# National Institute for Health and Care Excellence

Final

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

[K2] Evidence review for support for suspected bacterial meningitis or meningococcal disease

NICE guideline NG240

Evidence review underpinning recommendations 1.3.1 and 1.3.2 in the NICE guideline

March 2024

Final

This evidence review was developed by NICE



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ISBN: 978-1-4731-5782-8

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# Support for suspected bacterial meningitis or meningococcal disease

### **Review question**

What support is valued by patients and their families or carers, when concerns arise about the possibility of bacterial meningitis or meningococcal disease?

#### 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 the possibility of these conditions is first raised, patients and their families or carers will naturally have many concerns and questions.

The aim of this review is to determine what support patients and their families or carers value when concerns first arise about the possibility of bacterial meningitis or meningococcal disease.

#### Summary of the protocol

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

Table 1: Summary of the protocol

rable i. Gaillinary of the	o protoco.
	<ul> <li>People with suspected bacterial meningitis or meningococcal disease.</li> </ul>
	<ul> <li>Parents or carers of babies, children, and young people with suspected bacterial meningitis or meningococcal disease.</li> <li>Families or carers of adults with suspected bacterial meningitis or</li> </ul>
Population	meningococcal disease.
Phenomenon of interest	Views and experiences of the support available when bacterial meningitis and/or meningococcal disease is suspected.
	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):
	Type of support
	Timing of support
	Availability of support
Context	Studies sought will be those published in the English language from OECD high-income European countries, Australia, Canada, New Zealand, from 2000 until the date the searches are run.
	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.

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 <a href="Developing NICE guidelines: the manual">Developing NICE guidelines: the manual</a>. 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

Four qualitative studies were included for this review (De 2014, Jones 2014, Sweeney 2013, Walsh 2007).

The included studies are summarised in Table 2.

Three studies reported the views and experiences of parents and carers of babies and children suspected of having bacterial meningitis (De 2014, Jones 2014, Walsh 2007) and 1 study reported views and experiences of parents and carers of babies, children and young people who had confirmed meningococcal disease (Sweeney 2013) but only views and experiences of information pre-diagnosis of the disease have been included in this review.

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

Two studies were from Australia (De 2014, Walsh 2007), and 2 studies were from the UK (Jones 2014, Sweeney 2013).

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

Table 2. Gaillia	y or included studie	3	
Study	Population	Methods	Themes applied after thematic synthesis
De 2014  General qualitative inquiry  Australia	N=36  Parents of febrile infants aged <3 months admitted to tertiary children's	Setting: Purposive sampling by reviewing daily hospital admissions in Tertiary children's hospital in Sydney	<ul><li>Type of support</li><li>Need for support during diagnosis</li></ul>
	hospital.  Age, years: n = 23-44	Data collection and analysis: Semi structured face-to-face interviews, thematically analysed following grounded theory principles.	
Jones 2014  General qualitative inquiry	N=27  Parents with at least one child under the	Setting: Maximum variation sampling from first contact care settings, community centres,	Type of support

		Themes applied after
Population	Methods	thematic synthesis
age of 5 years who are able to speak English	children's centres and nurseries in the Midlands, UK	
Age (years): <20: n = 1 20–29: n = 5 30–39: n = 16 40–49: n = 5	Data collection and analysis: Focus groups and/or interviews, analysed using the grounded theory method of constant comparison.	
N=244  Parents/carers of survivors of serogroup B meningococcal disease in childhood	Setting: Purposive sampling as part of a UK (MOSAIC)  Data collection and analysis: Structured telephone interviews,	<ul><li>Type of support</li><li>Need for support during diagnosis</li></ul>
Age: NR	content analysis.	
N=15  Parent and primary caregiver for a child	Setting: Purposive convenience sample from advertisement in online newspaper	Type of support
months and five years  Age, years, mean: n	Data collection and analysis: Interviews and focus groups, data was thematically analysed	
	age of 5 years who are able to speak English  Age (years): <20: n = 1 20–29: n = 5 30–39: n = 16 40–49: n = 5 N=244  Parents/carers of survivors of serogroup B meningococcal disease in childhood  Age: NR N=15  Parent and primary caregiver for a child aged between six months and five years	age of 5 years who are able to speak English  Age (years):  <20: n = 1  20–29: n = 5  30–39: n = 16  40–49: n = 5  N=244  Parents/carers of survivors of serogroup B meningococcal disease in childhood  Age: NR  N=15  Parent and primary caregiver for a child aged between six months and five years  Age, years, mean: n  Children's centres and nurseries in the Midlands, UK  Data collection and analysis: Focus groups and/or interviews, analysed using the grounded theory method of constant comparison.  Setting: Purposive sampling as part of a UK (MOSAIC)  Data collection and analysis: Structured telephone interviews, analysed using qualitative content analysis.  Setting: Purposive convenience sample from advertisement in online newspaper  Data collection and analysis: Interviews and focus groups, data was thematically analysed

MOSAIC: meningococcal outcomes in adolescents and in children; NR: not reported.

See the full evidence tables in appendix D.

The themes identified through analysis of all the included studies are listed here: type of support and need for support during diagnosis.

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 2 main themes in relation to the support valued by parents, their families and carers when bacterial meningitis or meningococcal disease is suspected. Two studies provided the evidence relating to need for support during diagnosis, which had 2 subthemes (empathy and parental involvement). Three studies provided the evidence relating to type of support, which had 3 subthemes (reassurance, engagement, and validation). 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 type of support all related to different types of support that parents and carers had reported using and what their views about these different types were. Figure 1 shows the themes and the subthemes.

Figure 1: Theme map



BM: Bacterial Meningitis; MD: Meningococcal disease

+ = moderate quality evidence

No evidence emerged relevant to the theme of timing or availability of support that were included in the protocol.

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 methodological limitations of the primary studies (for example, no justification for data collection methods as it relates to data saturation), concerns about relevance (for example, because studies focused on fever as the main context for the study), concerns about adequacy (for review findings when evidence offered only some 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 focussed on the views and experiences of the support available when bacterial meningitis or meningococcal disease is suspected. The committee identified a number of potential themes as illustrative of the main themes to guide the review. These themes were type of support, timing of support and availability of support. 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 quality was moderate for all the review findings. Assessment of the potential methodological

limitations of the primary studies was undertaken using the CASP checklist; overall concerns regarding methodological limitations ranged from "no or very minor" to "minor concerns". The most common issue was no justification for data collection methods as it relates to data saturation. Concerns about relevance were moderate for all the review findings. This was due to studies focusing on fever as the main context of the study with all participants admitted to hospital and having a complete sepsis work up or studies focusing on confirmed meningitis or meningococcal disease as the main context of the study but with data on support available pre-diagnosis. 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 "minor". There were minor concerns for review findings when the evidence offered moderately rich data. The number of studies contributing to each subtheme ranged from 1 to 3.

No evidence was identified for the following outcomes: timing of support and availability of support.

#### Benefits and harms

The committee considered the evidence but did not make any recommendations based solely on the subthemes identified from this review as they recognised that there is an overlap between offering information and offering support when bacterial meningitis or meningococcal disease is suspected. Therefore, the committee agreed that this evidence could be used as additional support for the recommendations made regarding information for patients who are in hospital with suspected bacterial meningitis or meningococcal disease (see evidence report K1). The committee were also aware of existing NICE guidance on patient experience in adult NHS services and babies, children and young people's experience of healthcare, and only made recommendations on information and support needs that were specific to bacterial meningitis and meningococcal disease.

The committee discussed that the moderate quality evidence from subtheme K2.1.2 (parental involvement), that parents valued clear communication to enable them to be involved in decision-making, provided support for the recommendation (based on evidence review K1) about providing information. The moderate quality evidence from subtheme K2.2.2 (engagement), that parents valued timely updates and opportunities to voice their concerns, also provided support for this recommendation, as the recommendation includes informing people when they can expect to know more. The committee considered the moderate quality evidence from subtheme K2.1.1 (empathy) showing parents' desires to receive empathy and sensitivity when relaying the news of the diagnosis, as well as the moderate quality evidence from subthemes K2.2.1 (reassurance) and K2.2.3 (validation) that parents valued reassurance and validation of their concerns from healthcare professionals. They discussed that these subthemes also supported the recommendation about providing information (based on evidence review K1), as the need to provide reasons for the suspected diagnosis and any uncertainty about this diagnosis is highlighted, and this both informs hospitalised patients and their families and carers but also includes them in the decisionmaking process.

#### 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. The committee felt their recommendations largely reflected current NHS practice and other NICE guidance. Therefore, they did not believe their recommendations would have a significant resource impact. They believed that the support recommended in the guideline would improve health related quality of life at an acceptable opportunity cost to the NHS.

#### Recommendations supported by this evidence review

This evidence review supports recommendations 1.3.1 and 1.3.2. Other evidence supporting these recommendations can be found in the evidence review on information for suspected bacterial meningitis or meningococcal disease (see evidence review K1).

#### References - included studies

#### Qualitative

#### De 2014

De, S, Tong, A, Isaacs, D et al. Parental perspectives on evaluation and management of fever in young infants: an interview study. Archives of Disease in Childhood, 99(8), 717-723, 2014

#### **Jones 2014**

Jones, C. H. D, Neill, S, Lakhanpaul, M et al. Information needs of parents for acute childhood illness: Determining 'what, how, where and when' of safety netting using a qualitative exploration with parents and clinicians. BMJ open, 4 (1), 2014

#### Sweeney 2013

Sweeney, F, Viner, R. M, Booy, R et al. Parents' experiences of support during and after their child's diagnosis of meningococcal disease. Acta Paediatrica, 102(3), e126-30, 2013

#### **Walsh 2007**

Walsh, A; Edwards, H; Fraser, J. Influences on parents' fever management: beliefs, experiences and information sources. Journal of Clinical Nursing, 16(12), 2331-2340, 2007

#### **Economic**

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

#### Other

#### **NICE 2012**

National Institute for Health and Care Excellence (2012). Patient experience in adult NHS services: improving the experience of care for people using adult NHS services. Available at: https://www.nice.org.uk/guidance/cg138 [Accessed 18/07/2022]

#### **NICE 2021**

National Institute for Health and Care Excellence (2021). Babies, children and young people's experience of healthcare. Available at: <a href="https://www.nice.org.uk/guidance/ng204">https://www.nice.org.uk/guidance/ng204</a> [Accessed 18/07/2022]

# **Appendices**

# **Appendix A Review protocols**

Review protocol for review question: What support is valued by patients and their families or carers, when concerns arise about the possibility of bacterial meningitis or meningococcal disease?

Table 3: Review protocol

Field	Content
PROSPERO registration number	CRD42020221142
Review title	Support for suspected bacterial meningitis or meningococcal disease
Review question	What support is valued by patients and their families or carers, when concerns arise about the possibility of bacterial meningitis or meningococcal disease?
Objective	To determine what support is valued by patients and their families or carers, when concerns arise about the possibility of bacterial meningitis or meningococcal disease
Searches	The following databases will be searched:
	Cochrane Central Register of Controlled Trials (CENTRAL)
	Cochrane Database of Systematic Reviews (CDSR)
	• Embase
	MEDLINE
	PsycInfo
	Emcare or Cinahl
	Searches will be restricted by:
	Date limitations: studies after 2000.
	English language
	Human studies
	The full search strategies for MEDLINE database will be published in the final review. For each search, the principal database search strategy is quality assured by a second information scientist

Field	Content
	using an adaptation of the PRESS 2015 Guideline Evidence-Based Checklist.
Condition or domain being studied	People with suspected bacterial meningitis or meningococcal disease
Population	Inclusion:
	People with suspected bacterial meningitis or meningococcal disease.
	<ul> <li>Parents or carers of babies, children, and young people with suspected bacterial meningitis or meningococcal disease.</li> </ul>
	• Families or carers of adults with suspected bacterial meningitis or meningococcal disease.
	Exclusion:
	People and families or carers of people:
	o with known immunodeficiency.
	<ul> <li>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.</li> </ul>
	o with confirmed viral meningitis or viral encephalitis.
	<ul><li>with confirmed tuberculous meningitis.</li><li>with confirmed fungal meningitis</li></ul>
	o confirmed 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 support available when bacterial meningitis and/or meningococcal disease is suspected.
Comparator/Reference standard/Confounding factors	Not applicable.
Types of study to be included	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.

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Field	Content
	<ul> <li>Exclusions:</li> <li>Quantitative studies (including surveys reporting only quantitative data)</li> <li>Surveys which quantify open-ended answers for analysis</li> <li>Conference abstracts.</li> </ul>
Other exclusion criteria	<ul> <li>Countries other than OECD high income countries, Australia, New Zealand and Canada.</li> <li>Studies conducted prior to 2000 as microbiology has not changed much since 2000 and most relevant interventions (e.g., steroids) were available by then.</li> <li>Studies published not in English-language</li> </ul>
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)	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):  • Type of support • Timing of support • Availability of support
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 deduplicated. 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.

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Field	Content		
Risk of bias (quality) assessment	Quality assessment of individual studies will be performed using the following checklists:  ROBIS tool for systematic reviews  CASP checklist for qualitative studies  The quality assessment will be performed by one reviewer and this will be quality assessed by a senior reviewer.		
Strategy for data synthesis	Secondary thematic analysis will be used to synthesise the evidence from individual studies. 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.  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.		
Analysis of sub-groups	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:  • Suspected diagnosis (Bacterial meningitis or meningococcal disease).  • Population.  • 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		Intervention Diagnostic Prognostic Qualitative	

Field	Content			
		Epidemiologic		
	□ Service Delivery			
	☐ Other (please specify)		ify)	
Language	English			
Country	England			
Anticipated or actual start date	24/11/2020			
Anticipated completion date	07/12/2023			
Stage of review at time of this submission	Review stage		Started	Completed
	Preliminary searches		<b>V</b>	<b>V</b>
	Piloting of the study selection process		•	<b>V</b>
	Formal screening of search results against eligibility criteria			
	Data extraction		<u>~</u>	V
	Risk of bias (quality) assessment		•	<u> </u>
	Data analysis		•	<b>▽</b>
Named contact	Named contact: National Guideline 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			

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Field	Content		
	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 <a href="Developing NICE guidelines: the manual">Developing NICE guidelines: the manual</a> . 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=CRD42020221142		
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		
	, , ,		
	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, m	neningococcal disease, support, qualitative	
Details of existing review of same topic by same authors	None		
Current review status		Ongoing	
		Completed but not published	
		Completed and published	
		Completed, published and being updated	
		Discontinued	
Details of existing review of same topic by same authors	social media channels, and publicising the guideline within NICE.  Bacterial meningitis, meningococcal disease, support, qualitative  None  Ongoing  Completed but not published  Completed and published  Completed, published and being updated		

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Field	Content	
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; GRADE: 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; ROBIS: risk of bias in Systematic Reviews

# Appendix B Literature search strategies

Literature search strategies for review question: What support is valued by patients and their families or carers, when concerns arise about the possibility of bacterial meningitis or meningococcal disease?

#### **Clinical Search**

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

r Sych	
#	Searches
1	Meningitis/ or Meningitis, Bacterial/ or Meningitis, Escherichia Coli/ or Meningitis, Haemophilus/ or Meningitis, Listeria/ or Meningitis, Meningococcal/ or Meningitis, Pneumococcal/ or Meningococcal/ or Meningitis/
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 meningococcal meningitis/
4	3 use emczd
5	exp Meningitis/ use psyh
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 streptococcc* 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 Literacy/ or exp Health Promotion/ or exp Hot Line Services/ 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 healthcareseek* or healthcareseek* 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 38	or/20,22,24-36 Qualitative Research/
39	interview/ use medall
40 41	exp interview/ use emczd
41	interviews/ use psyh 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	(dissatisf* 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
100	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

	oriast 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 "hinfluenz*" or "listeria* or meningococc* or pneumococc* or "gram-negativ* bacill*" or "gram negativ* bacill*" or streptococc* or "group B streptococcc*" 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 "n influenz*" or "s reptacocct" or pneumococct or "gram-negativ" bacill*" or "gram negativ" bacill*" or streptococct or "group B streptococct" or GBS or "streptococcus pneumon*" or "s pneumon*") NEAR/3 (septic* or sepsis* or bacteraemia* or bacteremia*))))):ti,ab,kw
#12	((((meningencephalitis* 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
	MeSH descriptor: [Decision Support Systems, Clinical] this term only  MeSH descriptor: [Internet] explode all trees
#40	
#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 #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-seek* or healthcareseek* or care-seek* or care-seek* or care-seek*)):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 caregive* 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	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 preumococcal meningitis/ or meningococcal meningitis/		
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  heard intervention/ or web browser/ or social media/ or blogging/ or social network/ or smartphone/ or mebile
	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 healthcare-seek* or healthcare-seek* or healthcare-seek* or healthcare-seek* or care-seek* or care-seek*).tw.
15	((discussion* or online* or on-line*) adj3 (forum* or fora)).tw.
16	messag* board*.tw.
17 18	(hotline* or helpline* or hot-line* or help-line*).tw. (social adj (network* or media)).tw.
19	((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.
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 23	((information* or support* or advice or guidance) adj3 (type* or content* or method* or quality or format*)).tw. information sheet.tw.
24	patient guidance.tw.
25	or/12-24
26	Qualitative Research/ or exp interview/
27	interview*.tw.
28	thematic analysis/
29 30	(theme* or thematic).mp. qualitative.af.
31	questionnaire\$.mp.
32	ethnological research.mp.
33	ethnograph*.mp.
34	ethnonursing.af.
35	phenomenol*.af.
36 37	(life stor* or women* stor*).mp. (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 43	((purpos\$ adj4 sampl\$) or (focus adj group\$)).af. 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 49	narrative analys?s.af. parental attitude/ or patient satisfaction/ or patient preference/ or personal experience/
50	(dissatisf* 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 55	*acute disease/ or *fever/ or *sepsis/ or *bacterial infection/ or exp *bacteremia/ ((acute* adj2 (ill or illness)) or fever or sepsis or bacter?emia or (bacteria* adj infection*)).m titl.
56	((acute adj2 (iii of limess)) of level of sepsis of bacter? emila of (bacteria adj miection )).m_titi.
57	25 and 51 and 56
58	(appropriat* adj informat*).tw.
59	(6 or 11 or 56) and 51 and 58
60 61	57 or 59 limit 60 to (English language and yr="1980 -Current")
62	letter.pt.
63	Letter/
64	letter\$/
65	editorial.pt.
66	historical article.pt.
67 68	anecdote.pt. 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

	n 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 streptococcc* 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

,	mi rocco a care individual calatione and bany
#	Searches
1	Meningitis/ or Meningitis, Bacterial/ or Meningitis, Escherichia Coli/ or Meningitis, Haemophilus/ or Meningitis, Listeria/ or Meningitis, Meningococcal/ or Meningitis, Pneumococcal/ or Meningococcahlitis/
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.

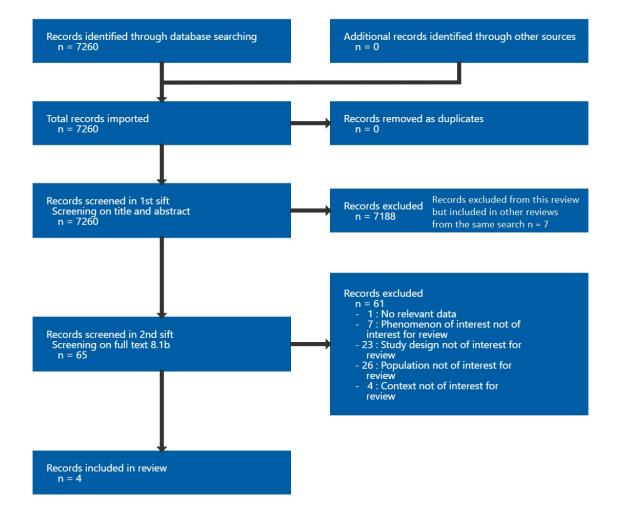
#	Searches
7	((e coli or escherichia coli or h?emophilus or hib or h?emophilus influenz* or h influenz* or listeria* or meningococc* or pneumococc* or gram-negativ* bacill* or gram negativ* bacill* or streptococc* or group B streptococc* or GBS or streptococcus pneumon* or s pneumon*) adj3 (septic* or 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 16	(meningococcus* or meningococci* or meningococc?emi?).ti,ab. (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 28	health economics/ use emczd 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 39	(financ* or fee or fees).ti,ab. (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 49	(hui or hui2 or hui3).tw. (multiattibute* 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 euroquol* or europan qol).tw.
53	(euro* adj3 (5 d* or 5d* or 5 dimension* or 5 dimension* or 5 domain* or 5 domain*)).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 50	Quality of Life/ and ec.fs.
58 59	Quality of Life/ and (health adj3 status).tw. (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 63	Cost-Benefit Analysis/ use ppez and cost-effectiveness ratio*.tw. and (cost-effectiveness ratio* and (perspective* or life expectanc*)).tw.  cost benefit analysis/ use emczd and cost-effectiveness ratio*.tw. and (cost-effectiveness ratio* and (perspective* or
64	cost benefit analysis/ use emczd and cost-effectiveness ratio*.tw. and (cost-effectiveness ratio* and (perspective* or life expectanc*)).tw.  *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.

70 ((capability\$ or capability-based\$) adj (measure\$ or index or instrument\$)).tw,kw. social care outcome\$.tw,kw.  71 social care and (utility or utilities)).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  86 letter/  81 editorial/  82 exp historical article/  83 news/  84 news/  85 exp historical article/  84 necdotes as Topic/  85 case report/  86 (etter or comment*).ti.  87 or 77 or 78 or 79 or 80 or 81 or 82 or 83  88 randomized controlled trial/ or random*.ti,ab.  88 ah not 85  89 animals/ not humans/  80 exp Animal Experimentation/  80 exp Animal Experimentation/  80 exp Rodential/  91 (rato rats or mouse or mice).ti.  93 86 or 87 or 88 or 89 or 90 or 91 or 92  94 letter, to reltter/  95 note.pt.  96 editorial,t.  97 case report/ or case study/  98 (letter or comment*).ti.  99 4 or 95 or 96 or 97 or 98  90 100  100 animal/ not human/  101 exp Animal Experimental  102 animal/ not human/  103 exp Animal Experiment/  104 exp Animal Experiment/  105 exp Experiment/  106 animal model/  107 exp Experimental Animal/  108 animal/ not human/  109 100 animal/ not human/  101 or 102 or 103 or 104 or 105 or 106 or 107 or 108  103 104 or 115  105 112  110 or 111  111 115 to English language  111 116 limit 115 to English language	#	Searches
71         social care and (utility or utilities)).tw.kw.           73         or/41-72           74         (9 or 17) and 40           75         (9 or 17) and 40           76         letter/           77         editorial/           78         news/           9         exp historical article/           80         Anecdotes as Topic/           81         comment/           82         case report/           83         (letter or comment*)-til.           84         76 or 77 or 78 or 79 or 80 or 81 or 82 or 83           85         randomized controlled trial/ or random*.ti,ab.           84         40 85           87         animals/ not humans/           8         exp Animal Experimentation/           90         exp Animal Experimentation/           91         exp Rodential           92         (rat or rats or mouse or mice).tii.           93         86 or 87 or 88 or 89 or 90 or 91 or 92           94         letter.pt. or letter/           95         note,t           96         editorial.pt.           97         case report/ or case study/           (letter or comment**).ti.           90         o		
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73 or/41-72  74 (9 or 17) and 40  75 (9 or 17) and 73  76 letter/  77 editorial/  78 news/  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.  88 4 not 85  89 animals/ not humans/  80 exp Animals, Laboratory/  90 exp Animals, Laboratory/  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, b. or letter/  95 note, pt.  96 editorial,b.  97 case report/ or case study/  (letter or comment*),ti.  98 py 40 or 95 or 96 or 97 or 98  100 randomized controlled trial/ or random*.ti,ab.  91 exp Rodentia/  92 exp Animals (premientation)/  93 exp Animals (premientation)/  94 exp Rodentia/  95 editorial,b.  97 case report/ or case study/  (letter or comment*),ti.  98 or 95 or 96 or 97 or 98  100 randomized controlled trial/ or random*.ti,ab.  99 40 or 95 or 96 or 97 or 98  100 animal/ not human/  101 or 102 or 103 or 104 or 105 or 106 or 107 or 108  102 animal/ not human/  103 animal/ model/  104 exp Rodenti/  105 exp Experimental Animal/  106 animal model/  107 exp Rodenti/  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  101 192 use emczd  112 110 or 111  113 74 hot 112  114 limit 113 to English language		
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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		animal/ not human/
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# Appendix C Qualitative evidence study selection

Study selection for: What support is valued by patients and their families or carers, when concerns arise about the possibility of bacterial meningitis or meningococcal disease?

Figure 2: Study selection flow chart



# **Appendix D Evidence tables**

Evidence tables for review question: What support is valued by patients and their families or carers, when concerns arise about the possibility of bacterial meningitis or meningococcal disease?

Table 4: Evidence tables - qualitative evidence

De, 2014

Bibliographic Reference

De, S; Tong, A; Isaacs, D; Craig, J. C.; Parental perspectives on evaluation and management of fever in young infants: an interview study; Archives of Disease in Childhood; 2014; vol. 99 (no. 8); 717-723

#### Study details

Country/ies where study was carried out	Australia
Setting	Tertiary children's hospital in Sydney, Australia
Data collection and analysis	Semi structured face-to-face interviews were conducted just prior to discharge from hospital. Data collection and analysis were conducted concurrently following grounded theory principles; data were coded and thematically analysed.
Recruitment strategy	Purposive sampling was used to include a range of demographics characteristics such as age, gender and birth order. Eligible participants were identified by reviewing daily hospital admissions and were approached towards the end of their hospital stay to determine their willingness to participate. Either one or both parents were interviewed depending on their preference.
Study dates	1 November 2011 to 31 December 2012
Sources of funding	Not reported
Inclusion criteria	<ul> <li>Parents of febrile infants aged &lt;3 months admitted to a tertiary children's hospital in Sydney</li> <li>Parents of previously healthy febrile infants with an unremarkable clinical course and uneventful recovery</li> </ul>

Exclusion criteria	<ul> <li>Parents of infants with complex medical background, prematurity, prolonged hospitalisation and complex interventions because their perspectives were likely be influenced by these additional factors.</li> <li>Non-English speaking parents were excluded due to lack of resources for interpretation</li> </ul>
Sample size	36 parents of 27 infants
Participant characteristics	Age, years n = 23-44  First time parents = 41%  Female, n = 22  Male, n= 14  Infant's age, n  ≤ 4 weeks = 9  >4 - 8 weeks = 14  >8 - 12 weeks = 4
Results	Themes (information in bullet points are theme(s) applied after thematic synthesis)  Original theme: Parental attitudes and experiences during the course of hospitalisation: Expectation of reassurance and support - unmet expectation of support  • Need for support  • Empathy  • "May be they should tell us these things in a quieter place or with the curtains drawn. As they were explaining the procedures for our baby the little girl in the bed next to us started fitting so we were listening to what was going to happen to our baby and also going 'oh my God that little girl is fitting'." Mother 31, page 721

"When walking over here to do something to acknowledge us perhaps in the first instance, maybe actually talk to us, saying 'how are you?', maybe explain to parents what you are actually doing. When you walk past the nurse's station they don't engage in eye contact because I might speak to them and I might have a problem that is just extra work for them. That's how you feel. You feel like you are a hindrance." Father, 30, page721

Original theme: Parental attitudes and experiences during the course of hospitalisation: Facilitators of parental empowerment - medical attentiveness

- Type of support
  - Reassurance
    - "The nurse reassured me it should be fine, she was taking his temperature often every half an hour and it was coming down so that made me feel reassured that he was getting better." Mother, 28, page 718/721

Original theme: Parental attitudes and experiences during the course of hospitalisation: Facilitators of parental empowerment - a sense of validation

- Type of support
  - o Reassurance
    - "We were in Emergency and wondering whether we were being overprotective parents and one of the doctors said, 'you did the right thing'. We were relieved." Father, 34, page 719/721
    - "I remember the nurse asking me do you want to leave, I think that helped because the difficult time that me and my husband were going through was noticed and that helped. But I said, "I don't want to leave my baby alone I am staying here although it's hard". Mother, 37, page 719/721
  - Validation
    - "We were in Emergency and wondering whether we were being overprotective parents and one of the doctors said, 'you did the right thing'. We were relieved." Father, 34, page 719/721
    - "I remember the nurse asking me do you want to leave, I think that helped because the difficult time that me and my husband were going through was noticed and that helped. But I said, "I don't want to

leave my baby alone I am staying here although it's hard". Mother, 37, page 719/721

Original theme: Parental attitudes and experiences during the course of hospitalisation: Facilitators of parental empowerment - medical partnership

- Type of support
  - Parental involvement
    - "I went in with him [infant] and it was actually quite nice to be there with him. It was reassuring to see what had happened and I was able to hold his hand and comfort him." Mother, 33, page 719/721

Original theme: Barriers to parental empowerment: limited capacity for advocacy

- Type of support
  - o Parental involvement
    - "The next day I was told you have the right to say no, I didn't know that. You feel a little bit like you are at the mercy of say the nurses or the doctor no one said if you are really uncomfortable with this we can stop." Mother, 27, page 720/721
    - "As a parent you want the best for your child but when you are in an environment where you are worried it gets hard sometimes to speak up and say this needs to happen." Father 34, page 720/722
    - "I would have stayed in the room. Maybe if I was there I could have stopped it [multiple unsuccessful attempts at cannulation]. No matter how difficult it may be for me to watch I have to be present." Mother, 27, page 720/722

Original theme: Parental attitudes and experiences during the course of hospitalisation: Barriers to parental empowerment - relinquished control

- Need of support during diagnosis
  - Involving parents
    - "It was about 40 minutes before we got spoken to or even told well this is what is going to happen.

That was the only thing I was a little bit upset about. I never mind waiting. I just wanted to know whether I could wrap him up and put him to sleep or whether he had to be left unwrapped to be assessed and probably for me it was racing through my head and the big thing was fever we have been admitted what is going on what is it they were thinking." Mother, 33, page 719/721

• "We were already stressed and worried and imagining the worst. It was four hours until the results were ready, four hours of us holding hands and crying imagining how our lives would be with a disabled baby that has been well and thinking why it happened...it was a nightmare." Mother, 37, page 719/721

#### **Critical appraisal - CASP**

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	No or very minor concerns

CASP: Critical Appraisal Skills Programme

#### Jones, 2014

# Bibliographic Reference

Jones, C. H. D; Neill, S; Lakhanpaul, M; Roland, D; Singlehurst-Mooney, H; Thompson, M.; Information needs of parents for acute childhood illness: Determining 'what, how, where and when' of safety netting using a qualitative exploration with parents and clinicians; BMJ open; 2014; vol. 4 (no. 1)

#### Study details

Country/ies where study was carried out	United Kingdom
Setting	First contact care settings, community centres, children's centres and nurseries in the Midlands, UK.
Data collection and analysis	<ul> <li>Data collection was by focus groups and/or interviews in each parent community and at each first contact care workplace</li> </ul>

	Data were analysed using the grounded theory method of constant comparison.
Recruitment strategy	Maximum variation sampling was used to recruit parents from a wide range of communities, and doctors and nurses working in different first contact care settings in the Midlands, UK. Recruitment was coordinated by email or in person using the local Primary Care Research Network, the Comprehensive Local Research Network for clinicians, community facilitators, health ambassadors and day nursery/children's centre managers for parents.
Study dates	May to December 2012
Sources of funding	Funded by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research funding scheme and arising from a Career Development Fellowship supported by the NIHR (MT)
Inclusion criteria	<ul> <li>Parents with at least one child under the age of 5 years, or</li> <li>Clinicians treating children under 5 years of age at first contact, and</li> <li>Be able to speak English</li> </ul>
Exclusion criteria	Not reported
Sample size	N = 27 parents
Participant characteristics	Community  Travelling families n = 6  Asian British n = 11  White British n = 10  Gender  Female n = 24  Male n = 3

#### Age (years)

Under 20 = 1

20-29 = 5

30 - 39 = 16

40-49 = 5

#### Number of children

1 child = 6

2 children = 8

3 children = 5

4 or more children = 6

Missing information = 2

#### Results

#### Themes (information in bullet points are theme(s) applied after thematic synthesis)

Original theme: Format and delivery of safety netting

- Type of support
  - Reassurance
    - "only physical contact with somebody who you trust and feel can answer your question will ever give you the reassurance with regards to a child that you're looking for... ultimately you really just want to speak to someone and show them your child, you want to speak to someone who you feel is experienced and knowledgeable about what you are talking about and can help you with your child". White British mother, page 7

#### NIHR: National Institute for Health Research

### **Critical appraisal - CASP**

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

CASP: Critical Appraisal Skills Programme

### 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 details

Study type	General qualitative inquiry
Country/ies where study was carried out	United Kingdom
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 reported
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	N = 244 parents
Participant characteristics	Not reported
Results	Themes (information in bullet points are theme(s) applied after thematic synthesis)
	Original theme: Communication during diagnosis and treatment
	<ul> <li>Need of support during diagnosis         <ul> <li>Involving parents</li> <li>"it was faultless from start to finish - from the paramedic to the hospital. They kept us informed - the good and the bad". Page e127</li> </ul> </li> </ul>

MOSAIC: Meningococcal outcome study in adolescents and in children.

### Critical appraisal - CASP

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

CASP: Critical Appraisal Skills Programme

### Walsh, 2007

Bibliographic	Walsh, A; Edwards, H; Fraser, J.; Influences on parents' fever management: beliefs, experiences and information sources;
Reference	Journal of Clinical Nursing; 2007; vol. 16 (no. 12); 2331-2340

Study details	
Study type	General qualitative inquiry
Country/ies where study was carried out	Australia
Setting	Naturalistic settings (home, office and childcare centre)
Data collection and analysis	Six interviews and three group discussions were conducted. Data was thematically analysed
Recruitment strategy	An advertisement in Playgroup Queensland's monthly online newsletter and letters distributed to parents of children enrolled at two Childcare centres. A purposive convenience sample of 15 metropolitan parents volunteered to participate
Study dates	Not reported
Sources of funding	Margaret Sullivan Scholarship from the Australian Confederation of Paediatric and Child Health Nursing Queensland Inc.
Inclusion criteria	<ul> <li>aged 18 years or older</li> <li>able to read and converse in English and</li> <li>being a parent and primary caregiver for a child aged between six months and five years</li> </ul>
Exclusion criteria	Not reported
Sample size	N = 15 parents
Participant characteristics	Female = 100%  Married = 86–87%  Age range (mean, SD) = 29–42 years (34.1, 3.63).

	Primary caregiver of two or more children = 66.7%.
	University degree = 53.3%
	Training And Further Education (TAFE) certificate = 40%
	Employed = 93.3%
	Part-time = 86.7%
Results	Themes (information in bullet points are theme(s) applied after thematic synthesis)
	Original theme: Influencing factors: positive factors reduce concerns
	<ul> <li>Type of support         <ul> <li>Reassurance</li> <li>"But because they were so young I went to the GP more for reassurance more than anything, more to see what I was planning on doing, for reassurance. So I received that reassurance." P6, page 2335</li> </ul> </li> </ul>

SD: standard definition; TAFE: Training And Further Education

## Critical appraisal - CASP

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Minor concerns (No information on participant and researcher relationship)

CASP: Critical Appraisal Skills Programme

# **Appendix E Forest plots**

Forest plots for review question: What support is valued by patients and their families or carers, when concerns arise about the possibility of bacterial meningitis or meningococcal disease?

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 support is valued by patients and their families or carers, when concerns arise about the possibility of bacterial meningitis or meningococcal disease?

Table 5: Evidence summary profile for (GRADE-CERQual) theme 1. Need for support during diagnosis

Study information			CERQual assessment of the evidence		
Number of studies	Design	Description of theme or finding	Criteria	Level of concern	Overall quality
Sub-theme K2.1	I.1: Empathy				
1 (De 2014) Qualitative study using semi-structured	Parents reported that they would have liked some empathy and sensitivity when relaying the news of the diagnosis for example being in a quiet and private space or just being acknowledged and engaged with.	Methodological limitations	No concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate	
	interviews (face-to-face)	ws	Relevance	Moderate concerns. Most evidence is from a substantially different context to the review question (study focused on fever with all participants admitted to hospital and had a complete sepsis work up)	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns. Studies together offered moderately rich data	
Sub-theme K2.1	I.2: Parental inv	volvement			
2 (De 2014, Sweeney 2013)	Qualitative studies using semi- structured	Parents reported feeling stressed and frustrated when excluded from the medical process and expressed desires to be included in the decision-making. Clear communication of the entire process was an important factor to achieve patient satisfaction	Methodological limitations	Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
n=280	interviews	with the support received.	Relevance	Moderate concerns. Most evidence is from a	

Study information			CERQual assessment of the evidence		CERQual assessment of the evidence		
Number of studies	Design	Description of theme or finding	Criteria	Level of concern	Overall quality		
(face-to-face) and "We v structured It was interviews holdin (over the a disa	and structured interviews (over the	· · · · · · · · · · · · · · · · · · ·		substantially different context to the review question (1 study (n=244) focused on confirmed meningitis and 1 study (n=36) focused on fever, with all participants admitted to hospital and had a complete sepsis work up)			
		Coherence	None or very minor concerns				
			Adequacy	Minor concerns. Studies together offered moderately rich data			

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

Table 6: Evidence summary profile for (GRADE-CERQual) theme 2. Type of support

Study informat	dy information CERQual assessment of the evidence				
Number of studies	Design	Description of theme or finding	Criteria	Level of concern	Overall quality
Sub-theme K2.	2.1: Reassurand	ce			
3 (De 2014, Jones 2014, Walsh 2007)	Qualitative studies using semi- structured	Parents reported the importance of face-to-face reassurance by	Methodological limitations	Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
n=78	interviews, interviews (unspecified) and focus groups (face- to-face)	making the right decision in seeking medical assistance.  "only physical contact with somebody who you trust and feel can answer your question will ever give you the reassurance with regards to a child that you're looking for ultimately you really just want to speak to someone and show them your child, you	Relevance	Moderate concerns. Most evidence is from a substantially different context to the review question (1 study (n=36) focused on fever with all participants admitted to hospital and had a complete	

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Study information			CERQual assessment of the evidence		
Number of studies	Design	Description of theme or finding	Criteria	Level of concern	Overall quality
		want to speak to someone who you feel is experienced and knowledgeable about what you are talking about and can help		sepsis work up and 2 studies focused on fever)	
		you with your child" (Jones 2014, page 7)	Coherence	None or very minor concerns	
		"But because they were so young I went to the GP more for reassurance more than anything, more to see what I was planning on doing, for reassurance. So I received that reassurance." (Walsh 2007, pg 2335)	Adequacy	None or very minor concerns	
Sub-theme K2.	2.2: Engagemer	nt			
n=36 study semi- struct interv	Qualitative study using semi- structured	the care of their child, having a clear explanation of the management plan, timely updates and opportunities to voice their concerns and fears.  tructured concerns and fears.	Methodological limitations	No concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
	interviews (face-to-face)		Relevance	Moderate concerns. Most evidence is from a substantially different context to the review question (study focused on fever with all participants admitted to hospital and had a complete sepsis work up)	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns. Studies together offered moderately rich data	
Sub-theme K2.	2.3: Validation				
n= 36	Qualitative studies using semi- structured	Parents reported feeling worried seeking doctor's advice for fear of bothering the doctor, or being labelled over-protective or paranoid. However, they desired support with assessing their child's ill health with a professional and felt relieved when their	Methodological limitations	No concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
	interviews concerns were acknowledged as appropriate. (face-to-face)	concerns were acknowledged as appropriate.  "We were in Emergency and wondering whether we were being	Relevance	Moderate concerns. Most evidence is from a substantially different context to the review	

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Study information			CERQual assessment of the evidence		
Number of studies	Design	Description of theme or finding	Criteria	Level of concern	Overall quality
		overprotective parents and one of the doctors said, 'you did the right thing'. We were relieved." (De 2014, page 719/721)		question (study focused on fever with all participants admitted to hospital and had a complete sepsis work up)	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	

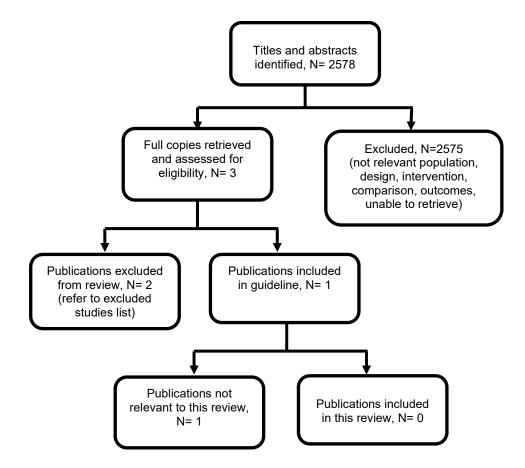
CASP: Critical Appraisal Skills Programme; CERQual: Confidence in the Evidence from Reviews of Qualitative research

## Appendix G Economic evidence study selection

Study selection for: What support is valued by patients and their families or carers, when concerns arise about the possibility of bacterial meningitis or meningococcal disease?

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 3).

Figure 3: Study selection flow chart



# **Appendix H Economic evidence tables**

Economic evidence tables for review question: What support is valued by patients and their families or carers, when concerns arise about the possibility of bacterial meningitis or meningococcal disease?

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

# Appendix I Economic model

Economic model for review question: What support is valued by patients and their families or carers, when concerns arise about the possibility of bacterial meningitis or meningococcal disease?

No economic analysis was conducted for this review question.

## Appendix J Excluded studies

Excluded studies for review question: What support is valued by patients and their families or carers, when concerns arise about the possibility of bacterial meningitis or meningococcal disease?

#### **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=61) and not studies (N=7) 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 7: Excluded studies and reasons for their exclusion

Table 7. Excluded studies and reasons for	
Study	Code [Reason]
Ahronheim, S. R, McGillivray, D, Barbic, S et al. (2015) Expectant parents 'understanding of the implications and management of fever in the neonate. PLoS ONE 10 (4)	- Study design not of interest for review Quantitative study
Al-Eissa, Y.A, al-Zamil, F.A, al-Sanie, A.M et al. (2000) Home management of fever in children: Rational or ritual?. International Journal of Clinical Practice 54(3): 138-142	- Population not of interest for review No indication of suspected meningitis or meningococcal disease
Al-Nouri, L and Basheer, K. (2006) Mothers' perceptions of fever in children. Journal of Tropical Pediatrics 52(2): 113-116	- Study design not of interest for review Quantitative study
Ames, N. J, Peng, C, Powers, J. H et al. (2013) Beyond intuition: Patient fever symptom experience. Journal of pain and symptom management 46(6): 807-816	- Population not of interest for review No indication of suspected meningitis or meningococcal disease
Apitzsch, S, Larsson, L, Larsson, A. K et al. (2021) The physical and mental impact of surviving sepsis - a qualitative study of experiences and perceptions among a Swedish sample. Archives of Public Health 79(1): 66	- Population not of interest for review No indication of suspected meningitis or meningococcal disease
Arica, S. G, Arica, V, Onur, H et al. (2012) Knowledge, attitude and response of mothers about fever in their children. Emergency medicine journal 29(12): e4	- Study design not of interest for review Quantitative study
Aurel, M, Dubos, F, Motte, B et al. (2011) Recognising haemorrhagic rash in children with fever: a survey of parents' knowledge. Archives of Disease in Childhood 96(7): 697-698	- Study design not of interest for review Quantitative study
Blake Jr, R. L; Spencer, D; Daugird, A. (1981) After-hours management of febrile children. The Journal of family practice 13(5): 613-617	- Study design not of interest for review Quantitative study
Brunt, Kimberly Coder (1997) Parental beliefs and action regarding fever in children. Dissertation Abstracts International: Section B: The Sciences and Engineering 57(9b): 5908	- Population not of interest for review No indication of suspected meningitis or meningococcal disease
Carter, B, Roland, D, Bray, L et al. (2020) A systematic review of the organizational, environmental, professional and child and family	- Study design not of interest for review A systematic review study; individual included studies have been assessed and none meet the

Study	Code [Reason]
factors influencing the timing of admission to hospital for children with serious infectious illness. 15(7): e0236013	inclusion criteria
Cuzzolin, L, Zaffani, S, Gangemi, M et al. (2004) Parental attitudes about the most common symptoms/pathologies in pre-school children. Italian Journal of Pediatrics 30(4): 248-253	<ul> <li>Population not of interest for review</li> <li>No indication of suspected meningitis or meningococcal disease</li> </ul>
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
De Bont, E. G. P. M, Francis, N. A, Dinant, G. J et al. (2014) Parents' knowledge, attitudes, and practice in childhood fever: An internet-based survey. British Journal of General Practice 64(618): e10-e16	- Population not of interest for review No indication of suspected meningitis or meningococcal disease
de Bont, E. G, Loonen, N, Hendrix, D. A et al. (2015) Childhood fever: a qualitative study on parents' expectations and experiences during general practice out-of-hours care consultations. BMC family practice 16: 131	- Population not of interest for review No indication of suspected meningitis or meningococcal disease
Diorio, C, Martino, J, Boydell, K. M et al. (2011) Parental perspectives on inpatient versus outpatient management of pediatric febrile neutropenia. Journal of pediatric oncology nursing 28(6): 355-362	- Population not of interest for review No indication of suspected meningitis or meningococcal disease
Fee, N, Hartigan, L, McAuliffe, F. M et al. (2017) Education in Sepsis: A Review for the Clinician of What Works, for Whom, and in What Circumstances. Journal of Obstetrics and Gynaecology Canada 39(9): 772-780	- Phenomenon of interest not of interest for review Focused on medical education for recognition and management of sepsis in pregnant patients
Fletcher, J.L; Jr; Creten, D. (1986) Perceptions of fever among adults in a family practice setting. Journal of Family Practice 22(5): 427-430	- Population not of interest for review No indication of suspected meningitis or meningococcal disease
Forsner, M; Jansson, L; Sorlie, V. (2005) The experience of being ill as narrated by hospitalized children aged 7-10 years with short-term illness. Journal of child health care: for professionals working with children in the hospital and community 9(2): 153-165	- Population not of interest for review No indication of suspected meningitis or meningococcal disease
Gallop, K. H, Kerr, C. E. P, Nixon, A et al. (2015) A qualitative investigation of patients' and caregivers' experiences of severe sepsis. Critical care medicine 43(2): 296-307	<ul> <li>Population not of interest for review</li> <li>No indication of suspected meningitis or meningococcal disease</li> </ul>
Gehrke-Beck, S, Banfer, M, Schilling, N et al. (2017) The specific needs of patients following sepsis: A nested qualitative interview study. BJGP open 1(1)	- Population not of interest for review No indication of suspected meningitis or meningococcal disease
Haines, C. (2005) Parents' experiences of living through their child's suffering from and surviving severe meningococcal disease. Nursing in critical care 10(2): 78-89	<ul> <li>Phenomenon of interest not of interest for review</li> <li>No data on support when meningitis is suspected</li> </ul>
Hancock, Rebecca D. (2018) Qualitative analysis of older adults' experiences with sepsis.	- Phenomenon of interest not of interest for review

Study	Code [Reason]
Dissertation Abstracts International: Section B:	Study focused on experiences when seeking
The Sciences and Engineering 79(12be): No- Specified	care for sepsis
Hiller, M. G; Caffery, M. S; Begue, R. E. (2019) A Survey About Fever Knowledge, Attitudes, and Practices Among Parents. Clinical pediatrics 58(6): 677-680	- Study design not of interest for review Quantitative study
Jeddian, A. R, Lindenmeyer, A, Marshall, T et al. (2016) Caring for Acutely III Patients in General Wards: A Qualitative Study. Archives of Iranian Medicine 19(9): 639-44	- Population not of interest for review Study focused on health professionals in Iran
Jensen, J.F, Tonnesen, L.L, Soderstrom, M et al. (2010) Paracetamol for feverish children: parental motives and experiences. Scandinavian Journal of Primary Health Care 28(2): 115-120	- Population not of interest for review No indication of suspected meningitis or meningococcal disease
Kai, J. (1996) Parents' difficulties and information needs in coping with acute illness in preschool children: A qualitative study. British medical journal 313(7063): 987-990	- Context not of interest for review Study date precedes 2000
Kai, J. (1996) What worries parents when their preschool children are acutely ill, and why: a qualitative study. BMJ 313(7063): 983-986	- Context not of interest for review Study date precedes 2000
Karwowska, Anna, Nijssen-Jordan, Cheri, Johnson, David, Davies, H. Dele (2002) Parental and health care provider understanding of childhood fever: a Canadian perspective. CJEM 4(6): 394-400	- Study design not of interest for review Quantitative study
Kelly, M, Sahm, L. J, Shiely, F et al. (2015) The knowledge, attitudes and beliefs of carers (parents, guardians, healthcare practitioners, creche workers) around fever and febrile illness in children aged 5 years and under: Protocol for a qualitative systematic review. Systematic Reviews 4 (1)	- Study design not of interest for review Study protocol
Kelly, M, Sahm, L. J, Shiely, F et al. (2016) Parental knowledge, attitudes and beliefs regarding fever in children: an interview study. BMC public health 16: 540	- Phenomenon of interest not of interest for review No data on support when BM or MD is suspected
Koksal, A. O, Ozdemir, O, Yilmaz, A. A et al. (2014) Mother approaches to children with fever. Gazi Medical Journal 25(2): 63-69	- Study design not of interest for review Quantitative study
Kramer, M.S; Naimark, L; Leduc, D.G. (1985) Parental fever phobia and its correlates. Pediatrics 75(6): 1110-1113	- Study design not of interest for review Quantitative study
Kuijpers, D. L, Peeters, D, Boom, N. C et al. (2021) Parental assessment of disease severity in febrile children under 5 years of age: A qualitative study. BMJ Open 11(3)	- Population not of interest for review  No indication of suspected meningitis or meningococcal disease - parents of children with a life threatening condition needing immediate medical attention were excluded
Lagerlov, Per, Helseth, Solvi, Holager, Tanja (2003) Childhood illnesses and the use of paracetamol (acetaminophen): a qualitative study of parents' management of common childhood illnesses. Family practice 20(6): 717-23	- Population not of interest for review No indication of suspected meningitis or meningococcal disease

Study	Code [Reason]
Langer, T, Pfeifer, M, Soenmez, A et al. (2013)	- Population not of interest for review
Activation of the maternal caregiving system by childhood fevera qualitative study of the experiences made by mothers with a German or a Turkish background in the care of their children. BMC family practice 14: 35	No indication of suspected meningitis or meningococcal disease
Light, Patricia A; Hupcey, Judith E; Clark, Mary Beth (2005) Nursing telephone triage and its influence on parents' choice of care for febrile children. Journal of Pediatric Nursing 20(6): 424-9	- Study design not of interest for review Quantitative study
Marchetti, M; Minghetti, P; Donzelli, P. (1991) Treatment of children's fevers in Italy after the withdrawal of aspirin pediatric formulations from OTC products. Journal of Social and Administrative Pharmacy 8(3): 121-129	- Population not of interest for review No indication of suspected meningitis or meningococcal disease
McIlvoy, L. (2012) Fever management in patients with brain injury. AACN advanced critical care 23(2): 204-211	- Study design not of interest for review Narrative review
Neill, S. J, Jones, C. H, Lakhanpaul, M et al. (2015) Parent's information seeking in acute childhood illness: what helps and what hinders decision making?. Health expectations: an international journal of public participation in health care and health policy 18(6): 3044-3056	<ul> <li>No relevant data</li> <li>Study reports the same population as Jones</li> <li>2014 which has been included in the review, and no additional themes were identified from this study</li> </ul>
Neill, S. J, Jones, C. H, Lakhanpaul, M et al. (2016) Parents' help-seeking behaviours during acute childhood illness at home: A contribution to explanatory theory. Journal of child health care: for professionals working with children in the hospital and community 20(1): 77-86	- Phenomenon of interest not of interest for review No data on support when BM or MD is suspected
Rawson, Timothy M; Moore, Luke S. P; Hernandez, Bernard, Castro-Sanchez, Enrique, Charani, Esmita, Georgiou, Pantelis, Ahmad, Raheelah, Holmes, Alison H. (2016) Patient engagement with infection management in secondary care: a qualitative investigation of current experiences. BMJ open 6(10): e011040	- Population not of interest for review No indication of suspected meningitis or meningococcal disease
Sahm, L. J, Kelly, M, McCarthy, S et al. (2016) Knowledge, attitudes and beliefs of parents regarding fever in children: A Danish interview study. Acta Paediatrica, International Journal of Paediatrics 105(1): 69-73	- Phenomenon of interest not of interest for review No data on support when BM or MD is suspected
Sakai, R; Niijima, S; Marui, E. (2009) Parental knowledge and perceptions of fever in children and fever management practices: differences between parents of children with and without a history of febrile seizures. Pediatric Emergency Care 25(4): 231-237	- Context not of interest for review Study set in Tokyo
Sivakumar, A; Venkatramanan, P; Premkumar, S. (2020) Role of the internet in the health-seeking behaviour of parents of children underfive during fever. Indian Journal of Public Health Research and Development 11(3): 482-484	- Study design not of interest for review Quantitative study
Strifler, L, Morris, S. K, Dang, V et al. (2014) The health burden of invasive meningococcal disease: A systematic review. Paediatrics and	- Study design not of interest for review Systematic review of quantitative studies

Study	Code [Reason]
Child Health (Canada) 19(6): e92	
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. Journal of Public Health 32(1): 32-37	- Population not of interest for review No indication of suspected meningitis or meningococcal disease
Thompson, A. P, Nesari, M, Hartling, L et al. (2020) Parents' experiences and information needs related to childhood fever: A systematic review. Patient education and counseling 103(4): 750-763	- Study design not of interest for review Systematic review study, included studies have been reviewed and relevant ones are already included in the review
Thompson, Alison P and Le, Anne, Hartling, Lisa, Scott, Shannon D. (2020) Fading confidence: A qualitative exploration of parents' experiences caring for a febrile child. Journal of clinical nursing 29(05jun): 964-973	- Population not of interest for review No indication of suspected meningitis or meningococcal disease
Urbane, U. N, Likopa, Z, Gardovska, D et al. (2019) Beliefs, Practices and Health Care Seeking Behavior of Parents Regarding Fever in Children. Medicina (Kaunas, Lithuania) 55(7)	- Study design not of interest for review Quantitative study
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. Journal of Tropical Pediatrics 58(4): 275-9	- Context not of interest for review Study set in South Africa
Van Stuijvenberg, M, De Vos, S, Tjiang, G. C. H et al. (1999) Parents' fear regarding fever and febrile seizures. Acta Paediatrica, International Journal of Paediatrics 88(6): 618-622	- Study design not of interest for review Quantitative study
Villarejo-Rodriguez, M. G and Rodriguez-Martin, B. (2019) Parental approach to the management of childhood fever: Differences between health professional and non-health professional parents. International Journal of Environmental Research and Public Health 16(20): 4014	- Population not of interest for review No indication of suspected meningitis or meningococcal disease
Villarejo-Rodriguez, M. G and Rodriguez-Martin, B. (2019) A qualitative study of parents' conceptualizations on fever in children aged 0 to 12 years. International Journal of Environmental Research and Public Health 16(16): 2959	- Phenomenon of interest not of interest for review No data on support when BM or MD is suspected
Villarejo-Rodriguez, M. G and Rodriguez-Martin, B. (2020) Behavior of Parents Seeking Care From Emergency Services Due to Fever in Children. Journal of nursing scholarship: an official publication of sigma theta tau international honor society of nursing 52(2): 136-144	- Population not of interest for review No indication of suspected meningitis or meningococcal disease
Villarejo-Rodriguez, M. G and Rodriguez-Martin, B. (2020) Parents' and primary caregivers' conceptualizations of fever in children: A systematic review of qualitative studies. Nursing & health sciences 22(2): 162-170	- Study design not of interest for review Systematic review study, included studies have been reviewed and relevant ones are already included in the review
Wagstaff, B. (2006) Impact of antibiotic restrictions: The patient's perspective. Clinical microbiology and infection 12(suppl5): Oct-15	- Study design not of interest for review Narrative review

Study	Code [Reason]
Walsh, A; Edwards, H; Fraser, J. (2008) Parents' childhood fever management: community survey and instrument development. Journal of Advanced Nursing 63(4): 376-388	- Population not of interest for review No indication of suspected meningitis or meningococcal disease
Walsh, A; Edwards, H; Fraser, J. (2009) Attitudes and subjective norms: determinants of parents' intentions to reduce childhood fever with medications. Health education research 24(3): 531-45	- Study design not of interest for review Quantitative study
Walsh, Anne, Edwards, Helen, Abdullah, Ajzen Al-Eissa Al-Eissa Ames Anderson Banco Barrett Blatteis Blumenthal Blumenthal Broome Bursey Casey Connell Cranswick Crocetti Curtis Drwal-Klein Edwards Edwards Edwards Ferraro Fischer Goldman Gribetz Grossman Hyam Impicciatore Janke Kai Kai Kapasi Karwowska Kelly Kilmon Kinmonth Kluger Knoebel Kramer Lagerlov Li Linder Lorin Lorin Lorin Mackowiak May McCamish McCaul McErlean Murphy O'Neill-Murphy Poirier Porter Robinson Roth Sarrell Sarrell Schmitt Schmitt Singhi Taveras Thomas Usherwood Walsh Wambach Wambach Zeisberger (2006) Management of childhood fever by parents: Literature review. Journal of advanced nursing 54(2): 217-227	- Study design not of interest for review Literature review. Studies included were checked and none met the inclusion criteria
Westin, E and Sund Levander, M. (2018) Parent's Experiences of Their Children Suffering Febrile Seizures. Journal of Pediatric Nursing 38(pp6873)	- Population not of interest for review No indication of suspected meningitis or meningococcal disease
Wisemantel, Melinda, Maple, Myfanwy, Massey, Peter D and 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 Vermunt (2018) Psychosocial challenges of invasive meningococcal disease for children and their families. Australian Social Work 71(4): 478-490	- Population not of interest for review Confirmed cases of Invasive Meningococcal disease included with no data pre-diagnosis

#### **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 support is valued by patients and their families or carers, when concerns arise about the possibility of bacterial meningitis or meningococcal disease?

No research recommendation was made for this review.