Models, Economic/ use ppez
68	economic model/ use emczd
69	care-related quality of life.tw,kw.

#	Searches
70	((capability\$ or capability-based\$) adj (measure\$ or index or instrument\$)).tw,kw.
71	social care outcome\$.tw,kw.
72	(social care and (utility or utilities)).tw,kw.
73	or/41-72
74	(9 or 17) and 40
75	(9 or 17) and 73
76	letter/
77	editorial/
78	news/
79	exp historical article/
80	Anecdotes as Topic/
81	comment/
82	case report/
83	(letter or comment*).ti.
84	76 or 77 or 78 or 79 or 80 or 81 or 82 or 83
85	randomized controlled trial/ or random*.ti,ab.
86	84 not 85
87	animals/ not humans/
88	exp Animals, Laboratory/
89	exp Animal Experimentation/
90	exp Models, Animal/
91	exp Rodentia/
92	(rat or rats or mouse or mice).ti.
93	86 or 87 or 88 or 89 or 90 or 91 or 92
94	letter.pt. or letter/
95	note.pt.
96	editorial.pt.
97	case report/ or case study/
98	(letter or comment*).ti.
99	94 or 95 or 96 or 97 or 98
100	randomized controlled trial/ or random*.ti,ab.
101	99 not 100
102	animal/ not human/
103	nonhuman/
104	exp Animal Experiment/
105	exp Experimental Animal/
106	animal model/
107	exp Rodent/
108	(rat or rats or mouse or mice).ti.
109	101 or 102 or 103 or 104 or 105 or 106 or 107 or 108
110	93 use ppez
111	109 use emczd
112	110 or 111
113	74 not 112
114	limit 113 to English language
115	75 not 112
116	limit 115 to English language
117	114 or 116

Appendix C Qualitative evidence study selection

Study selection for: What information is valued by patients with confirmed bacterial meningitis or meningococcal disease, and their families or carers?

Figure 2: Study selection flow chart



Appendix D Evidence tables

Evidence tables for review question: What information is valued by patients with confirmed bacterial meningitis or meningococcal disease, and their families or carers?

Table 4: Evidence tables – qualitative evidence

Clark, 2013

Bibliographic Reference Clark, Laura J; Glennie, Linda, Audrey, Suzanne, Hickman, Matthew, Trotter, Caroline L.; The health, social and educational needs of children who have survived meningitis and septicaemia: the parents' perspective; BMC public health; 2013; vol. 13; 954

Study Characteristics

Study type	Grounded theory
Country/ies where study was carried out	United Kingdom & Ireland
Setting	Meningitis Research Foundation's member.
Data collection and analysis	Semi-structured interviews, either face-to-face in their homes or by telephone, analysed using the constant comparison method from grounded theory.
Recruitment strategy	Participants recruited from Meningitis Research Foundation's member database and social media. Individuals with experience of meningitis and septicaemia, were sent a targeted email invitation or letter and a participant information sheet. Only those parents reporting permanent after-effects, and who had accessed aftercare and support, were invited for interview.
Study dates	January 2000 to May 2010
Sources of funding	Not industry funded
Inclusion criteria	Parent/legal guardian of children (aged <18 years at the time of illness) who had survived meningitis or septicaemia.
Exclusion criteria	Children who did not come from the UK or Ireland, were not the parent or legal guardian, had experienced meningitis or septicaemia prior to 2000, had experience of adult illness (18 years old or more at the time of disease), or had experienced the disease in the last six months.

Sample size	<p>Survey n = 194</p> <p>Interview n = 18</p>
Participant characteristics	<p>Survey n = 194</p> <p>Meningitis n = 76</p> <p>Septicaemia n = 16</p> <p>Both meningitis and septicaemia n = 102</p> <p>Mean age of children at the time of illness = 3.83 years</p> <p>Median time since illness = 5 years</p> <p>Interview n = 18 (face-to-face = 9; telephone = 9)</p>
Results	<p>Themes (information in bullet points are theme(s) applied after thematic synthesis)</p> <p>Original theme: Accessing appropriate support and follow-up care: Navigating the system.</p> <ul style="list-style-type: none"> • Information on discharge from hospital <ul style="list-style-type: none"> ○ Navigating the system <ul style="list-style-type: none"> ▪ P1: “Because her needs are so complicated and they’re in so many different areas... there is physio, speech and language, OT, neurology...so many different people for us to learn, to keep up with and to learn the language, we didn’t know what to ask...we’re just completely ... overwhelmed.” page 4 • Access to support <ul style="list-style-type: none"> ○ Navigating the system <ul style="list-style-type: none"> ▪ P8: “He’s now gone into a specialist educational provision and now because they’re on-site he’s kind of accessing all those services again on a really regular basis.” page 4 <p>Original theme: Accessing appropriate support and follow-up care: Poorly appreciated link between meningitis and sequelae</p>

- Access to support
 - Educational
 - P2: “You look at him against all his other class and you wouldn’t straight away say this is the child who’s had meningitis, this is the child who can’t hear in one ear, this is the child who struggles in these areas of social behaviour ...so just trying to access any extra help in school is like pulling teeth.” page 5

Original theme: Accessing appropriate support and follow-up care: Appropriateness of support and aftercare

- Type of support
 - Individualised
 - P1: “... she has a helmet from orthopaedics because of her epilepsy...it fits poorly and she pushed it back so the bit of the head it’s supposed to protect, it doesn’t protect. I went back and said, ‘is there something better we can do with it?’, and she said, ‘no that’s it’. Really, she cannot be the only child to be doing this.” page 5
 - P2: “They spent a lot of time on his spatial awareness, and those types of things because he does seem to be quite clumsy...they picked up this constant need he has of stimulation to the head, which I hadn’t noticed.” page 5

Original theme: Communication: Debrief before discharge

- Information on discharge from hospital
 - Long-term effects
 - P12: “I don’t know if there [is] something standard on discharge that parents are given, a booklet or something like that would have been so useful...I didn’t know of any time scales or what things I should be looking for.” page 6
 - Follow-up
 - P3: “[Hospital] said, ‘he might be ok you know he might have problems, but you won’t know at the moment’...which I felt wasn’t really helpful either because it was kind of like well you have to go home and you just wait and see how he turns out...I don’t think I had the right support for that.” page 5-6

Original theme: Communication: Involving parents

- Communication
 - Standardised

	<ul style="list-style-type: none"> ▪ P3: “[Hospital] said, ‘he might be ok you know he might have problems, but you won’t know at the moment’...which I felt wasn’t really helpful either because it was kind of like well you have to go home and you just wait and see how he turns out...I don’t think I had the right support for that.” page 5-6 ○ Involving parents <ul style="list-style-type: none"> ▪ P7: “The fact that he’d had an assessment [at school] and I don’t know what the outcome is... I don’t know if that’s in anyway had any bearing on what’s happening with him now.” page 6 <p>Original theme: Communication: Healthcare professionals</p> <ul style="list-style-type: none"> • Communication <ul style="list-style-type: none"> ○ Enhanced communication between healthcare professionals <ul style="list-style-type: none"> ▪ P15: “They’ve just given her some words to practise, she doesn’t say the endings of any of the words ... probably because she can’t hear them...speech and language can’t sort her hearing out, they can just try and help her with pronouncing the words, but if she can’t hear them then they’re hitting their heads against a brick wall.” Page 6 ▪ P13: “... and nothing was ever planned without [consultant]’s say so...to me that said we have got your son’s best interests at heart we have a plan and we know what we’re doing.” page 6
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Critical appraisal

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Minor concerns <i>(Concerns around the recruitment of participants)</i>

Haines, 2005

Bibliographic Reference Haines, C.; Parents' experiences of living through their child's suffering from and surviving severe meningococcal disease; Nursing in critical care; 2005; vol. 10 (no. 2); 78-89

Study Characteristics

Study type	Phenomenological
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Country/ies where study was carried out	England
Setting	Parents of children admitted to PICU
Data collection and analysis	Face-to-face interviews 1-month following discharge from hospital, either in the parent's home or in a private room in the hospital. The parents were asked to discuss their experiences prior to and during their child's admission to PICU, how they felt, their coping strategies and what they felt influenced their experience. Data was analysed using Colaizzi's Interpretation Process.
Recruitment strategy	Parents of children admitted to PICU who survived severe meningococcal disease were invited to participate following their child's discharge from hospital.
Study dates	Not stated. Participants recruited over a 6-month period.
Sources of funding	Not industry funded
Inclusion criteria	Parents whose child has suffered from and survived severe MD
Exclusion criteria	Not reported
Sample size	7 parents
Participant characteristics	Parents n = 7 No further details reported
Results	<p>Themes (information in bullet points are theme(s) applied after thematic synthesis)</p> <p>Original theme: Complications/side effects of the disease</p> <ul style="list-style-type: none"> • Information during hospitalisation <ul style="list-style-type: none"> ○ Complications of the disease <ul style="list-style-type: none"> ▪ 'It was such a shock, I thought children with meningitis they either lived or they died. I didn't think that they survived with problems . . . and if they lived it was just a course of antibiotics like you, perhaps you'd even have them at home or something and umm. . . it would be fine'. Isabelle page 81 ▪ 'I watched the rash turn black, the areas of tissue dying and turning black and hard scabs forming on the surface, and I thought that was it. I didn't realize that those wounds went so deep underneath . . . and I watched that, those areas happen and uhhh with all the weeping and the blisters appearing and all these horrid things that happen after the bug umm . . . you know stops killing the tissue and I

watched all that happen in almost as a matter of fact thing'. Isabelle page 81

Original theme: Child's physical appearance

- Information during hospitalisation
 - Child's physical appearance
 - 'It was really . . . difficult to see it, him turn blue, I didn't recognize him, I just didn't recognize him at all. I was so traumatised, I didn't know what to do' Isabelle page 82
 - 'I thought the worst thing out of all of it, . . . was when she started coming round, and she was having withdrawal symptoms . . . She was seeing spiders, she was saying the man was getting her, . . . she was screaming the whole intensive care down,' Ellen page 83

Original theme: Need for support and understanding

- Need for support
 - During hospitalisation
 - 'They'd try (other parents) and cheer you up a bit if they saw you going past in a bit of state.' Molly page 84
- Source of support
 - Parents
 - 'They'd try (other parents) and cheer you up a bit if they saw you going past in a bit of state.' Molly page 84

Original theme: Need and value of communication/information/publicity

- Information during hospitalisation
 - Disease process
 - No quotes
- Information sources
 - Nursing staff
 - 'the nurse, she was brilliant, she explained everything they were doing . . . she was great, . . . everybody else was just rushing about doing stuff. and uhhh . . . then we went up on to the ward, when she was better. and they was fantastic up there' . . Dave page 84
- Communication
 - Involving parents

	<ul style="list-style-type: none"> ▪ 'the nurse, she was brilliant, she explained everything they were doing . . . she was great, . . . everybody else was just rushing about doing stuff. and uhhh . . . then we went up on to the ward, when she was better. and they was fantastic up there' . . Dave page 84 <p>Original theme: The impact of care delivery</p> <ul style="list-style-type: none"> • Source of support <ul style="list-style-type: none"> ○ Medical staff <ul style="list-style-type: none"> ▪ ' . . . and I'd also just sit there and just . . .notice just all the care and attention each child was having . . . , it was just overwhelming really, I didn't feel frightened'. Olivia page 8 ○ Nursing staff <ul style="list-style-type: none"> ▪ 'and the nurses I found were brilliant, I mean they were such, . . . I feel like they were my friends really, that they befriended me, they gave me support'. Isabelle page 85
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MD: meningococcal disease; PICU: Paediatric Intensive Care Unit

Critical appraisal

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Minor concerns (Concerns around data saturation not discussed)

Sweeney, 2013

Bibliographic Reference Sweeney, F; Viner, R. M; Booy, R; Christie, D.; Parents' experiences of support during and after their child's diagnosis of meningococcal disease; Acta Paediatrica; 2013; vol. 102 (no. 3); e126-30

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried	United Kingdom

out	
Setting	Meningococcal outcome study in adolescents and in children (MOSAIC)
Data collection and analysis	Structured telephone interviews exploring parents experience of support at the time of their child's diagnosis and at the time of the interview. Data were analysed using qualitative content analysis.
Recruitment strategy	Parents/carers of survivors of serogroup B meningococcal disease in childhood, drawn from a population-based case-control study.
Study dates	Not stated
Sources of funding	This project was commissioned and funded by the Meningitis Trust, who were not involved in the study design; collection, analysis and interpretation of data or writing of the paper.
Inclusion criteria	Not reported
Exclusion criteria	Not reported
Sample size	244 parents
Participant characteristics	No details reported
Results	<p>Themes (information in bullet points are theme(s) applied after thematic synthesis)</p> <p>Original theme: Information provision: Information about the disease specifics of MenB</p> <ul style="list-style-type: none"> • Information before discharge from hospital <ul style="list-style-type: none"> ○ long-term effects <ul style="list-style-type: none"> ▪ No quotes • Information format <ul style="list-style-type: none"> ○ Written <ul style="list-style-type: none"> ▪ 'We were worried afterwards but we had a leaflet to look over and knew we could call the hospital if necessary'. page e127 ○ Detailed <ul style="list-style-type: none"> ▪ 'More information would put my mind at rest'. page e127 <p>Original theme: Information provision: Communication during diagnosis and treatment</p> <ul style="list-style-type: none"> • Information at diagnosis <ul style="list-style-type: none"> ○ Information at diagnosis

- ‘Getting the balance better in communication’ included having the treatment process explained clearly ‘more information on what is going on, like what meningitis is and how it is diagnosed’ page e127
- Information during hospitalisation
 - Disease process
 - ‘More communication - it was very frightening and we didn’t know when he was out of danger. We were not sure it was meningitis because we weren’t really told. My partner was asking questions but was ignored completely’. page e127
- Communication
 - Clear
 - ‘it was faultless from start to finish - from the paramedic to the hospital. They kept us informed - the good and the bad’. page e127
 - Lay language
 - ‘Doctors could have explained everything more clearly because they explained everything in medical terms’. page e127
 - Involving parents
 - ‘More communication - it was very frightening and we didn’t know when he was out of danger. We were not sure it was meningitis because we weren’t really told. My partner was asking questions but was ignored completely’. page e127

MOSAIC: meningococcal outcome study in adolescents and in children

Critical appraisal

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Minor concerns (Concerns around recruitment and data collection)

Wisemantel, 2018

Bibliographic Reference Wisemantel, Melinda, Maple, Myfanwy, Massey, Peter D; Osbourn, Maggi, Kohlhagen, Julie, Allport, Balluffi Board Borg Braun Bronner Buysse Diaz-Caneja Fereday Garralda Grimwood Haines Heymann Israel Johnson Judge Koomen Koomen Liamputtong Massey Miller Rees Shears Shears Shurdy Sweeney Tak Vermont; Psychosocial challenges of invasive meningococcal disease for children and their families; Australian Social Work; 2018; vol. 71 (no. 4); 478-490

Study Characteristics

Meningitis (bacterial) and meningococcal disease: recognition, diagnosis and management: evidence reviews on information for confirmed bacterial meningitis or meningococcal disease

Study type	General qualitative inquiry
Country/ies where study was carried out	Australia
Setting	A regional area of northern New South Wales, Australia that includes a large city, regional centres, and rural and remote areas.
Data collection and analysis	Semi structured interviews (range from 20 to 50 minutes, average 45 minutes) conducted in families homes or workplace. Parents were asked who provided support during the illness, what worked, and their opinions on what could have been done differently to make the experience with the illness easier during admissions. Data analysed using thematic analysis with inductive and deductive techniques.
Recruitment strategy	A convenience sample of parents who had experienced a child or young person with an invasive Meningococcal Disease (IMD) within the previous 5-6 years. Parents were selected based on the outcome for the child to include only families who did not experience their child dying, being revived, or ventilated.
Study dates	2010-2012
Sources of funding	Not industry funded
Inclusion criteria	<ul style="list-style-type: none"> • IMD admissions within the 2010–2012 period recorded in the study region • parents were selected based on the outcome for the child to include only families who did not experience their child dying, being revived, or ventilated
Exclusion criteria	None reported
Sample size	6 parents
Participant characteristics	Parents n=6
Results	<p>Themes (information in bullet points are theme(s) applied after thematic synthesis)</p> <p>Original theme: Unclear about IMD: Prior Understanding; Need for More Information; and Medical Teams Lacking Information</p> <ul style="list-style-type: none"> • Diagnosis <ul style="list-style-type: none"> ◦ Diagnosis <ul style="list-style-type: none"> ▪ 'Cause everyone's very busy at the hospital...[we] just did our own little bit of research, giving

- ourselves more information so we knew what questions to ask...we did have bits of information, but to be thorough, you just always want to know more'. Page 482
- Information format
 - Detailed
 - "I think they gave me a printed piece of paperand that's all I had...not really enough, because I was really confused". page 482
 - Lay language
 - One participant described her main questions as "Where did it come from? How did he get it?...you do a bit of...internet searching". She described how she found the information not very accessible "I mean there is all that big terminology and you go 'oh I really don't understand that'." page 6
 - Information sources
 - Medical staff
 - "The doctors didn't know much.... When I did ask the doctor on the ward at the time something about it [IMD], she said she couldn't answer me because she wasn't familiar with it and she'd never treated it...very annoyed with the fact that they didn't know what they were doing because then they're treating him for something that they know nothing about...frustrating when you're in the moment and you had a question and they were like..."we don't know". page 483
 - Internet
 - One participant described her main questions as "Where did it come from? How did he get it?...you do a bit of...internet searching". She described how she found the information not very accessible "I mean there is all that big terminology and you go 'oh I really don't understand that'." page 6
 - Communication
 - Clear
 - "The doctors didn't know much.... When I did ask the doctor on the ward at the time something about it [IMD], she said she couldn't answer me because she wasn't familiar with it and she'd never treated it...very annoyed with the fact that they didn't know what they were doing because then they're treating him for something that they know nothing about...frustrating when you're in the moment and you had a question and they were like..."we don't know". page 483

IMD: *invasive meningococcal disease*

Critical appraisal

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Minor concerns (<i>concerns around recruitment and data collection</i>)

FINAL

Information for confirmed bacterial meningitis or meningococcal disease

CASP: Critical Appraisal Skills Programme; MOSAIC: Meningococcal outcome study in adolescents and in children; PICU: paediatric intensive care unit

Appendix E Forest plots

Forest plots for review question: What information is valued by patients with confirmed bacterial meningitis or meningococcal disease, and their families or carers?

No meta-analysis was conducted for this review question and so there are no forest plots.

Appendix F GRADE-CERQual tables

GRADE tables for review question: What information is valued by patients with confirmed bacterial meningitis or meningococcal disease, and their families or carers?

Table 5: Evidence summary profile for theme 1 (Information at diagnosis)

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
2 (Sweeney 2013; Wisemantel 2018) n=250	Qualitative studies using structured and semi-structured interviews (over the phone and face-to-face)	<p>Parents reported that they would have liked more information and better communication at the time of diagnosis, for example general information about meningitis, diagnosis, and treatment.</p> <p><i>'Getting the balance better in communication''more information on what is going on, like what meningitis is and how it is diagnosed' (Sweeney 2013, page e127)</i></p> <p><i>'Cause everyone's very busy at the hospital...[we] just did our own little bit of research, giving ourselves more information so we knew what questions to ask...we did have bits of information, but to be thorough, you just always want to know more' (Wisemantel 2018, page 482)</i></p>	<p>Methodological limitations</p> <p>Relevance</p> <p>Coherence</p> <p>Adequacy</p>	<p>Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist</p> <p>Minor concerns. Population restricted to MD. Less severe forms of disease under represented</p> <p>None or very minor concerns</p> <p>Minor concerns. Studies together offered moderately rich data</p>	Moderate

CASP: Critical Appraisal Skills Programme; CERQual: Confidence in the Evidence from Reviews of Qualitative research; MD: Meningococcal disease

Table 6: Evidence summary profile for theme 2 (Information during hospitalisation)

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
Sub-theme 2.1: Child's physical appearance					
1 (Haines 2005) n=8	Qualitative study using semi-structured interviews (face-to-face)	<p>Parents reported that they were not prepared to see how different their child looked whilst on the intensive care unit, which was distressing. Parents highlighted that they were also inadequately prepared for their child's reactions when they were 'waking up' or withdrawing from drug therapy. Better information provision would have enabled parents to feel more prepared.</p> <p><i>'It was really . . . difficult to see it, him turn blue, I didn't recognize him, I just didn't recognize him at all. I was so traumatised, I didn't know what to do'</i> (Haines 2005; Isabelle page 82)</p> <p><i>'I thought the worst thing out of all of it, . . . was when she started coming round, and she was having withdrawal symptoms . . . She was seeing spiders, she was saying the man was getting her, . . . she was screaming the whole intensive care down,'</i> (Haines 2005; Ellen page 83)</p>	Methodological limitations	Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	Minor concerns. Population restricted to MD. Less severe forms of disease under represented	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns. Studies together offered some rich data	
Sub-theme 2.2: Disease process					
2 (Haines 2005; Sweeney 2013) n=252	Qualitative studies using structured and semi-structured interviews (over the phone and face-to-face)	<p>Parents reported that they would have liked more information on the disease process and an opportunity to ask questions. This was of particular importance on the intensive care unit.</p> <p><i>'More communication - it was very frightening and we didn't know when he was out of danger. We were not sure it was meningitis because we weren't really told. My partner was asking questions but was ignored completely.'</i> (Sweeney 2013; page e127)</p>	Methodological limitations	Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	Minor concerns. Population restricted to MD. Less severe forms of disease under	

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
				represented	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns. Studies together offered moderately rich data	
Sub-theme 2.3: Complications of disease					
1 (Haines 2005) n=8	Qualitative study using semi-structured interviews (face-to-face)	<p>Parents reported that they realised that their child was severely ill. However, parents highlighted that they were unaware of the potential complications or long-term effects associated with the disease. Better information provision would have enabled parents to feel more prepared.</p> <p><i>'It was such a shock, I thought children with meningitis they either lived or they died. I didn't think that they survived with problems . . . and if they lived it was just a course of antibiotics like you, perhaps you'd even have them at home or something and umm. . . it would be fine'.</i> (Haines 2005; Isabelle page 81)</p> <p><i>'I watched the rash turn black, the areas of tissue dying and turning black and hard scabs forming on the surface, and I thought that was it. I didn't realize that those wounds went so deep underneath . . . and I watched that, those areas happen and uhhh with all the weeping and the blisters appearing and all these horrid things that happen after the bug umm . . . you know stops killing the tissue and I watched all that happen in almost as a matter of fact thing'.</i> (Haines 2005; Isabelle page 81)</p>	Methodological limitations	Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	Minor concerns. Population restricted to MD. Less severe forms of disease under represented	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns. Studies together offered some rich data	

CASP: Critical Appraisal Skills Programme; CERQual: Confidence in the Evidence from Reviews of Qualitative research; MD: Meningococcal disease

Table 7: Evidence summary profile for theme 3 (Information on discharge from hospital)

Study information	Description of theme or finding	CERQual assessment of the evidence
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Number of studies	Design		Criteria	Level of concern	Overall quality
Sub-theme 3.1: Navigating the system					
1 (Clark 2013) n=18	Qualitative study using semi-structured interviews (face-to-face or over the phone)	<p>Parents reported of having to learn to navigate the support system and familiarise themselves with the language used when accessing support. Parents reported that on discharge from hospital that they didn't know what to do next in terms of accessing support. Better information provision on how to access support, for example disability allowance or respite social care would be helpful.</p> <p><i>"Because her needs are so complicated and they're in so many different areas... there is physio, speech and language, OT, neurology...so many different people for us to learn, to keep up with and to learn the language, we didn't know what to ask...we're just completely ... overwhelmed."</i> (Sweeney 2013; P1 page 4)</p>	<p>Methodological limitations</p> <p>Relevance</p> <p>Coherence</p> <p>Adequacy</p>	<p>Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist</p> <p>Minor concerns. Less severe forms of disease under represented</p> <p>None or very minor concerns</p> <p>Serious concerns. Studies together did not offer rich data</p>	Low
Sub-theme 3.2: Long-term effects					
2 (Clark 2013; Sweeney 2013) n=262	Qualitative studies using structured and semi-structured interviews (over the phone and face-to-face)	<p>Parents reported that the uncertainty around the potential long-term effects associated with meningitis and meningococcal disease were often a worry or concern. Parents reported that the most frequent request for information provision was on the long-term effects. Some parents reported that they were not informed about the long-term effects, where as other parents reported that they were told to take a 'wait and see' approach.</p> <p><i>"I don't know if there [is] something standard on discharge that parents are given, a booklet or something like that would have been so useful...I didn't know of any time scales or what things I should be looking for."</i> (Clark 2013 P12 page 6)</p>	<p>Methodological limitations</p> <p>Relevance</p> <p>Coherence</p> <p>Adequacy</p>	<p>Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist</p> <p>Minor concerns. Less severe forms of disease under represented</p> <p>None or very minor concerns</p> <p>Minor concerns.</p>	Moderate

Study information			CERQual assessment of the evidence		
Number of studies	Design	Description of theme or finding	Criteria	Level of concern	Overall quality
				Studies together offered moderately rich data	
Sub-theme 3.3: Follow-up					
1 (Clark 2013) n=18	Qualitative study using semi-structured interviews (face-to-face or over the phone)	Parents reported that there was lack of clarity on the follow-up plan for their child after discharge from hospital. Some parents reported that they were told to take a 'wait and see' approach, which parents didn't find helpful. <i>"[Hospital] said, 'he might be ok you know he might have problems, but you won't know at the moment'...which I felt wasn't really helpful either because it was kind of like well you have to go home and you just wait and see how he turns out...I don't think I had the right support for that."</i> (Clark 2013 P3 page 5-6)	Methodological limitations	Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	Minor concerns. Less severe forms of disease under represented	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns. Studies together offered some rich data	

CASP: Critical Appraisal Skills Programme; CERQual: Confidence in the Evidence from Reviews of Qualitative research; MD: Meningococcal disease; OT: occupational therapy

Table 8: Evidence summary profile for theme 4 (Information format)

Study information			CERQual assessment of the evidence		
Number of studies	Design	Description of theme or finding	Criteria	Level of concern	Overall quality
Sub-theme 4.1: Written					
1 (Sweeney 2013)	Qualitative study using structured interviews	Parents reported that having information on meningitis in a written format was helpful and informative. Parents reported that they had all their 'questions answered' and were 'given all the information needed' in written format.	Methodological limitations	Minor concerns about methodological limitations of the	Moderate

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
n=244	(over the phone)	<p><i>"We were worried afterwards but we had a leaflet to look over and knew we could call the hospital if necessary". (Sweeney 2013; page e127)</i></p> <p>.</p>		evidence as per CASP qualitative checklist	
			Relevance	Minor concerns. Population restricted to MD. Less severe forms of disease under represented	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns. Studies together offered some rich data	
Sub-theme 4.2: Detailed					
2 (Sweeney 2013; Wisemantel 2018)	Qualitative studies using structured and semi-structured interviews (over the phone and face-to-face)	<p>Parents reported that they would have liked detailed information on meningitis and meningococcal disease. Some parents mentioned that information provision was minimal and not beneficial. Parents also reported that detailed information provision meant that they were well informed, which decreased anxiety.</p> <p><i>'More information would put my mind at rest'. (Sweeney 2013, page e127)</i></p> <p><i>"I think they gave me a printed piece of paper....and that's all I had...not really enough, because I was really confused". (Wisemantel 2018, page 482)</i></p>	Methodological limitations	Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
n=250			Relevance	Minor concerns. Population restricted to MD. Less severe forms of disease under represented	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns.	

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
				Studies together offered moderately rich data	
Sub-theme 4.3: Lay language					
1 (Wisemantel 2018) n=6	Qualitative studies using semi-structured interviews (face-to-face)	Parents reported that the language used in information sources were complex and difficult to understand. Parents reported that the complex language used in information sources were a barrier to understanding their child's condition. <i>"I mean there is all that big terminology and you go 'oh I really don't understand that'." (Wisemantel 2018, page 482)</i>	Methodological limitations	Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	Minor concerns. Population restricted to MD. Less severe forms of disease under represented	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns. Studies together offered some rich data	

CASP: Critical Appraisal Skills Programme; CERQual: Confidence in the Evidence from Reviews of Qualitative research; MD: Meningococcal disease

Table 9: Evidence summary profile for theme 5 (Information sources)

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
Sub-theme 5.1: Medical staff					
1 (Wisemantel 2018)	Qualitative studies using	Parents reported that some of the medical staff were unable to answer some questions related to meningococcal disease, indicating a lack of understanding	Methodological limitations	Minor concerns about	Low

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
n=6	semi-structured interviews (face-to-face)	<p>of the disease. Some parents reported that they were left frustrated and concerned with their unanswered questions given the serious nature of the condition.</p> <p><i>"The doctors didn't know much.... When I did ask the doctor on the ward at the time something about it [IMD], she said she couldn't answer me because she wasn't familiar with it and she'd never treated it...very annoyed with the fact that they didn't know what they were doing because then they're treating him for something that they know nothing about...frustrating when you're in the moment and you had a question and they were like..."we don't know".</i> (Wisemantel 2018, page 483)</p>		methodological limitations of the evidence as per CASP qualitative checklist	
			Relevance	Minor concerns. Population restricted to MD. Less severe forms of disease under represented	
			Coherence	None or very minor concerns	
			Adequacy	Serious concerns. Studies together did not offer rich data	
Sub-theme 5.2: Nursing staff					
1 (Haines 2005) n=8	Qualitative study using semi-structured interviews (face-to-face)	<p>Parents reported that they valued an open, information-sharing process about their child's care with nursing staff.</p> <p><i>'the nurse, she was brilliant, she explained everything they were doing . . . she was great, . . . everybody else was just rushing about doing stuff. and uhhh . . . then we went up on to the ward, when she was better. and they was fantastic up there'</i> (Haines 2005, Dave page 84)</p>	Methodological limitations	Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	Minor concerns. Population restricted to MD. Less severe forms of disease under represented	
			Coherence	None or very minor concerns	

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
			Adequacy	Moderate concerns. Studies together offered some rich data	
Sub-theme 5.3: Internet					
1 (Wisemantel 2018) n=6	Qualitative studies using semi-structured interviews (face-to-face)	Parents reported that in addition to the information provided by healthcare professionals, that they used the internet to find more information. Parents reported that the information that they found wasn't always accessible due to the complex language used. <i>"Where did it come from? How did he get it?...you do a bit of...internet searching"</i> (Wisemantel 2018, page 483)	Methodological limitations	Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist	Low
			Relevance	Minor concerns. Population restricted to MD. Less severe forms of disease under represented	
			Coherence	None or very minor concerns	
			Adequacy	Serious concerns. Studies together did not offer rich data	

CASP: Critical Appraisal Skills Programme; CERQual: Confidence in the Evidence from Reviews of Qualitative research; MD: Meningococcal disease

Table 10: Evidence summary profile for theme 6 (Communication)

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
Sub-theme 6.1: Standardised					
1 (Clark 2013)	Qualitative	Parents reported that standardised ways of communication may reduce a lot of	Methodological	Minor concerns	Low

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
n=18	study using semi-structured interviews (face-to-face or over the phone)	<p>the frustration and distress associated with information provision.</p> <p><i>"[Hospital] said, 'he might be ok you know he might have problems, but you won't know at the moment'...which I felt wasn't really helpful either because it was kind of like well you have to go home and you just wait and see how he turns out...I don't think I had the right support for that."</i> (Clark 2013, P3 page 5-6)</p>	<p>limitations</p> <p>Relevance</p> <p>Coherence</p> <p>Adequacy</p>	<p>about methodological limitations of the evidence as per CASP qualitative checklist</p> <p>Minor concerns. Less severe forms of disease under represented</p> <p>None or very minor concerns</p> <p>Serious concerns. Studies together did not offer rich data</p>	
Sub-theme 6.2: Clear					
2 (Sweeney 2013; Wisemantel 2018) n=250	Qualitative studies using structured and semi-structured interviews (over the phone and face-to-face)	<p>Parents reported that clear communication was a key factor for satisfaction with information provision.</p> <p><i>'it was faultless from start to finish - from the paramedic to the hospital. They kept us informed - the good and the bad'.</i> (Sweeney 2013, page e127)</p> <p><i>"The doctors didn't know much.... When I did ask the doctor on the ward at the time something about it [IMD], she said she couldn't answer me because she wasn't familiar with it and she'd never treated it...very annoyed with the fact that they didn't know what they were doing because then they're treating him for something that they know nothing about...frustrating when you're in the moment and you had a question and they were like..."we don't know".</i> (Wisemantel 2018, page 483)</p>	<p>Methodological limitations</p> <p>Relevance</p> <p>Coherence</p>	<p>Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist</p> <p>Minor concerns. Population restricted to MD. Less severe forms of disease under represented</p> <p>None or very minor concerns</p>	Moderate

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
			Adequacy	Minor concerns. Studies together offered some rich data	
Sub-theme 6.3: Lay language					
1 (Sweeney 2013) n=244	Qualitative study using structured interviews (over the phone)	Parents reported that the use of lay language during communication was important, so that they understood everything that was going on with their child. <i>'Doctors could have explained everything more clearly because they explained everything in medical terms'. (Sweeney 2013, page e127)</i>	Methodological limitations	Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	Minor concerns. Population restricted to MD. Less severe forms of disease under represented.	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns. Studies together offered some rich data	
Sub-theme 6.4: Involving parents					
3 (Clark 2013; Haines 2005; Sweeney 2013) n=270	Qualitative studies using structured and semi-structured interviews (over the phone and face-to-face)	Parents reported that they wanted to be involved and informed about their child's care and support. In cases where the parents felt listened to and involved, the care package appeared more tailored to the needs of the parent and child. Parents reported that when they were involved in an open, information-sharing process about their child they had a sense of control over what was happening. <i>"The fact that he'd had an assessment [at school] and I don't know what the outcome is... I don't know if that's in anyway had any bearing on what's</i>	Methodological limitations	Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist	High
			Relevance	Minor concerns.	

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
		<p><i>happening with him now.</i>" (Clark 2013, P7 page 6)</p> <p><i>"Yeah I think they've listened to whatever we thought about, you know we've always been of the mind that we wanted [him] to be as independent as he can be and so they've worked with that."</i> (Clark 2013, P13 page 6)</p> <p><i>'More communication - it was very frightening and we didn't know when he was out of danger. We were not sure it was meningitis because we weren't really told. My partner was asking questions but was ignored completely'. (Sweeney 2013, page e127)</i></p>		Less severe forms of disease under represented	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Sub-theme 6.5: Enhanced communication between healthcare professionals					
1 (Clark 2013) n=18	Qualitative study using semi-structured interviews (face-to-face or over the phone)	<p>Parents reported on the poor communication between different specialists, resulting in support that was unresponsive to the child's needs. Parents reported that when professionals did communicate, they felt that there were shared plans and goals which facilitated meeting their child's needs.</p> <p><i>"They've just given her some words to practise, she doesn't say the endings of any of the words ... probably because she can't hear them...speech and language can't sort her hearing out, they can just try and help her with pronouncing the words, but if she can't hear them then they're hitting their heads against a brick wall."</i> (Clark 2013; P15 page 6)</p> <p><i>"... and nothing was ever planned without [consultant]'s say so...to me that said we have got your son's best interests at heart we have a plan and we know what we're doing."</i> (Clark 2013, P13 page 6)</p>	Methodological limitations	Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	Minor concerns. Less severe forms of disease under represented	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns. Studies together offered some rich data	

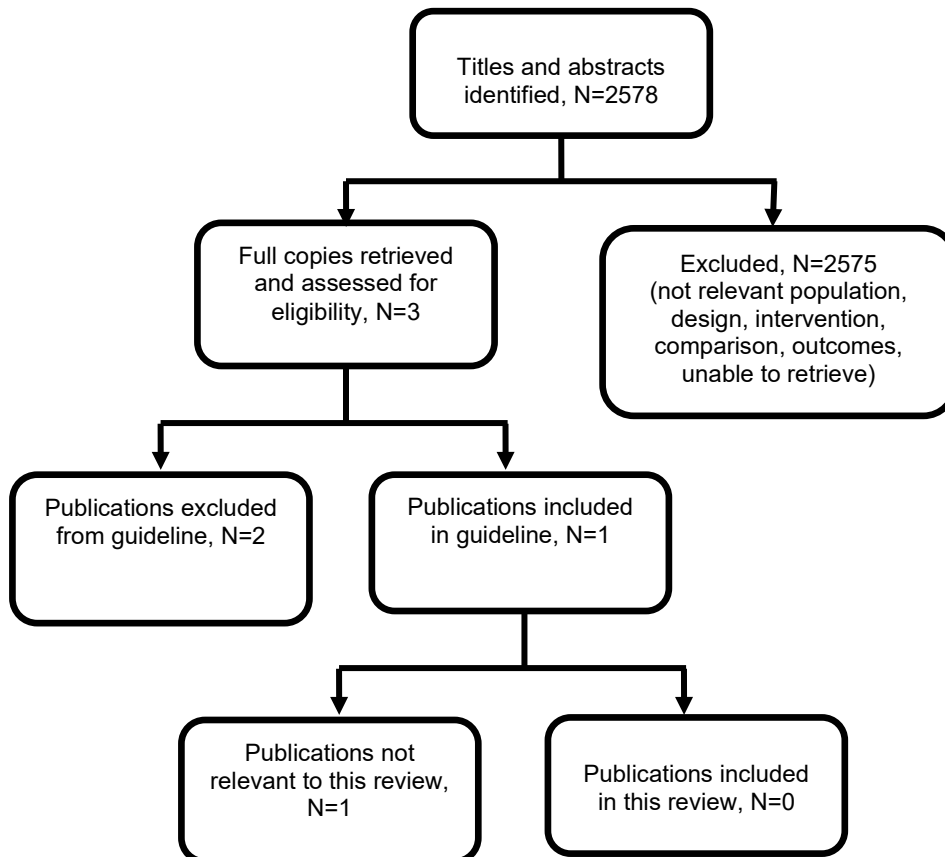
CASP: Critical Appraisal Skills Programme; CERQual: Confidence in the Evidence from Reviews of Qualitative research; MD: Meningococcal disease

Appendix G Economic evidence study selection

Study selection for: What information is valued by patients with confirmed bacterial meningitis or meningococcal disease, and their families or carers?

A global economic search was undertaken for the whole guideline, but no economic evidence was identified which was applicable to this review question (see Figure 2).

Figure 3: Study selection flow chart



Appendix H Economic evidence tables

Economic evidence tables for review question: What information is valued by patients with confirmed bacterial meningitis or meningococcal disease, and their families or carers?

No evidence was identified which was applicable to this review question.

Appendix I Economic model

Economic model for review question: What information is valued by patients with confirmed bacterial meningitis or meningococcal disease, and their families or carers?

No economic analysis was conducted for this review question.

Appendix J Excluded studies

Excluded studies for review question: What information is valued by patients with confirmed bacterial meningitis or meningococcal disease, and their families or carers?

Excluded qualitative studies

The excluded studies table only lists the studies that were considered and then excluded at the full-text stage for this review (N=11) and not studies (N=57) that were considered and then excluded from the search at the full-text stage as per the PRISMA diagram in Appendix C for the other review questions in the same search.

Table 11: Excluded studies and reasons for their exclusion

Study	Code [Reason]
(2018) Raising awareness of the signs and symptoms, and ensuring early diagnosis and treatment of meningococcal disease.	- Study design not of interest for review Overview of research and other activities by meningitis patient groups. No qualitative data presented
Carter, B, Roland, D, Bray, L et al. (2020) A systematic review of the organizational, environmental, professional and child and family factors influencing the timing of admission to hospital for children with serious infectious illness. 15(7): e0236013	- Study design not of interest for review A systematic review study; individual included studies have been assessed and none meet the inclusion criteria
Davie, S; Glennie, L; Rowland, K. (2012) Towards a meningitis free world-Can we eliminate meningococcal meningitis?. Contribution of the meningitis patient groups. Vaccine 30(suppl2): B98-B105	- Study design not of interest for review Overview of research and other activities by meningitis patient groups. No qualitative data presented
Duramaz, B. B, Kihitir, H. S, Petmezci, M. T et al. (2020) Analysis of meningitis cases in pediatric intensive care unit: 8-year single center experience. Medical Journal of Bakirkoy 16(1): 26-32	- Study design not of interest for review Quantitative study
Perez, S. L, Paterniti, D. A, Wilson, M et al. (2015) Characterizing the Processes for Navigating Internet Health Information Using Real-Time Observations: A Mixed-Methods Approach. Journal of Medical Internet Research 17(7): e173	- Population not of interest for review Participants did not have suspected BM or MD but responded to a fictional clinical scenario of BM
Shevlin, Mark, Coen, Pietro G; Borg, Jennie, Booy, Robert, Viner, Russell M; Christie, Deborah, Apajasalo, Arnau Aspesberro Baraff Beck Bellamy Borg Bowling Chin Christie de Winter Deyo Eiser Erickson Fellick Garratt Gill Guyatt Harrison Jenkinson Jenkinson Jones Joreskog Khan Krefetz Linstone Mobily Naess Nunnally Oranga Raphael Ridley Sander Starfield Steiger Viner Ware Ware (2016) Development of a health related quality of life measure for adolescents and young adults following invasive meningococcal disease. Applied Research in Quality of Life 11(3): 971-	- Insufficient presentation of results Describes using focus groups of IMD survivors to develop questionnaire, but no presentation of qualitative data

Study	Code [Reason]
982	
Strifler, L, Morris, S. K, Dang, V et al. (2014) The health burden of invasive meningococcal disease: A systematic review. <i>Paediatrics and Child Health (Canada)</i> 19(6): e92	- Study design not of interest for review Systematic review of quantitative studies
Taylor-Robinson, D, Elders, K, Milton, B et al. (2010) Students' attitudes to the communications employed during an outbreak of meningococcal disease in a UK school: A qualitative study. <i>Journal of Public Health</i> 32(1): 32-37	- Population not of interest for review None of the respondents had suspected or confirmed meningitis or IMD
van Elsland, S. L, Springer, P, Steenhuis, I. H et al. (2012) Tuberculous meningitis: barriers to adherence in home treatment of children and caretaker perceptions. <i>Journal of Tropical Pediatrics</i> 58(4): 275-9	- Not a high-income OECD country Study set in South Africa
Vermunt, L. C, Buysse, C. M, Joosten, K. F et al. (2011) Survivors of septic shock caused by <i>Neisseria meningitidis</i> in childhood: Psychosocial outcomes in young adulthood. <i>Pediatric Critical Care Medicine</i> 12(6): e302-e309	- Insufficient presentation of results No thematic analysis conducted. Responses to free-text questions and focus groups presented as quantitative outcomes
Williams, C. N, Eriksson, C, Piantino, J et al. (2018) Long-term Sequelae of Pediatric Neurocritical Care: The Parent Perspective. <i>Journal of Pediatric Intensive Care</i> 7(4): 173-181	- Population not of interest for review Parents of children admitted to neurocritical care. Only 22% admitted for meningitis or encephalitis (67% admitted for TBI, 22% admitted for stroke). Results not presented or analysed separately for target population

Excluded economic studies

No studies were identified which were applicable to this review question.

Appendix K Research recommendations – full details

Research recommendations for review question: What information is valued by patients with confirmed bacterial meningitis or meningococcal disease, and their families or carers?

No research recommendation was made for this review.