National Institute for Health and Care Excellence

Final

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

[K1] Evidence review for information 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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Review question

What information 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 information patients and their families or carers value when concerns first arise about the possibility of bacterial meningitis or meningococcal disease, but before the diagnosis is confirmed.

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

Population	• People with suspected bacterial meningitis or meningococcal disease. • Parents or carers of babies, children, and young people with suspected bacterial meningitis or meningococcal disease. • Families or carers of adults with suspected bacterial meningitis or meningococcal disease.

Phenomenon of interest	Views and experiences of the information provided 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): • Information content • Information format • Information sources • Decision making • Timing of information provision • Language • Communication
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 Developing NICE guidelines: the manual. Methods specific to this review question are described in the review protocol in appendix A and the methods document (supplementary document 1).

Declarations of interest were recorded according to NICE's conflicts of interest policy.

Qualitative evidence

Included studies

Nine qualitative studies were included in this review (De 2014, Haines 2005, Jones 2014, Kelly 2016, Neill 2015, Sahm 2016, Sweeney 2013, Villarejo-Rodriguez 2019, Walsh 2007).

The included studies are summarised in Table 2.

Seven studies reported views and experiences of parents and carers of babies, children and young people suspected of having bacterial meningitis (De 2014, Jones 2014, Kelly 2016, Neill 2015, Sahm 2016, Villarejo-Rodriguez 2019, Walsh 2007). Two studies reported the views and experiences of parents and carers of children and young people who had confirmed meningococcal disease (Haines 2005, Sweeney 2013) but only views and experiences of information pre-diagnosis of the disease has 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), 1 study was from England (Haines 2005), 3 studies were from the UK (Jones 2014, Neill 2015, Sweeney 2013), 1 study was from Ireland (Kelly 2016), 1 study was from Denmark (Sahm 2016), and 1 study was from Spain (Villarejo-Rodriguez 2019).

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

Excluded studies

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

Summary of included studies

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

Table 2: Summary of included studies.

Study	Population	Methods	Themes applied after thematic synthesis
De 2014 General qualitative inquiry Australia	N=36 Parents of febrile babies aged <3 months admitted to tertiary children's hospital. Age, years: n = 23-44	**Setting:** Purposive sampling by reviewing daily hospital admissions in Tertiary children's hospital in Sydney **Data collection and analysis:** Semi structured face-to-face interviews, thematically analysed following grounded theory principles.	• Information format • Communication • Information at diagnosis
Haines 2005 Phenomenological study England	N= 7 Parents whose child has suffered from and survived severe MD Age: NR	**Setting:** Purposive sampling of parents of children admitted to PICU **Data collection and analysis:** Semi structured face-to-face interviews, analysed using Colaizzi's Interpretation Process.	• Communication
Jones 2014 General qualitative inquiry United Kingdom	N=27 Parents with at least one child under the age of 5 years who are able to speak	**Setting:** Maximum variation sampling from first contact care settings, community centres, children's centres and nurseries in the Midlands,	• Information format • Communication • Information sources • Timing of information • Information content

Study	Population	Methods	Themes applied after thematic synthesis
	English Age (years): <20: n = 1 20–29: n = 5 30–39: n = 16 40–49: n = 5	UK **Data collection and analysis:** Focus groups and/or interviews, analysed using the grounded theory method of constant comparison.	
Kelly 2016 Phenomenological study Ireland	N= 23 Parents of children where at least one child was aged 5 years or younger at the time of the study Age, years, mean: 31.7	**Setting:** Convenience sampling from ante-natal clinics **Data collection:** Semi-structured interviews, analysed using thematic analysis.	• Information format • Information sources • Communication
Neill 2015 General qualitative inquiry United Kingdom	N=27 Parents of at least one child less than 5 years Age, years: <30: n = 6 30 – 39: n = 16 40 -49: n = 5	**Setting**: Maximum variation sampling from South Asian and Gypsy/Travelling communities, a SureStart Children's Centre and a private sector day nursery **Data collection and analysis:** Focus groups and individual interviews, analysed using constant comparative analysis.	• Information format • Information sources
Sahm 2016 General qualitative inquiry Denmark	N=21 Parents of healthy children where at least one child was aged five years or younger at the time of the study Age, years, median: n = 32.4 (female) n = 35.5 (male)	**Setting**: Convenience sampling from the Nørrebro area of Copenhagen **Data collection and analysis:** Semi-structured face-to-face interviews, analysed using constant comparison method.	• Information format • Information sources • Communication
Sweeney 2013 General qualitative inquiry United Kingdom	N=244 Parents/carers of survivors of serogroup B meningococcal disease in childhood Age: NR	**Setting:** Purposive sampling as part of a UK (MOSAIC) **Data collection and analysis:** Structured telephone interviews, analysed using qualitative content analysis.	• Communication • Information at diagnosis
Villarejo-Rodriguez 2019	N=57	**Setting:** Theoretical sampling and snowball	• Information format • Information sources

Study	Population	Methods	Themes applied after thematic synthesis
Grounded Theory Spain	Parents of Spanish nationality with children aged between 0 and 12 years who had received care at the Primary Care Emergency Services of the health clinics due to a fever Age, years: <30: n = 0 (male), n = 4 (female) 30–40: n = 15 (male), n = 14 (female) >40: n = 12 (male), n = 12 (female)	sampling from the Emergency Primary Care Services in two Spanish municipalities **Data collection and analysis:** Focus groups, analysed using constant comparative method.	• Information content
Walsh 2007 General qualitative inquiry Australia	N=15 Parent and primary caregiver for a child aged between six months and five years Age, years, mean: n = 34.1	**Setting:** Purposive convenience sample from advertisement in online newspaper **Data collection and analysis:** Interviews and focus groups, data was thematically analysed.	• Information format • Information sources • Timing of information • Information at diagnosis • Information content

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

See the full evidence tables in appendix D.

The themes identified through analysis of all the included studies are listed here: information format, communication, information at diagnosis, information sources, timing of information and information content.

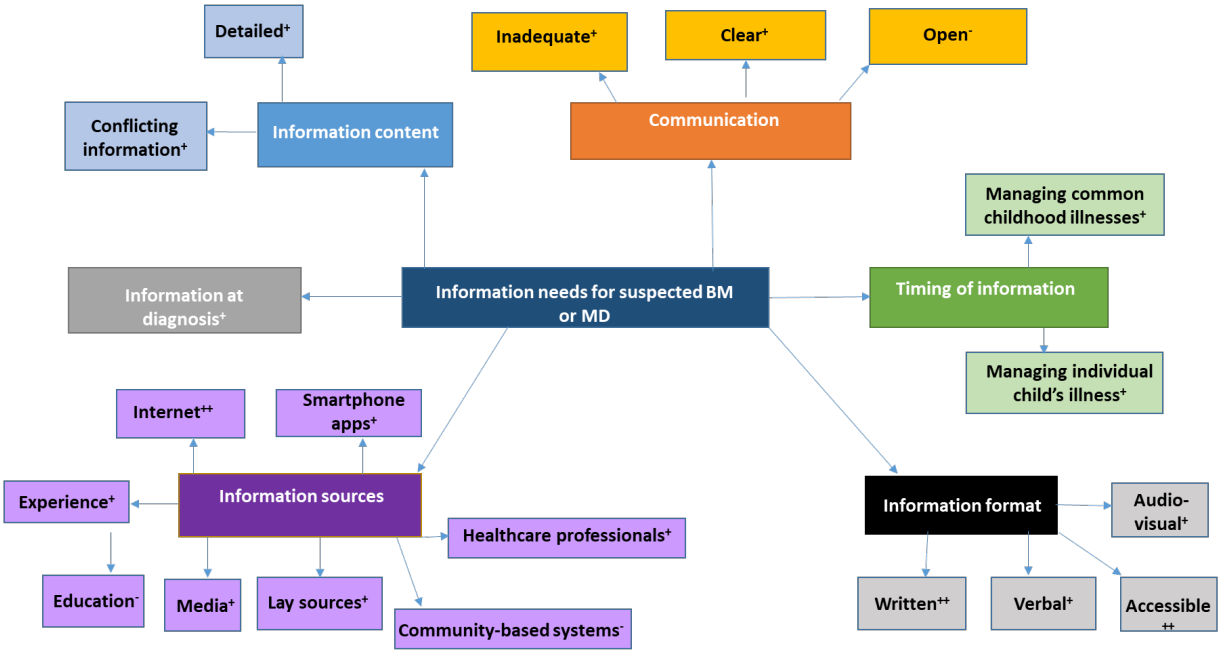
This was a qualitative meta-synthesis, so no quantitative meta-analysis was conducted (and there are no forest plots in appendix E).

Summary of the evidence

The evidence generated 6 main themes in relation to the information valued by parents, their families, and carers when bacterial meningitis or meningococcal disease is suspected. Seven studies provided the evidence relating to information format, which had 4 sub-themes (written, verbal, accessible, and audio-visual). Six studies provided the evidence relating to information sources, which had 8 subthemes (internet, smartphone apps, media, lay sources, healthcare professionals, community-based systems, education, and experience). Three studies provided the evidence relating to information content, which had 2 subthemes (detailed and conflicting information). Six studies provided the evidence relating to communication, which had 3 subthemes (inadequate, clear, and open). Two studies provided the evidence relating to timing of information, which had 2 subthemes (managing common childhood illness and managing individual child's illness). Four studies provided the evidence relating to information at diagnosis, which had no subthemes. The overarching themes and subthemes were developed to allow subthemes on a common topic to be grouped to aid

presentation of results, without obscuring the detail included within the individual subthemes. For example, the subthemes on information sources all related to different sources of information that parents and carers had reported using and what their views about these different sources were. Figure 1 shows the themes and the subthemes.

Figure 1: Theme map



BM: Bacterial Meningitis; MD: Meningococcal disease
++ = high quality evidence; + = moderate quality evidence; - = low quality evidence

Whilst there was not a specific theme or subtheme about language, the subtheme about clear communication included that information should be presented in simple language and multiple languages. However, no evidence emerged relevant to the theme of decision making, stated in the phenomenon of interest 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, because of a lack of consideration of the relationship between researcher and participants, no justification for data collection methods as it relates to data saturation and potential for recruitment bias), concerns about relevance (for example, because studies focused on fever), and concerns about adequacy (for example, for review findings when evidence offered no or 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 focused on the views and experiences of the information provided when bacterial meningitis and/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 information content, information format, information sources, decision making, timing of information provision, language, and communication. However, the potential themes were not exhaustive, as the committee did not want to constrain the evidence, and an emergent approach was taken to the thematic synthesis.

The quality of the evidence

The evidence was assessed using GRADE-CERQual methodology and the overall quality ranged from low to high. Assessments of the potential methodological limitations of the primary studies were undertaken using the CASP checklist; overall concerns regarding methodological limitations ranged from "no or very minor" to "moderate concerns". The most common issues were lack of consideration of the relationship between researcher and participants, no justification for data collection methods as it relates to data saturation and potential for recruitment bias. Concerns about relevance ranged from "no or very minor" to "moderate". The minor concerns were due to studies focusing on fever as the main context for the study with meningitis as one of the potential causes of fever. Moderate concerns were because of studies that focused on confirmed meningitis or meningococcal disease as the main context of the study but focused on fever as the main context of the study with all participants admitted to hospital and having a complete sepsis work up. Concerns about coherence were "no or very minor" for all the review findings, as there was no data that contradicted the findings nor was there ambiguous data. Concerns about adequacy ranged from "no or very minor" to "serious". There were serious concerns for review findings when evidence offered no rich data, moderate concerns for review findings when evidence offered some rich data and minor concerns for review findings that were based on evidence offering moderately rich data. The number of studies contributing to each subtheme ranged from 1 to 6.

No evidence was identified for the following outcomes: decision making and language.

Benefits and harms

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

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

There was moderate quality evidence from subtheme K1.4.1 (inadequate communication) and theme 6 (information at diagnosis) that parents felt they did not receive adequate information from health professionals during the period of diagnosis. Similarly, there was moderate quality evidence from subthemes K1.3.1 (detailed information content) and K1.4.3 (clear communication) that parents expressed a need for detailed and clear information on all aspects of their child's illness. Specifically, parents highlighted the need for more information about the suspected diagnosis (theme 6 and subtheme K1.3.1), the disease (subtheme K1.3.1; severity, symptoms, causes, management, and trajectory), when to seek professional advice (subtheme K1.3.1) and procedures such as lumbar puncture (subtheme K1.4.1). In addition, there was moderate quality evidence from subthemes K1.1.2 (verbal information format) and subtheme K1.2.5 (healthcare professionals as source of information) that information was usually not voluntarily offered by healthcare professionals. The committee considered the evidence and recommended that clear information is provided about the reasons for their suspected diagnosis and any uncertainty about their initial diagnosis, the need for investigations (including lumbar puncture for bacterial meningitis), and any considerations around the timing of investigations and administration of antibiotics. The committee agreed that healthcare professionals need to establish the right time to offer information to patients and their families, including timing of investigations and administrations of antibiotics, whilst also considering the amount of time available for them to digest the information. The committee highlighted that, in their experience, fear often originates from a lack of information and, therefore, agreed that keeping people with suspected bacterial meningitis or meningococcal disease and their parents or carers informed on when they can expect to know more is important to reduce anxiety while they wait for a confirmation of the diagnosis.

Based on their experience, the committee discussed the need for information in situations where people are considered unlikely to have bacterial meningitis or meningococcal disease but are sent home from hospital with an unconfirmed diagnosis. The committee agreed that everyone in these circumstances should be provided with safety-netting information on symptoms and signs to look out for and what changes should prompt return to hospital. The committee considered the high quality evidence from subtheme K1.1.1 (written information format) where parents expressed a preference for information in written format, and the moderate quality evidence from subtheme K1.3.1 (detailed information content) where parents expressed the need for detailed information on all aspects of the illness, including when to seek professional advice. In addition, they considered the moderate to high quality evidence from subthemes K1.1.3 (audio-visual information format), K1.2.1 (internet as source of information), K1.2.2 (smartphone apps as source of information) and K1.2.3 (media as source of information) where parents reported seeking information from digital sources such as the internet and smartphone apps. Based on this evidence and their clinical knowledge and experience, the committee agreed that people should be directed to sources of online information. This was additionally supported by high quality evidence from subtheme K1.1.4 (accessible information format) that parents needed easily accessible, credible information without having to navigate through this themselves.

Cost effectiveness and resource use

This qualitative review question did not consider decisions between competing alternatives and therefore is not directly relevant to the tools of economic evaluation. Whilst communication and information provision do consume resources, they are also a vital and routine part of healthcare provision. The committee felt their recommendations reflected good practice which would not entail a significant resource impact to the NHS and would help

promote the provision of information that is valued by patients and carers where bacterial meningitis or meningococcal disease is suspected.

Recommendations supported by this evidence review

This evidence review supports recommendations 1.3.1 and 1.3.2. Other evidence supporting the recommendations can be found in the evidence review on support for suspected bacterial meningitis or meningococcal disease (see evidence review K2).

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

Haines 2005

Haines, C. Parents' experiences of living through their child's suffering from and surviving severe meningococcal disease. Nursing in critical care, 10(2), 78-89, 2005

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

Kelly 2016

Kelly, M, Sahm, L. J, Shiely, F et al. Parental knowledge, attitudes and beliefs regarding fever in children: an interview study. BMC public health, 16, 540, 2016

Neill 2015

Neill, S. J, Jones, C. H, Lakhanpaul, M et al. 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, 2015

Sahm 2016

Sahm, L. J, Kelly, M, McCarthy, S et al. Knowledge, attitudes and beliefs of parents regarding fever in children: A Danish interview study. Acta Paediatrica, International Journal of Paediatrics, 105(1), 69-73, 2016

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

Villarejo-Rodriguez 2019

Villarejo-Rodriguez, M. G and Rodriguez-Martin, B. 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, 2019

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: https://www.nice.org.uk/guidance/ng204 [Accessed 18/07/2022]

Appendices

Appendix A Review protocols

Review protocol for review question: What information 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	CRD42020221138
Review title	Information for suspected bacterial meningitis or meningococcal disease
Review question	What information 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 information 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.
	• Parents or carers of babies, children, and young people with suspected bacterial meningitis or meningococcal disease.
	• Families or carers of adults with suspected bacterial meningitis or meningococcal disease.
	
	Exclusion:
	• People and families or carers of people:
	  ○ with known immunodeficiency.
	  ○ who have brain tumours, pre-existing hydrocephalus, intracranial shunts, previous neurosurgical procedures, or known cranial or spinal anomalies that increase the risk of bacterial meningitis.
	  ○ with confirmed viral meningitis or viral encephalitis.
	  ○ with confirmed tuberculous meningitis.
	  ○ with confirmed fungal meningitis
	  ○ 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 the information provided 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.

Field	Content
	Exclusions: • Quantitative studies (including surveys reporting only quantitative data) • Surveys which quantify open-ended answers for analysis • Conference abstracts
Other exclusion criteria	• Countries other than OECD high income countries, Australia, New Zealand and Canada. • Studies conducted prior to 2000 as microbiology has not changed much since 2000 and most relevant interventions (e.g., steroids) were available by then. • Studies published not in English-language
Context	This guidance will fully update the following: Meningitis (bacterial) and meningococcal septicaemia in under 16s: recognition, diagnosis and management (CG102)
Primary outcomes (critical outcomes)	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): • Information content • Information format • Information sources • Decision making • Timing of information provision • Language • Communication
Secondary outcomes (important outcomes)	Not applicable
Data extraction (selection and coding)	All references identified by the searches and from other sources will be uploaded into STAR and de-duplicated. Titles and abstracts of the retrieved citations will be screened to identify studies that potentially meet the inclusion criteria outlined in the review protocol. Dual sifting will not be undertaken for this question. Full versions of the selected studies will be obtained for assessment. Studies that fail to meet the inclusion criteria once the full version has been checked will be excluded at this stage. Each study excluded after checking the full version will be listed, along with the reason

Field	Content
	for its exclusion. A standardised form will be used to extract data from studies. The following data will be extracted: study details (reference, country where study was carried out, type and dates), recruitment strategy, participant characteristics, setting, methods of data collection and analysis, relevant findings and source of funding. One reviewer will extract relevant data into a standardised form, and this will be quality assessed by a senior reviewer.
Risk of bias (quality) assessment	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

Field	Content		
	☐	Diagnostic	
	☐	Prognostic	
	☒	Qualitative	
	☐	Epidemiologic	
	☐	Service Delivery	
	☐	Other (please specify)	
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	☑	☑
	Piloting of the study selection process	☑	☑
	Formal screening of search results against eligibility criteria	☑	☑
	Data extraction	☑	☑
	Risk of bias (quality) assessment	☑	☑
	Data analysis	☑	☑
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		

Field	Content	
Review team members	National Guideline Alliance	
Funding sources/sponsor	This systematic review is being completed by the National Guideline Alliance which receives funding from NICE.	
Conflicts of interest	All guideline committee members and anyone who has direct input into NICE guidelines (including the evidence review team and expert witnesses) must declare any potential conflicts of interest in line with NICE's code of practice for declaring and dealing with conflicts of interest. Any relevant interests, or changes to interests, will also be declared publicly at the start of each guideline committee meeting. Before each meeting, any potential conflicts of interest will be considered by the guideline committee Chair and a senior member of the development team. Any decisions to exclude a person from all or part of a meeting will be documented. Any changes to a member's declaration of interests will be recorded in the minutes of the meeting. Declarations of interests will be published with the final guideline.	
Collaborators	Development of this systematic review will be overseen by an advisory committee who will use the review to inform the development of evidence-based recommendations in line with section 3 of Developing NICE guidelines: the manual. Members of the guideline committee are available on the NICE website: https://www.nice.org.uk/guidance/indevelopment/gid-ng10149.	
Other registration details	None	
Reference/URL for published protocol	https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42020221138	
Dissemination plans	NICE may use a range of different methods to raise awareness of the guideline. These include standard approaches such as: notifying registered stakeholders of publication publicising the guideline through NICE's newsletter and alerts issuing a press release or briefing as appropriate, posting news articles on the NICE website, using social media channels, and publicising the guideline within NICE.	
Keywords	Bacterial meningitis, meningococcal disease, information, qualitative	
Details of existing review of same topic by same authors	None	
Current review status	☐	Ongoing
	☒	Completed but not published

Field	Content	
	☐	Completed and published
	☐	Completed, published and being updated
	☐	Discontinued
Additional information	None	
Details of final publication	www.nice.org.uk	

CASP: Critical Appraisal Skills Programme; CDSR: Cochrane Database of Systematic Reviews; CENTRAL: Cochrane Central Register of Controlled Trials; 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 information 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 K2 on support 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

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

#	Searches
22	21 use emczd
23	exp Audiovisual Communications Media/ or exp Advocacy/ or exp Bibliotherapy/ or exp Blog/ or exp Client Attitudes/ or exp Client Education/ or exp Client Participation/ or exp Communication/ or exp Communications Media/ or exp Computer Assisted Therapy/ or exp Computer Mediated Communication/ or exp Counseling/ or exp Decision Support Systems/ or exp Digital Interventions/ or exp Educational Audiovisual Aids/ or exp Educational Programs/ or exp Electronic Communication/ or exp Empowerment/ or exp Health Attitudes/ or exp Health Education/ or exp Health Care Utilization/ or exp Information Seeking/ or exp Help Seeking Behavior/ or exp Health Care Seeking Behavior/ or exp Health Literacy/ or exp Health Promotion/ or exp Hot Line Services/ or exp Internet/ or exp Interpersonal Communication/ or exp Information/ or exp Information Dissemination/ or exp Information Services/ or exp Mass Media/ or exp Mobile Applications/ or exp Mobile Devices/ or exp Mobile Phones/ or exp Peers/ or exp Reading Materials/ or exp Support Groups/ or exp Self-Help Techniques/ or exp Smartphones/ or exp Social Support/ or exp Social Media/ or exp Social Networks/ or exp Telecommunications Media/ or exp Telephone Systems/ or exp Telemedicine/ or exp Text Messaging/ or exp Treatment Compliance/ or exp Verbal Communication/ or exp Websites/ or exp Written Communication/
24	23 use psyh
25	((group* or psychosocial*) adj2 support*).tw.
26	(blog* or "mobile* app*" or "mobile* phone* app*" or "mobile* health* app*" or "download* app*" or ipad app* or booklet* or brochure* or cellphone* or dvd* or handout* or ict or internet* or leaflet* or manual or manuals or media or mobile* or online app* or pamphlet* or phone* or publication* or smartphone* or telephone* or webpage* or web based or website* or web site* or web page* or video* or helpseek* or help-seek* or healthcareseek* or healthcare-seek* or healthseek* or health-seek* or care-seek* or careseek*).tw.
27	((discussion* or online* or on-line*) adj3 (forum* or fora)).tw.
28	messag* board*.tw.
29	(hotline* or helpline* or hot-line* or help-line*).tw.
30	(social adj (network* or media)).tw.
31	((user* or family or families or parent* or father* or mother* or carer* or caregive* or care giv*) adj3 (advice or inform* or support* or guidance)).tw.
32	(information* adj3 (model* or program* or need* or require* or seek* or access* or dissem* or shar* or provid* or provision)).tw.
33	((inform* or support*) adj3 (help* or support* or benefi* or hinder* or hindran* or barrier* or facilitate* or practical* or clear* or accurate*)).tw.
34	((information* or support* or advice or guidance) adj3 (type* or content* or method* or quality or format*)).tw.
35	information sheet.tw.
36	patient guidance.tw.
37	or/20,22,24-36
38	Qualitative Research/
39	interview/ use medall
40	exp interview/ use emczd
41	interviews/ use psyh
42	interview*.tw.
43	thematic analysis/ use emczd
44	(theme* or thematic).mp.
45	qualitative.af.
46	questionnaire$.mp.
47	ethnological research.mp.
48	ethnograph*.mp.
49	ethnonursing.af.
50	phenomenol*.af.
51	(life stor* or women* stor*).mp.
52	(grounded adj (theor* or study or studies or research or analys?s)).af.
53	((data adj1 saturat$) or participant observ$).tw.
54	(field adj (study or studies or research)).tw.
55	biographical method.tw.
56	theoretical sampl$.af.
57	((purpos$ adj4 sampl$) or (focus adj group$)).af.
58	open ended questionnaire/ use emczd
59	((open end* or openend*) adj3 questionnaire*).tw.
60	(account or accounts or unstructured or openended or open ended or text$ or narrative$).mp.
61	(life world or life-world or conversation analys?s or personal experience$ or theoretical saturation).mp.
62	((lived or life) adj experience$).mp.
63	narrative analys?s.af.
64	or/38-63
65	(10 or 18) and 37 and 64
66	Patient Preference/ or exp Patient Satisfaction/
67	66 use medall
68	parental attitude/ or patient satisfaction/ or patient preference/ or personal experience/
69	68 use emczd
70	exp Parental Attitudes/ or exp Client Attitudes/ or exp Consumer Satisfaction/ or exp Client Satisfaction/ or exp Preferences/
71	70 use psyh
72	(dissatisf* or expectation* or experienc* or opinion* or perceive* or perspective* or preferenc* or satisf* or view*).tw.

#	Searches
73	(or/67,69,71) or 72
74	(10 or 18) and 37 and 73
75	65 or 74
76	Letter/ use medall
77	letter.pt. or letter/ use emczd
78	note.pt.
79	editorial.pt.
80	Editorial/ use medall
81	News/ use medall
82	news media/ use psyh
83	exp Historical Article/ use medall
84	Anecdotes as Topic/ use medall
85	Comment/ use medall
86	Case Report/ use medall
87	case report/ use emczd
88	case study/ use emczd
89	Case report/ use psyh
90	(letter or comment*).ti.
91	or/76-90
92	randomized controlled trial/ use medall
93	randomized controlled trial/ use emczd
94	random*.ti,ab.
95	cohort studies/ use medall
96	cohort analysis/ use emczd
97	cohort analysis/ use psyh
98	case-control studies/ use medall
99	case control study/ use emczd
100	or/92-99
101	91 not 100
102	(animals/ not humans/) or exp animals, laboratory/ or exp animal experimentation/ or exp models, animal/ or exp rodentia/
103	102 use medall
104	(animal/ not human/) or nonhuman/ or exp animal experiment/ or exp experimental animal/ or animal model/ or exp rodent/
105	104 use emczd
106	"primates (nonhuman)"/ or animal research/ or animal models/ or rodents/
107	106 use psyh
108	(rat or rats or mouse or mice).ti.
109	or/101,103,105,107-108
110	75 not 109
111	*Acute Disease/ or *Fever/ or *Sepsis/ or *Bacterial Infections/
112	111 use medall
113	*acute disease/ or *fever/ or *sepsis/ or *bacterial infection/ or exp *bacteremia/
114	113 use emczd
115	Infectious Disorders/ or Bacterial Disorders/ or *Hyperthermia/
116	115 use psyh
117	((acute* adj2 (ill or illness)) or fever or sepsis or bacter?emia or (bacteria* adj infection*)).m_titl.
118	112 or 114 or 116 or 117
119	37 and (64 or 73) and 118
120	(appropriat* adj informat*).tw.
121	(10 or 18 or 118) and 120 and (64 or 73)
122	119 or 121
123	122 not 109
124	110 or 123
125	limit 124 to English language
126	limit 125 to yr="1980 -Current"
127	limit 126 to (conference abstract or conference paper or conference review or conference proceeding) [Limit not valid in Ovid MEDLINE(R),Ovid MEDLINE(R) Daily Update,Ovid MEDLINE(R) PubMed not MEDLINE,Ovid MEDLINE(R) In-Process,Ovid MEDLINE(R) Publisher; records were retained]
128	127 use emczd
129	126 not 128

Database(s): Cochrane Library – Wiley interface
Cochrane Database of Systematic Reviews, Issue 7 of 12, July 2021, **Cochrane Central Register of Controlled Trials**, Issue 7 of 12, July 2021
Date of last search: 14 July 2021

#	Searches
#1	MeSH descriptor: [Meningitis] this term only
#2	MeSH descriptor: [Meningitis, Bacterial] this term only
#3	MeSH descriptor: [Meningitis, Escherichia coli] this term only
#4	MeSH descriptor: [Meningitis, Haemophilus] this term only
#5	MeSH descriptor: [Meningitis, Listeria] this term only
#6	MeSH descriptor: [Meningitis, Meningococcal] this term only
#7	MeSH descriptor: [Meningitis, Pneumococcal] this term only
#8	MeSH descriptor: [Meningoencephalitis] this term only
#9	(((bacter* or infect*) NEAR/3 (meningit* or meninges* or leptomeninges* or "subarachnoid space*"))):ti,ab,kw
#10	((((meningit* NEAR/3 (“e coli” or “escherichia coli” or haemophilus or hemophilus or hib or “haemophilus influenz*” or “hemophilus influenz*” or “h influenz*” or listeria* or meningococc* or pneumococc* or “gram-negativ* bacill*” or “gram negativ* bacill*” or streptococc* or “group B streptococc*” or GBS or “streptococcus pneumon*” or “s pneumon*” or septic* or sepsis* or bacteraemia* or bacteremia*))))):ti,ab,kw
#11	(((((“e coli” or “escherichia coli” or haemophilus or hemophilus or hib or “haemophilus influenz*” or “hemophilus influenz*” or “h influenz*” or listeria* or meningococc* or pneumococc* or “gram-negativ* bacill*” or “gram negativ* bacill*” or streptococc* or “group B streptococc*” or GBS or “streptococcus pneumon*” or “s pneumon*”) NEAR/3 (septic* or sepsis* or bacteraemia* or bacteremia*))))):ti,ab,kw
#12	((((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
#40	MeSH descriptor: [Internet] explode all trees
#41	MeSH descriptor: [Internet-Based Intervention] this term only
#42	MeSH descriptor: [Web Browser] this term only
#43	MeSH descriptor: [Social Media] this term only
#44	MeSH descriptor: [Social Networking] this term only
#45	MeSH descriptor: [Mobile Applications] explode all trees
#46	MeSH descriptor: [Blogging] this term only
#47	MeSH descriptor: [Electronic Mail] this term only
#48	MeSH descriptor: [Text Messaging] this term only
#49	MeSH descriptor: [Hotlines] this term only
#50	MeSH descriptor: [Telephone] this term only
#51	MeSH descriptor: [Cell Phone] this term only
#52	MeSH descriptor: [Television] this term only
#53	MeSH descriptor: [Radio] this term only
#54	MeSH descriptor: [Bibliotherapy] this term only
#55	MeSH descriptor: [Health Literacy] this term only
#56	MeSH descriptor: [Therapy, Computer-Assisted] this term only and with qualifier(s): [methods - MT]

#	Searches
#57	MeSH descriptor: [Telemedicine] this term only
#58	MeSH descriptor: [Patient Advocacy] this term only
#59	MeSH descriptor: [Consumer Advocacy] this term only
#60	MeSH descriptor: [Social Support] explode all trees
#61	MeSH descriptor: [Self-Help Groups] this term only
#62	MeSH descriptor: [Peer Group] this term only
#63	MeSH descriptor: [Counseling] explode all trees
#64	MeSH descriptor: [Patient Participation] this term only
#65	MeSH descriptor: [Empowerment] this term only
#66	(((group* or psychosocial*) NEAR/2 support*)):ti,ab,kw
#67	((blog* or "mobile* app*" or "mobile* phone* app*" or "mobile* health* app*" or "download* app*" or “ipad app*” or booklet* or brochure* or cellphone* or dvd* or handout* or ict or internet* or leaflet* or manual or manuals or media or mobile* or “online app*” or pamphlet* or phone* or publication* or smartphone* or telephone* or webpage* or “web based” or website* or “web site*” or “web page*” or video* or helpseek* or help-seek* or healthcareseek* or healthcare-seek* or healthseek* or health-seek* or care-seek* or careseek*)):ti,ab,kw
#68	(((discussion* or online* or on-line*) NEAR/3 (forum* or fora))):ti,ab,kw
#69	("messag* board*"):ti,ab,kw
#70	((hotline* or helpline* or hot-line* or help-line*)):ti,ab,kw
#71	((social NEXT (network* or media))):ti,ab,kw
#72	(((user* or family or families or parent* or father* or mother* or carer* or 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 of last search: 14 July 2021

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

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

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

Economic Search

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

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

Date of last search: 11 March 2021

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

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

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

Date of last search: 11 March 2021

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

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

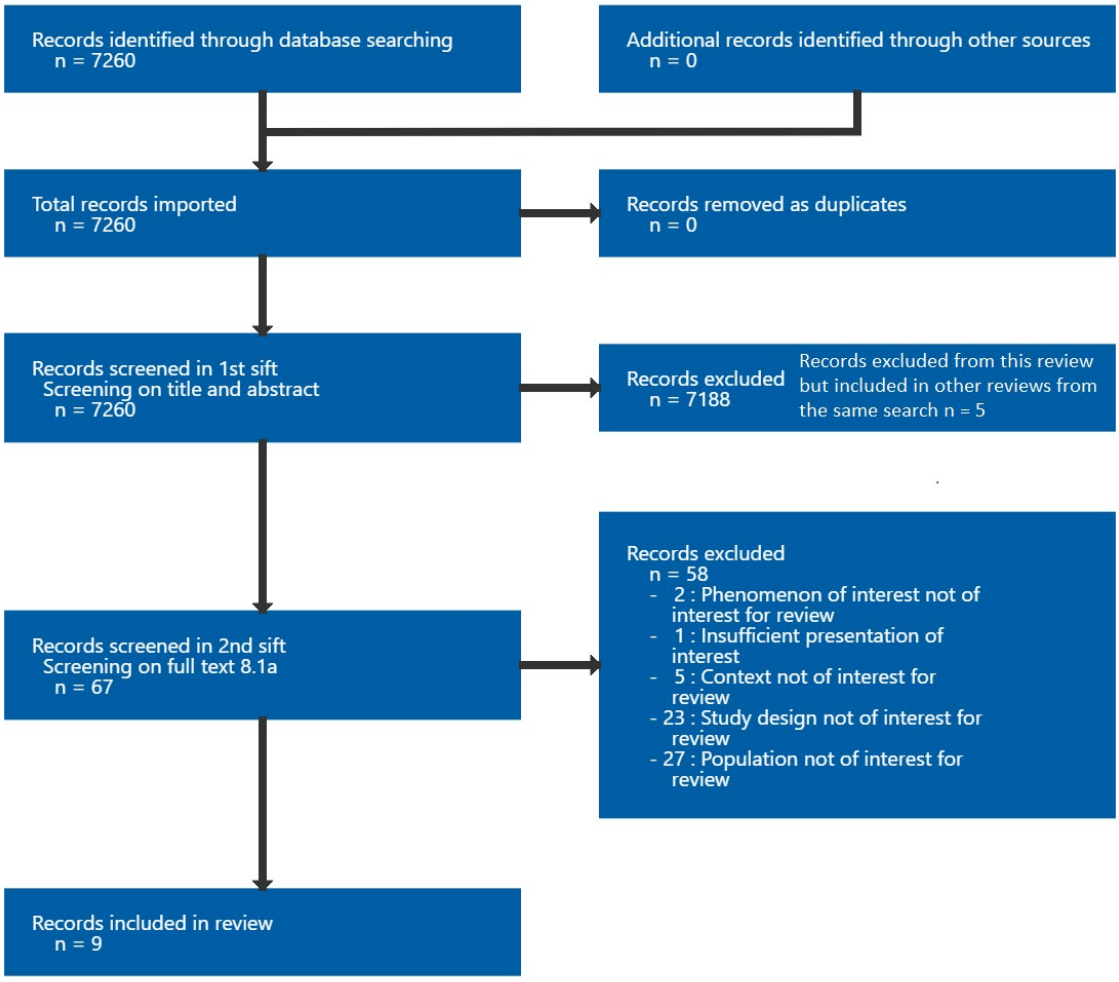
#	Searches
7	((e coli or escherichia coli or h?emophilus or hib or h?emophilus influenz* or h influenz* or listeria* or meningococc* or pneumococc* or gram-negativ* bacill* or gram negativ* bacill* or streptococc* or group B streptococc* or GBS or streptococcus pneumon* or s pneumon*) adj3 (septic* or sepsis* or bacter?emi?)).ti,ab.
8	(mening?encephalitis* or meningit*).ti,ab.
9	or/2,4-8
10	Meningococcal Infections/ or exp Neisseria meningitidis/
11	10 use ppez
12	Meningococcosis/ or Meningococcemia/ or Neisseria Meningitidis/
13	12 use emczd
14	(meningococc* adj3 (sepsis* or septic* or toxic* or endotoxic* or disease? or infection?)).ti,ab.
15	(meningococcus* or meningococci* or meningococc?emi?).ti,ab.
16	(Neisseria* mening* or n mening*).ti,ab.
17	or/11,13-16
18	Economics/ use ppez
19	Value of life/ use ppez
20	exp "Costs and Cost Analysis"/ use ppez
21	exp Economics, Hospital/ use ppez
22	exp Economics, Medical/ use ppez
23	Economics, Nursing/ use ppez
24	Economics, Pharmaceutical/ use ppez
25	exp "Fees and Charges"/ use ppez
26	exp Budgets/ use ppez
27	health economics/ use emczd
28	exp economic evaluation/ use emczd
29	exp health care cost/ use emczd
30	exp fee/ use emczd
31	budget/ use emczd
32	funding/ use emczd
33	budget*.ti,ab.
34	cost*.ti.
35	(economic* or pharmaco?economic*).ti.
36	(price* or pricing*).ti,ab.
37	(cost* adj2 (effective* or utilit* or benefit* or minimi* or unit* or estimat* or variable*)).ab.
38	(financ* or fee or fees).ti,ab.
39	(value adj2 (money or monetary)).ti,ab.
40	or/18-39
41	Quality-Adjusted Life Years/ use ppez
42	Sickness Impact Profile/
43	quality adjusted life year/ use emczd
44	"quality of life index"/ use emczd
45	(quality adjusted or quality adjusted life year*).tw.
46	(qaly* or qal or qald* or qale* or qtime* or qwb* or daly).tw.
47	(illness state* or health state*).tw.
48	(hui or hui2 or hui3).tw.
49	(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 euroqol*or euro quol* or euroquol* or euro quol5d* or euroquol5d* or eur qol* or eurqol* or eur qol5d* or eurqol5d* or eur?qul* or eur?qul5d* or euro* quality of life or european qol).tw.
53	(euro* adj3 (5 d* or 5d* or 5 dimension* or 5dimension* or 5 domain* or 5domain*)).tw.
54	(sf36 or sf 36 or sf thirty six or sf thirtysix).tw.
55	(time trade off*1 or time tradeoff*1 or tto or timetradeoff*1).tw.
56	Quality of Life/ and ((quality of life or qol) adj (score*1 or measure*1)).tw.
57	Quality of Life/ and ec.fs.
58	Quality of Life/ and (health adj3 status).tw.
59	(quality of life or qol).tw. and Cost-Benefit Analysis/ use ppez
60	(quality of life or qol).tw. and cost benefit analysis/ use emczd
61	((qol or hrqol or quality of life).tw. or *quality of life/) and ((qol or hrqol* or quality of life) adj2 (increas* or decreas* or improv* or declin* or reduc* or high* or low* or effect or effects or worse or score or scores or change*1 or impact*1 or impacted or deteriorat*)).ab.
62	Cost-Benefit Analysis/ use ppez and cost-effectiveness ratio*.tw. and (cost-effectiveness ratio* and (perspective* or life expectanc*)).tw.
63	cost benefit analysis/ use emczd and cost-effectiveness ratio*.tw. and (cost-effectiveness ratio* and (perspective* or life expectanc*)).tw.
64	*quality of life/ and (quality of life or qol).ti.
65	quality of life/ and ((quality of life or qol) adj3 (improv* or chang*)).tw.
66	quality of life/ and health-related quality of life.tw.
67	Models, Economic/ use ppez
68	economic model/ use emczd
69	care-related quality of life.tw,kw.

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

Appendix C Qualitative evidence study selection

Study selection for: What information is valued by patients 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 information 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

Study type	General qualitative inquiry
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, sex 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	1st November 2011 to 31st December 2012
Sources of funding	Not reported
Inclusion criteria	• Parents of febrile babies aged <3 months admitted to a tertiary children's hospital in Sydney

	• Parents of previously healthy febrile babies with an unremarkable clinical course and uneventful recovery
Exclusion criteria	• Parents of babies with complex medical background, prematurity, prolonged hospitalisation and complex interventions because their perspectives were likely be influenced by these additional factors. • Non-English speaking parents were excluded due to lack of resources for interpretation
Sample size	N = 36 parents of 27 babies
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: Barriers to parental empowerment: limited capacity for advocacy
	
	• Information format
	  ○ Written
	  ▪ “Fact sheets would be really good. It is hard to ask questions when the doctors are rushing in and out. By the time they are back you forget what you were about to ask.” Mother 31, page 721

- Communication
  - Clear
    - “When you are sleep deprived, when you are concerned, [and] when you are worried sick and things happen so quick, your head seems to go blank. I was in so much shock I couldn’t come up with any question.” Mother 31, page 720/722
    - “I did not know what they were talking about. They were talking their own language, like jargons, they said it is a UTI and I was like, ‘what is that?’ That’s when I looked on the internet did some research of my own.” Mother 28, page 722

Original theme: Parental attitudes and experiences during the course of hospitalisation: Barriers to parental empowerment - unmet expectation of support

- Communication
  - Inadequate
    - “I know the way they give information is straightforward and honest but there has to be some way to not stress us out.” Father 41, page 721
    - “It’s hard to take all the information in and the wording is important—when they talked about the lumbar puncture that they needed to take the fluid from around the baby’s brain we imagined the needle going into the head, I was standing, I felt my head spin and had to hold on to something.” Mother 31, page 720/721
- Information at diagnosis
  - Information at diagnosis
    - “If he gets a temperature again that means that things are not quite finished up he may have a relapse. The thing is we still don’t know what it is… a virus of some sort. It is nicer to know exactly what’s gone on.” Father 37, page 720/721

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

- Communication
  - Open

	▪ "If you are explaining that you gave someone an overdose you are being honest. They were apologising and reaching out and communicating and respecting us and telling us the truth and even telling what the possible consequences may be. At least in the end people were honest about it. The doctors were honest about that issue and spoke to us and communicated to us. That's all we are asking for. A lot of it really is communication." Father, 30, page 719 o Clear ▪ "One nurse came over and said 'I am going to take him in for the catheter' and it was good to be present while that was being done and she was very thorough and explaining what they were doing and she said they were going to eliminate all the big stuff first. The turning point was when the registrar came in and said they were going to do the lumbar puncture and he sat down and went over everything step by step from the start of the day up until then, what had happened—that was the turning point." Mother 33, page 719/721 ▪ "The manner of the doctor in emergency was excellent. He very clearly explained so we knew exactly what was going to happen, that our baby would go through a number of tests, and some would be hard to watch but he was gentle, kind. That in many ways was the key. If you get the explanation first and someone takes the time to sit to tell you what is happening you are prepared to go through a whole lot of things because you have been warned." Father, 30, page 719/721 ▪ "The doctor that saw us in emergency was brilliant. She drew a diagram of the lumbar puncture, explained what was going to happen, the risks associated with it, I was told what may happen if he didn't have it so I think I was quite pleased with the information." Mother, 27, page 719/721 ▪ "I did not know what they were talking about. They were talking their own language, like jargons, they said it is a UTI and I was like, 'what is that?' That's when I looked on the internet did some research of my own." Mother 28, page 722

UTI: urinary tract infections

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

Haines, 2005

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

Study details

Study type	Phenomenological
Country/ies where study was carried out	England
Setting	Parents of children admitted to PICU
Data collection and analysis	Face-to-face interviews 1-month following discharge from hospital, either in the parent's home or in a private room in the hospital. The parents were asked to discuss their experiences prior to and during their child's admission to PICU, how they felt, their coping strategies and what they felt influenced their experience. Data was analysed using Colaizzi's Interpretation Process.
Recruitment strategy	Parents of children admitted to PICU who survived severe meningococcal disease were invited to participate following their child's discharge from hospital.
Study dates	Not stated. Participants recruited over a 6-month period.
Sources of funding	Not industry funded
Inclusion criteria	Parents whose child has suffered from and survived severe MD
Exclusion criteria	Not reported
Sample size	N = 7 parents
Participant characteristics	Not reported

Results	**Themes (information in bullet points are theme(s) applied after thematic synthesis)**
	
	Original theme: Need and value if communication/information/publicity
	
	• Communication
	  ○ Open
	  ▪ No quotes

PICU: Paediatric Intensive Care Unit; MD: meningococcal disease.

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

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

Study type	General qualitative inquiry
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	• Data collection was by focus groups and/or interviews in each parent community and at each first contact care workplace • 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 2012 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	• Parents with at least one child under the age of 5 years, or • Clinicians treating children under 5 years of age at first contact, and • Be able to speak English
Exclusion criteria	Not reported
Sample size	N = 27 parents
Participant characteristics	<u>Community</u> Travelling families n = 6 Asian British n = 11 White British n = 10 <u>Sex</u> Female n = 24

	Male n = 3 <u>Age (years)</u> Under 20 n = 1 20–29 n = 5 30–39 n = 16 40–49 n = 5 <u>Number of children</u> 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: consultation-based safety netting ○ Information format Written ▪ Well half the time when you're taking your child to the doctors they're not very well, are they, so they're clingy, you've had to probably strip them off… so they're crying and they're trying to tell you all this information and getting them back dressed again really quickly… There is pressure to get out quickly, I think, so I think you do forget what the doctor has said. White British mother, page 6

Original theme: Format and delivery of safety netting: audio-visual material

- Information format Audio-visual
  - No quotes

Original theme: Safety netting quality criteria

- Information format Accessible
  - “I would do it on my phone, oh yeah, yeah, yeah, very much so. And that I actually find easier than picking up the phone because if you’ve got a crying child, trying to pick up the phone and talk to somebody is actually a lot more difficult than having a quick look on the internet to see…” White British mother, page 6

- Communication
  - Clear
    - No quotes

Original theme: Format and delivery of safety netting: internet-based resources

- Information format Accessible
  - "If you’ve got a sick child at home and they’re maunging at you, you haven’t got the time to go on the internet… you’ve got a child hanging off your leg going, “Mummy I feel poorly, mummy I want this, mummy I want that,” or you know, screaming or, I don’t think it’s that practical that often you don’t have the chance to go on the internet." White British mother, page 5/7
  - "Yes the phone it’s easily accessible and especially when you’ve got a baby. Rather than putting on the computer….I think the phone is a very good source because you keep it all the time with you. That’s a very good thing, yeah". White British mother page 5/7
- Information sources Internet
  - "if you’ve got an ill child and you’re wanting to find out what it could possibly be, you don’t want to spend hours looking for that information, you actually want to be able to go on a site." White British

mother, page 5/

Original theme: Format and delivery of safety netting

- Information sources Internet
  - "It can be on different forms of media, Internet. Obviously, Internet may not be accessible to many people and if it is accessible, they may not be able to go to the right information, right section so having it in different formats will be quite helpful". Asian British father, page 6
- Media
  - "It can be on different forms of media, Internet. Obviously, Internet may not be accessible to many people and if it is accessible, they may not be able to go to the right information, right section so having it in different formats will be quite helpful". Asian British father, page 6

Original theme: Format and delivery of safety netting: pre-consultation education

- Information sources Media
  - No quotes
- Healthcare professionals
  - No quotes
- Community-based systems
  - No quotes
- Experience
  - No quotes

- Timing of information provision
  - Managing common childhood illnesses
    - "I think I possibly looked at it when I was a new mum with you know, so much enthusiasm, and then about a week in I was like… I'm far too tired to do this, there's no way I'm reading through that book". White British mother, page 6

	Original theme: Safety netting content
	
	• Information content
	  ○ Detailed
	  ▪ No quotes

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

Kelly, 2016

Bibliographic Reference	Kelly, M; Sahm, L. J; Shiely, F; O'Sullivan, R; McGillicuddy, A; McCarthy, S.; Parental knowledge, attitudes and beliefs regarding fever in children: an interview study; BMC public health; 2016; vol. 16; 540

Study details

Study type	Phenomenological
Country/ies where study was carried out	Ireland
Setting	Ante-natal clinics located in Bantry General Hospital, Cork University Maternity Hospital, Mallow Primary Healthcare Centre, Mitchelstown Living Health Centre, St. Finbarr's Hospital and St. Mary's Health Campus.
Data collection and analysis	Semi-structured interviews Thematic analysis

Recruitment strategy	A convenience sampling was undertaken at the selected clinics where patients who presented at the clinic on a given day were invited to participate but had the option to decline
Study dates	March to April 2015
Sources of funding	The HRB Clinical Research Facility, Cork have provided funding to publish this paper.
Inclusion criteria	Parents of children where at least one child was aged 5 years or younger at the time of the study
Exclusion criteria	Not reported
Sample size	N = 23 parents in 21 interviews
Participant characteristics	Sex, n Mothers = 20 Fathers = 3 Country of origin, n Irish = 22 Polish =1 Age, years, mean (range) 31.7 (26 to 40)

	Number of children, mean (range) 1.5 (1 to 4) Age of children, years, mean (range) 4.6 (1 to 15)
Results	**Themes (information in bullet points are theme(s) applied after thematic synthesis)** Original theme: Initiatives ○ Information format Written ▪ No quotes ○ Audio-visual ▪ "It's something visual, if you could see the visuals, do you know". Interview 14, page 4 ○ Accessible ▪ "I suppose there would be a need for it, for people who wouldn't have any experience, especially people maybe with their first child or something like that". Interview 20, page 4 ▪ "I don't know where else that you would access it because I don't think that mothers, being first time or otherwise, have a lot of time to be reading stuff. A friend of mine said that her grandmother always said that first-time mums, you could be having a conversation with them, but they're thinking about something else entirely. They're not hearing you." Interview 8, page 4 Original theme: Knowledge source ○ Information sources Internet ▪ "I just kind of - I'd look at three or four of them (webpages), to be honest, and compare their answers" Interview 1, page 4 ○ Lay sources ▪ "First would be family, I would say, because I would be the youngest in my family so I have some olders that have kids" Interview 14, page 4

	○ Health professionals ▪ "Normally what we use, we go to the doctor and they tend to give us advice and that's kind of it then. wouldn't feel the need then to maybe second guess the doctor. If I think that it's working, what they've suggested, I just tend to leave it at that". Interview 20, page 4 ○ Experience ▪ "Finding out as time goes on, and getting to know the child, and know that this is not normal today, because she's never behaved like this" Interview 8, page 4 • Communication ○ Clear ▪ No quotes

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

Neill, 2015

Bibliographic Reference	Neill, S. J; Jones, C. H; Lakhanpaul, M; Roland, D. T; Thompson, M. J.; 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; 2015; vol. 18 (no. 6); 3044-3056

Study details

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

Setting	South Asian and Gypsy/Travelling communities, a SureStart Children's Centre (community centre supporting families with children up to the age of 5 years) and a private sector day nursery
Data collection and analysis	• Five focus groups having between 2 and 8 parents and 3 individual interviews were conducted. • Data was analysed using constant comparative analysis.
Recruitment strategy	• Sampling was designed to capture maximum variation in the socio-economic characteristics of parents through recruiting in communities with differing social, economic and ethnic profiles in natural settings. • Recruitment was facilitated by the local primary care research network, the Comprehensive Local Research Network and community centre leaders.
Study dates	May 2012 to December 2012
Sources of funding	National Institute for Health Research (NIHR) under its Programme Grants for Applied Research funding scheme
Inclusion criteria	Not reported
Exclusion criteria	Non-English speaking parents
Sample size	N = 27 parents; 24 mothers and 3 fathers
Participant characteristics	Age, n < 30 years = 6 30 - 39 years = 16 40 -49 years = 5 Ethnicity, n

	White British = 10 South Asian = 11 Gypsy/Travelling communities = 6

Results	**Themes (information in bullet points are theme(s) applied after thematic synthesis)**
	
	Original theme: Sources of information: health service use as a source of information
	
	• Information format
	  ○ Verbal
	  ▪ . . .again it was me instigating it, I think I could have walked out the door quite easily without the doctor saying anything was like, “Right, what happens next in terms of worst case scenario, what should I be looking out for? And if not, you know, how long should I be expecting this to go on for, when should they be getting better?” Day nurse interview mother, page 3049/3051
	• Information sources
	  ○ Healthcare professionals
	  ▪ "they ask you questions that to you feel completely irrelevant, they probably are relevant but it’s just really long winded and to try and get an answer and then they say, “Oh just go on hold and I’ll put you through to a nurse,” so I’ve just told you everything and I’ve got to tell somebody else again." Day nursery FG Mother, page 3051
	  ▪ "And then that’s really hard because you’re just like, “I’m sorry but I’ve got to get off the phone,” and then the doctor’s rang and then he’s moaning to you then that he’s tried to ring you and the phone was engaged, that’s happened to me." Day nursery FG Mother, page 3051
	  ▪ "I think even though we’ve got lots of ways of accessing the information I think we still trust the doctor, compared to our family, friends, community, colleagues. . ." South Asian Father, page 3051
	  ▪ "I think there’s, nothing can take you away from the physically seeing somebody and seeing your child." Day nursery FG mother, page 3051
	  ▪ ". . .again it was me instigating it, I think I could have walked out the door quite easily without the doctor saying anything was like, “Right, what happens next in terms of worst case scenario, what should I be looking out for? And if not, you know, how long should I be expecting this to go on for, when should they be getting better?” Day nursery interview mother, page 3051
	
	Original theme: Sources of information - independent information seeking: delivery systems

- Information format
  - Written
    - "would be handy to have it [printed information], I prefer that anyway, I prefer to have, look down and then it's always there to look back on, you know". Day nursery FG mother, page 3048/3049
    - "When S was younger. . . they used to give you cards with symptoms on like meningitis". Community Interview Mother, page 3048/3049
    - "I did have. . . they gave me a little credit card-sized book . . .and it pulled out, it was sort of concertina. . . about childhood illnesses". Day nursery FG Mother, page 3048/3049
- Information sources
  - Internet
    - "I have accessed the Internet, but I find it makes me more scared". South Asian FG Mother, page 3047-3048
    - "Uhm, I always find that there's quite a lot of information on there and you get bombarded with lots of paragraphs which you don't really want. . . On the NHS Direct. . . you have to go through the whole lot of the information before you get to what you want". South Asian FG mother, page 3047-3048
  - Smartphone apps
    - "It's when you've got a screaming child that's ill, you've got another two running around snapping at your feet and you're desperately trying to decide, work out what on earth to do with the sick child, anything that you can get an app for that you can literally press a button. . ." Day nursery interview mother. page 3048
  - Media
    - No quotes
  - Lay sources
    - "I suppose I use forums more because actually my friends are scattered throughout the country". Sure Start FG Mother, page 3047

Original theme: Sources of information: personal contact- lay sources and health service use

- Information sources
  - Lay sources
    - "My mum, because I still live at home with my daughter as well so my mum is a big one that I go to. . . especially when she's still so young, you can think, you know the silliest little thing like a cold or something, 'Oh is she OK, do I need to take her to the doctors?' but that's when my mum will come in and she'll be like, "No, she's fine, you know, all the things you went through when you were little," and

	that helps". Day nursery FG Mother 2, page 3051 ▪ "We have quite a few adults in the know and I will definitely. . ..my sister's [a nurse] my first port of call". Community interview mother, page 3051 ▪ "I mostly ask people that has loads of children. . . I wouldn't ask someone young like myself, I'd ask someone elder than me." Gypsy/Travelling Family FG Mother C, page 3051 ▪ "We are a very close community and asking for advice for children, yeah. It does work with us. I found it works with me and if I can help someone else and look at the child, I will. I think he needs to be brought to hospital then I'll say take them in." Gypsy/Travelling Family FG Mother B, page 3051

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

Sahm, 2016

Bibliographic Reference	Sahm, L. J; Kelly, M; McCarthy, S; O'Sullivan, R; Shiely, F; Romsing, J.; Knowledge, attitudes and beliefs of parents regarding fever in children: A Danish interview study; Acta Paediatrica, International Journal of Paediatrics; 2016; vol. 105 (no. 1); 69-73

Study details

Study type	General qualitative inquiry
Country/ies where study was carried out	Denmark
Setting	Not reported

Data collection and analysis	Semi-structured face-to-face interviews were conducted and data analysis was by thematic analysis. Data collection and thematic analysis were conducted concurrently using a constant comparison method
Recruitment strategy	Convenience sampling was used to identify participants for the study.
Study dates	July to August 2014
Sources of funding	No funding has been received to carry out this study.
Inclusion criteria	• Parents of healthy children where at least one child was aged five years or younger at the time of the study
Exclusion criteria	• Parents of children with complex medical backgrounds or prematurity were excluded because their perspectives were likely be influenced by these additional factors. • Non-English-speaking parents were excluded due to lack of resources for translation.
Sample size	N = 21 parents of 21 children
Participant characteristics	Female n= 12 Male n = 9 Age, years, median (range) Female = 32.4 (27-38) Male = 35.5 (31 - 43) First-time parents, n = 14 Children's ages, range 2 weeks to 4 years

Results

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

Original theme: Help-seeking behaviour

- Information format
  - Written
    - No quotes
  - Verbal
    - No quotes
  - Accessible
    - No quotes
  - Information sources Internet
    - No quotes
  - Smartphone app
    - "yeah, maybe an app. . .an app could be fine also'". Interview 7, page71
  - Lay sources
    - No quotes
  - Healthcare professionals
    - "I think, . . . (concerning fever) it would only be if, if they, were extraordinarily ill, if they were completely lacking energy". Interview 8, page 71
  - Experience
    - No quotes
  - Education
    - No quotes

Original theme: Initiatives

  - Information format Written
    - ". . .a little book. . . which ah described the first year of the child". Interview 1, page 71
  - Accessible
    - "I think it would be nice to have a little bit more information". Interview 4, page 71
  - Information sources Healthcare professionals
    - ". . .the doctor could say it at the 5-week or 5-months (check-up)". Interview 13, page 71
- Communication

	○ Clear ▪ ". . . as a parent it's always nice with very simple and straightforward guidelines that for instance when your child has a fever". Interview 12, page 71

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

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
	
	• Communication
	  ○ Open
	  ▪ "it was faultless from start to finish - from the paramedic to the hospital. They kept us informed - the good and the bad". Page e127
	  ○ Clear
	  ▪ "it was faultless from start to finish - from the paramedic to the hospital. They kept us informed - the good and the bad". Page e127
	• Information at diagnosis
	  ○ Information at diagnosis
	  ▪ *'Getting the balance better in communication'* included having the treatment process explained clearly *'more information on what is going on, like what meningitis is and how it is diagnosed'.* Page e127

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

Villarejo-Rodriguez, 2019

Bibliographic Reference	Villarejo-Rodriguez, M. G; Rodriguez-Martin, B.; A qualitative study of parents' conceptualizations on fever in children aged 0 to 12 years; International Journal of Environmental Research and Public Health; 2019; vol. 16 (no. 16); 2959

Study details

Study type	Grounded theory
Country/ies where study was carried out	Spain
Setting	Emergency Primary Care Services in two Spanish municipalities.
Data collection and analysis	Focus groups were used for data collection and the data analysis was based on the constant comparative method
Recruitment strategy	First, a theoretical sample was recruited, guided by the constant comparative method. Then, snowball sampling was used to select parents of children who, besides the previous inclusion criteria, were health professionals in the public or private healthcare sector, whether these were actively employed, on leave, unemployed or retired.
Study dates	November 2016 to October 2017
Inclusion criteria	• Parents of Spanish nationality with children aged between 0 and 12 years who, during the period of data collection had received care at the Primary Care Emergency Services of the health clinics (blinded for peer review) due to a fever and who voluntarily accepted to participate in the study • Parents with an academic title in the field of health as well as parents without such training
Exclusion criteria	Parents/caregivers of children with chronic cardiac or respiratory illnesses (asthma, pneumonia, bronchiolitis)
Sample size	N = 57 participants in 8 focus groups

Participant characteristics	**Age** <30 years old: Men n = 0; Women n = 4 30–40 years old: Men n = 15; Women n =14 >40 years old: Men n =12; Women n = 12 **Number of children** 1: Men n = 7; Women n =12 2: Men n = 11; Women n = 13 3–4: Men n = 7; Women n = 5 >4: Men n = 2; Women n = 0 **Place of residence (environment)** Rural environment: Men n = 13; Women n = 16 Urban environment: Men n =14: Women n = 14 **Profession** Non-health professional: Men n = 14; Women n = 15 Health professional: Medical degree: Men n = 7; Women n = 7 Nursing diploma or degree: Men n = 4; Women n = 8

	Nurse aide/Health technician: Men n = 2; Women n = 0

Results	**Themes (information in bullet points are theme(s) applied after thematic synthesis)**
	
	Original theme: Parental need for information on fever
	
	• Information content t
	  ○ Detailed
	  ▪ No quotes
	  ○ Information format Written
	  ▪ No quotes
	  ○ Information sources Internet
	  ▪ No quotes
	  ○ Smartphone apps
	  ▪ No quotes
	  ○ Lay sources
	  ▪ No quotes
	  ○ Healthcare professionals
	  ▪ No quotes

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

Walsh, 2007

Bibliographic Reference	Walsh, A; Edwards, H; Fraser, J.; Influences on parents' fever management: beliefs, experiences and information sources; 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	• aged 18 years or older • able to read and converse in English and • being a parent and primary caregiver for a child aged between six months and five years
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: Learning to manage fever ○ Information format Written ▪ "We had phone calls to Mum, we had phone calls to the child health people, visits to the chemist, to see what they thought down at the chemist. We were at the doctor's once. The doctor said 'It will be gone in 24 hours.' Finally, the second doctor's was after the hospital visit." P3, page 2336 ○ Accessible ▪ "We had phone calls to Mum, we had phone calls to the child health people, visits to the chemist, to see what they thought down at the chemist. We were at the doctor's once. The doctor said 'It will be gone in 24 hours.' Finally, the second doctor's was after the hospital visit." P3, page 2336 ○ Information sources Internet ▪ No quotes ○ Lay sources ▪ No quotes ○ Healthcare professionals ▪ No quotes Original theme: Influencing factors: positive factors reduce concern ○ Information format Written ▪ "The real beauty was you can give Panadol and Nurofen. Because they are two different types of medication they won't overdose. You can only give Panadol four or six hourly, he would be all right for

two hours, then – up again, whereas if you gave him Nurofen you could manage it pretty much the whole time without him spiking. That was really useful information and I didn't know that to start with." P2, page 2335

- Information sources Healthcare professionals
  - "The real beauty was you can give Panadol and Nurofen. Because they are two different types of medication they won't overdose. You can only give Panadol four or six hourly, he would be all right for two hours, then – up again, whereas if you gave him Nurofen you could manage it pretty much the whole time without him spiking. That was really useful information and I didn't know that to start with." P2, page 2335

Original theme: Influencing factors: fear of serious illness

- Information sources Media
  - "Meningococcal, like every other mother, because you see all these things on Today Tonight and A Current Affair (National current affair shows) like that because I suppose, right or wrong, they have kind of honed in that message, that you probably don't always have a lot of time." P7, page 2335
- Timing of information provision Managing individual child's illness
  - "If it is coming up to a weekend, I won't let her go for the, say if it is Friday I won't let it go for the weekend. I will get it checked in case its something like a sore throat, ears or coming down with a virus. It is reassurance for yourself." P5, page 2335

- Information at diagnosis
  - Information at diagnosis
    - No quotes

Original theme: High fever is harmful

- Information sources Healthcare professionals
  - "39 something, 40…I would be concerned if I couldn't get that fever down, that whole seizure thing, whether that would cause some sort of brain damage, something with the brain." P7, page 2334

	Original theme: Influencing factors: parental protective role - protecting from harm ○ Information sources Community-based systems ▪ No quotes Original theme: Need for timely consistent information • Content ○ Detailed ▪ No quotes • Timing of information ○ Managing common childhood illnesses ▪ "you are very busy with the baby postnatally." page 2337 ○ Managing individual child's illness ▪ *"If it is coming up to a weekend, I won't let her go for the, say if it is Friday I won't let it go for the weekend. I will get it checked in case its something like a sore throat, ears or coming down with a virus. It is reassurance for yourself."* (Walsh 2007, page 2335) Original theme: Influencing factors: inconsistent information • Content ○ Conflicting information ▪ "…one doctor will tell you something different to the nurse or tell you something different to the chemist. That sort of does make it a bit hard sometimes." P3, page 2336

SD: standard definition; TAFE: Training And Further Education

Critical appraisal - CASP

Section	Question	Answer

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 information 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 information 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. Information format

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Level of concern**	**Overall quality**
Sub-theme K1.1.1: Written					
6 (De 2014; Jones 2014; Kelly 2016; Sahm 2016; Villarejo-Rodriguez 2019; Walsh 2007) n= 179	Qualitative studies using semi-structured interviews, interviews (unspecified) and focus groups (face-to-face)	Parents reported a preference for having information on meningitis in a written format explaining that it is more handy and easier to access. Parents reported that they learnt a lot about fever and its management from written sources. However, some parents reported that some written information like that in the personal child heath record book (red book) was not well used. *"Fact sheets would be really good. It is hard to ask questions when the doctors are rushing in and out. By the time they are back, you forget what you were about to ask."* (De 2014; page 720) *"I think I possibly looked at it when I was a new mum with you know, so much enthusiasm, and then about a week in I was like… I'm far too tired to do this, there's no way I'm reading through that book"* (Jones 2014; page 6)	Methodological limitations	Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist	High
			Relevance	Minor concerns. Some evidence is from a substantially different context to the review question (studies focused on fever and one study had all participants hospitalised)	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Subtheme K1.1.2: Verbal					
3 (Neill 2015; Sahm 2016; Walsh 2007)	Qualitative studies using semi-structured interviews,	Parents reported receiving verbal information from health professionals, which could be in-person during a visit, or over the telephone. Parents reported that the information usually needed to be solicited.	Methodological limitations	Minor concerns about methodological limitations of the evidence as per	Moderate

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Level of concern**	**Overall quality**
n= 63	interviews (unspecified) and focus groups (face-to-face)	*'. . .again it was me instigating it, I think I could have walked out the door quite easily without the doctor saying anything was like, "Right, what happens next in terms of worst case scenario, what should I be looking out for? And if not, you know, how long should I be expecting this to go on for, when should they be getting better?"'* (Neill 2015, page 3051)		CASP qualitative checklist	
			Relevance	Minor concerns. Some evidence is from a substantially different context to the review question (studies focused on fever)	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns. Studies together offered some rich data	
Subtheme K1.1.3: Audio-visual					
2 (Jones 2014; Kelly 2016) n=50	Qualitative studies using semi-structured interviews, interviews (unspecified) and focus groups (face-to-face)	Parents reported that audio recordings (of certain symptoms for example) and videos are more effective means of sharing information, especially for parents with low literacy who are unable to read written language. *"It's something visual, if you could see the visuals, do you know"* (Kelly 2016, page 4)	Methodological limitations	Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	Minor concerns. Some evidence is from a substantially different context to the review question (studies focused on fever)	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns. Studies together offered some rich data	
Subtheme K1.1.4: Accessible					

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Level of concern**	**Overall quality**
4 (Jones 2014; Kelly 2016; Sahm 2016; Walsh 2007) n=86	Qualitative studies using semi-structured interviews, interviews (unspecified) and focus groups (face-to-face)	Parents described the need for credible information that is easily accessible, without the need to rummage through a lot of information or navigate which information is authentic. *"I don't know where else that you would access it because I don't think that mothers, being first time or otherwise, have a lot of time to be reading stuff. A friend of mine said that her grandmother always said that first-time mums, you could be having a conversation with them, but they're thinking about something else entirely. They're not hearing you."* (Kelly 2016, page 4) *"Yes the phone it's easily accessible and especially when you've got a baby. Rather than putting on the computer….I think the phone is a very good source because you keep it all the time with you. That's a very good thing, yeah"* (Jones 2014, page 5/7)	Methodological limitations	Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist	High
			Relevance	Minor concerns. Some evidence is from a substantially different context to the review question (studies focused on fever)	
			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

Table 6: Evidence summary profile for (GRADE-CERQual) theme 2. Information sources

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Level of concern**	**Overall quality**
Sub-theme K1.2.1: Internet					
5 (Kelly 2016; Neill 2015; Sahm 2016; Villarejo-Rodriguez 2019; Walsh 2007) n= 143	Qualitative studies using semi-structured interviews, interviews (unspecified) and focus groups (face-to-face)	Parents reported seeking information from web-based internet sources but could not necessarily trust the information it provided. They reported either comparing websites to get the most common views, or screening information and selecting based on websites considered credible. However, parents reported that internet searching sometimes led to more anxiety about their child's illness due to the vast amount of information available and a centralised trustworthy website will be beneficial. *"I just kind of - I'd look at three or four of them (webpages), to be honest, and compare their answers"* (Kelly 2016; page 4)	Methodological limitations	Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist	High
			Relevance	Minor concerns. Some evidence is from a substantially different context to the review question	

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
		"I have accessed the Internet, but I find it makes me more scared." (Neil 2015, page 3049) *'Trust is a big issue, 'cos there's so much information'* (Sahm 2016; page 70-71)		(studies focused on fever)	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Subtheme K1.2.2: Smartphone apps					
3 (Neill 2015; Sahm 2016; Villarejo-Rodriguez 2019) n=106	Qualitative studies using semi-structured interviews, interviews (unspecified) and focus groups (face-to-face)	Parents reported visiting smartphone apps for information due to their ease of use and the dosing of limited information at a time. *"It's when you've got a screaming child that's ill, you've got another two running around snapping at your feet and you're desperately trying to decide, work out what on earth to do with the sick child, anything that you can get an app for that you can literally press a button. . ."* (Neill 2015, page 3048)	Methodological limitations	Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	Minor concerns. Some evidence is from a substantially different context to the review question (studies focused on fever)	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns. Studies together offered some rich data.	
Subtheme K1.2.3: Media					
2 (Jones 2014; Walsh 2007) n=42	Qualitative studies using interviews (unspecified) and focus groups (face-to-face)	Parents suggested that various forms of media including digital media, television and other media reports may be a useful way to deliver information to parents. However, this may not be effective among patients with limited literacy or those with limited understanding of the English Language. *"Meningococcal, like every other mother, because you see all these things on Today Tonight and A Current Affair (National current affair shows) like that because I suppose, right or wrong, they have*	Methodological limitations	Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	Minor concerns. Some evidence is	

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
		kind of honed in that message, that you probably don't always have a lot of time." (Walsh 2007, page 2335)		from a substantially different context to the review question (studies focused on fever)	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns. Studies together offered some rich data	
Subtheme K1.2.4: Lay sources					
5 (Kelly 2016; Neill 2015; Sahm 2016; Villarejo-Rodriguez 2019; Walsh 2007) n=143	Qualitative studies using semi-structured interviews, interviews (unspecified) and focus groups (face-to-face)	Parents reported seeking advice and information first from their community (friends and family) and gave a lot of importance to this source of information. In addition, parents reported consulting online forums as supplemental to physical social networks. Nursery staff were also reported as a source of information. *We are a very close community and asking for advice for children, yeah. It does work with us. I found it works with me and if I can help someone else and look at the child, I will. I think he needs to be brought to hospital then I'll say take them in.* (Neill 2015, page 3051) *"First would be family, I would say, because I would be the youngest in my family so I have some olders that have kids"* (Kelly 2016; page 4) *"I suppose I use forums more because actually my friends are scattered throughout the country."* (Neill 2015, page 3047)	Methodological limitations	Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	Minor concerns. Some evidence is from a substantially different context to the review question (studies focused on fever)	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns. Studies together offered some rich data	
Subtheme K1.2.5: Healthcare professionals					
5 (Kelly 2016; Neill 2015; Sahm 2016; Villarejo-Rodriguez 2019;	Qualitative studies using interviews and focus groups	Parents reported that in addition to information from their community, they sought information from healthcare professionals including general practitioners (GPs), pharmacists, health visitors and NHS Direct national helpline. However, health visitors and pharmacies were the least consulted sources and parents reported the lack of desire for GPs to voluntarily offer	Methodological limitations	Minor concerns about methodological limitations of the evidence as per	Moderate

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
Walsh 2007) n=143	(face-to-face)	more information. Additionally, parents reported that although obtaining information from the NHS Direct national helpline was quicker than searching the internet and offered 24 hour access, there were some difficulties using the service such as the extensive questioning, waiting for a call back and prescribing medications when there are no local chemists. *". . .again it was me instigating it, I think I could have walked out the door quite easily without the doctor saying anything was like, "Right, what happens next in terms of worst case scenario, what should I be looking out for? And if not, you know, how long should I be expecting this to go on for, when should they be getting better?*" (Neill 2015, page 3051) *"they ask you questions that to you feel completely irrelevant, they probably are relevant but it's just really long winded and to try and get an answer and then they say, "Oh just go on hold and I'll put you through to a nurse," so I've just told you everything and I've got to tell somebody else again."* (Neill 2015, page 3051) *"I don't tend to use pharmacists that much for information for my children. . . Purely because they don't tend to be able to give me anything,. . . if they're under five they go, "Oh I'm sorry, we can't sell it to you," so I don't tend to use the pharmacist for information that much."* (Neill 2015, page 3050-3051)		CASP qualitative checklist	
			Relevance	Minor concerns. Some evidence is from a substantially different context to the review question (studies focused on fever)	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns. Studies together offered moderately rich data	
Subtheme K1.2.6: Community-based systems					
2 (Jones 2014; Walsh 2007) n=42	Qualitative studies using interviews and focus groups (face-to-face)	Parents suggested community based systems such as community champions, education in community centres, antenatal/baby clinics, and toddler groups as additional sources of information. *No quotes*	Methodological limitations	Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist	Low
			Relevance	Minor concerns. Some evidence is from a substantially different context to the review question (studies focused on fever)	
			Coherence	None or very minor	

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Level of concern**	**Overall quality**
				concerns	
			Adequacy	Serious concerns. Studies together did not offer rich data	
Subtheme K1.2.7: Experience					
3 (Jones 2014; Kelly 2016; Sahm 2016) n=65	Qualitative studies using semi-structured interviews, interviews (unspecified) and focus groups (face-to-face)	Parents reported relying on their experiences, their knowledge of their child and/or intuition to guide their management of their child's illness. *"Finding out as time goes on, and getting to know the child, and know that this is not normal today, because she's never behaved like this"* (Kelly 2016, page 4)	Methodological limitations	Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	Minor concerns. Some evidence is from a substantially different context to the review question (studies focused on fever)	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns. Studies together offered some rich data	
Subtheme K1.2.8: Education					
2 (Sahm 2016; Walsh 2007) n=36	Qualitative studies using semi-structured interviews, interviews (unspecified) and focus groups (face-to-face)	Parents reported learning about fever management from previous education in school, naming relevant subjects like biology. *No quotes*	Methodological limitations	Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist	Low
			Relevance	Minor concerns. Some evidence is from a substantially different context to	

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
				the review question (studies focused on fever)	
			Coherence	None or very minor concerns	
			Adequacy	Serious concerns. Studies together did not offer rich data	

CASP: Critical Appraisal Skills Programme; CERQual: Confidence in the Evidence from Reviews of Qualitative research; GPs: general practitioners (GPs); NHS: National Health Service.

Table 7: Evidence summary profile for (GRADE-CERQual) theme 3. Information content

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
Sub-theme K1.3.1: Detailed					
3 (Jones 2014; Villarejo-Rodriguez 2019; Walsh 2007) n= 99	Qualitative studies using interviews (unspecified) and focus groups (face-to-face)	Parents expressed the need for detailed information on all aspects of their child's illness including the diagnosis, the disease, severity, symptoms, causes, management, trajectory and when to seek professional advice *"Where I ask every question under the sun. What is it, why did they get that, how many times will they get it again?"* (Jones 2014, page 5)	Methodological limitations	Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	Minor concerns. Some evidence is from a substantially different context to the review question (studies focused on fever)	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns.	

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Level of concern**	**Overall quality**
				Studies together offered some rich data	
Sub-theme K1.3.2: Conflicting information					
1 (Walsh 2007) n=15	Qualitative study using interviews (unspecified) and focus groups (face-to-face)	Parents reported receiving conflicting information on definitions of fever and fever management. This was of particular concern when the information came from sources they considered reliable and trustworthy, creating anxiety. *"…one doctor will tell you something different to the nurse or tell you something different to the chemist. That sort of does make it a bit hard sometimes."* (Walsh 2007, page 2336)	Methodological limitations	Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	Minor concerns. Some evidence is from a substantially different context to the review question (study focused on fever)	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns. Studies together offered some rich data	

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

Table 8: Evidence summary profile for (GRADE-CERQual) theme 4. Communication

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Level of concern**	**Overall quality**
Sub-theme K1.4.1: Inadequate					
1 (De 2014) n= 36	Qualitative study using semi-structured interviews (face-to-face)	Parents reported an inadequate communication of the procedure or treatment, which left them feeling stressed and imagining the worst possibilities. *"It's hard to take all the information in and the wording is important—when they talked about the lumbar puncture that they needed to take the fluid from around the baby's brain we imagined the needle going into the head, I was standing, I felt my head spin and had to hold on to something."* (De 2014, page 721)	Methodological limitations	No concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			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	
Subtheme K1.4.2: Open					
3 (De 2014; Haines 2005, Sweeney 2013) n=288	Qualitative studies using semi-structured interviews (face-to-face),	Parents expressed that open and honest information sharing was an important part of managing their child's illness, regardless of whether it was positive or negative. *"If you are explaining that you gave someone an overdose you are being*	Methodological limitations	Minor concerns about methodological limitations of the evidence as per CASP	Low

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
	interviews (unspecified and face-to-face) and structured interviews (over the phone)	*honest. They were apologising and reaching out and communicating and respecting us and telling us the truth and even telling what the possible consequences may be. At least in the end people were honest about it. The doctors were honest about that issue and spoke to us and communicated to us. That's all we are asking for. A lot of it really is communication."* (De 2014, page 719) *'it was faultless from start to finish – from the paramedic to the hospital. They kept us informed – the good and the bad'* (Sweeney 2013, page e127)		qualitative checklist	
			Relevance	Moderate concerns. Most evidence is from a substantially different context to the review question (2 studies focused on participants with confirmed meningitis and 1 focused on fever with all participants admitted to hospital and had a complete sepsis work up)	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns. Studies together offered some rich data	
Subtheme K1.4.3: Clear					
5 (De 2014; Jones 2014; Kelly 2016; Sahm 2016; Sweeney 2013) n=351	Qualitative studies using structured and semi-structured interviews, interviews (unspecified) and focus groups (face-to-face and	Parents reported the importance of clear communication and expressed that information should be presented in simple language as well as multiple languages. However, parents were keen that information provided should not omit important details in an attempt to eliminate medical jargon. *"I did not know what they were talking about. They were talking their own language, like jargons, they said it is a UTI and I was like, 'what is that?' That's when I looked on the internet did some research of my own."* (De 2014, page 722)	Methodological limitations	Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	Moderate concerns. Most evidence is from	

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
	over the phone)	*'. . . as a parent it's always nice with very simple and straightforward guidelines that for instance when your child has a fever'* (Sahm 2016, page 71)		a 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; UTI: urinary tract infections.

Table 9: Evidence summary profile for (GRADE-CERQual) theme 5. Timing of information provision

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Level of concern	Overall quality
Sub-theme K1.5.1: Managing common childhood illnesses					
2 (Jones 2014; Walsh 2007) n= 42	Qualitative studies using interviews (unspecified) and focus groups (face-to-face)	Parents reported on the ideal times to receive information on childhood illnesses. Some believed that this information should be provided during antenatal clinics, others thought it should be provided post-delivery before the first illness, at a well-baby clinic or with the first immunisation. However, it was noted that parents may find it more challenging to embrace information in the postnatal period.	Methodological limitations	Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
		"you are very busy with the baby postnatally." (Walsh 2007, page 2337) *"I think I possibly looked at it when I was a new mum with you know, so much enthusiasm, and then about a week in I was like… I'm far too tired to do this, there's no way I'm reading through that book". (Jones 2014, page 6)*	Relevance	Minor concerns. Some evidence is from a substantially different context to the review question (study focused on fever)	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns. Studies together offered some rich data	
Sub-theme K1.5.2: Managing individual child's illness					
1 (Walsh 2007) n= 15	Qualitative study using interviews (unspecified) and focus groups (face-to-face)	Parents reported that the decision to seek information was influenced by the accessibility and availability of a doctor. Weekends and close proximity to a doctor increased advice seeking from doctors and parents reported seeking medical advice earlier than usual on a weekend. *If it is coming up to a weekend, I won't let her go for the, say if it is Friday I won't let it go for the weekend. I will get it checked in case its something like a sore throat, ears or coming down with a virus. It is reassurance for yourself.* (Walsh 2007, page 2335)	Methodological limitations	Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	Minor concerns. Some evidence is from a substantially different context to the review question (study focused on fever)	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns.	

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
				Studies together offered some rich data	

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

Table 10: Evidence summary profile for (GRADE-CERQual) theme 6. Information at diagnosis

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
4 (De 2014; Neill 2015; Sweeney 2013; Walsh 2007) n= 322	Qualitative studies using semi-structured interviews, interviews (unspecified) and focus groups (face-to-face and over the phone)	Parents reported that communication at time of diagnosis was inadequate and they would have liked more information and better communication about what was going on, for example, what is the diagnosis, and the severity of illness. *"If he gets a temperature again that means that things are not quite finished up he may have a relapse. The thing is we still don't know what it is… a virus of some sort. It is nicer to know exactly what's gone on."* (De 2014, page 720/721) *'It's just a virus.' I think how can you just look at them and say 'It's just a virus.' How do you know it's not meningitis?"* (Walsh 2007, page 2335)	Methodological limitations	Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	Moderate concerns. Most evidence is from a 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	

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall quality**
			Adequacy	None or very minor concerns	

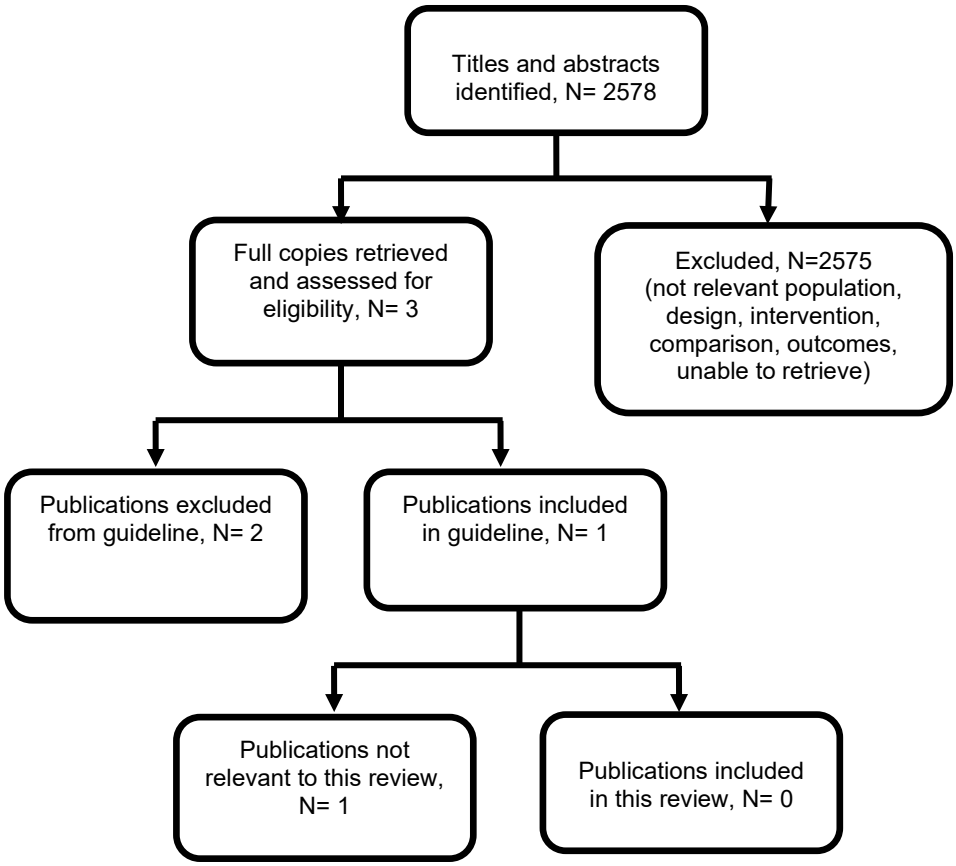
CASP: Critical Appraisal Skills Programme; CERQual: Confidence in the Evidence from Reviews of Qualitative research

Appendix G Economic evidence study selection

Study selection for: What information 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 information 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 information 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 information 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=58) and not studies (N=5) that were considered and then excluded from the search at the full-text stage as per the PRISMA diagram in Appendix C for the other review questions in the same search.

Table 11: Excluded studies and reasons for their exclusion

Study	Code [Reason]
(2018) Raising awareness of the signs and symptoms, and ensuring early diagnosis and treatment of meningococcal disease.	- Study design not of interest for review Recommendations made via expert consensus. No presentation of qualitative data
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 and no indication of suspected meningitis or meningococcal disease
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	- Phenomenon of interest not of interest for review Study is focused on how meningococcal disease is identified
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:	- Context not of interest for review Dissertation

Study	Code [Reason]
The Sciences and Engineering 57(9b): 5908	
Carter, B, Roland, D, Bray, L et al. (2020) A systematic review of the organizational, environmental, professional and child and family factors influencing the timing of admission to hospital for children with serious infectious illness. 15(7): e0236013	- Study design not of interest for review A systematic review study; individual included studies have been assessed and none meet the inclusion criteria
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	- Population not of interest for review No indication of suspected meningitis or meningococcal disease
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	- Population not of interest for review No indication of suspected meningitis or meningococcal disease
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
Hancock, Rebecca D. (2018) Qualitative analysis of older adults' experiences with sepsis.	- Context not of interest for review Dissertation

Study	Code [Reason]
Dissertation Abstracts International: Section B: The Sciences and Engineering 79(12be): No-Specified	
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 Ill 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) 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
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
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
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
Langer, T, Pfeifer, M, Soenmez, A et al. (2013) Activation of the maternal caregiving system by childhood fever--a qualitative study of the experiences made by mothers with a German or a Turkish background in the care of their	- Population not of interest for review No indication of suspected meningitis or meningococcal disease

Study	Code [Reason]
children. BMC family practice 14: 35	
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 and no indication of suspected meningitis or meningococcal disease
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 Literature review
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	- Population not of interest for review Study reports the same population as Neill 2015 which has been included in the review, and no additional themes were identified from this study
Perez, S. L, Paterniti, D. A, Wilson, M et al. (2015) Characterizing the Processes for Navigating Internet Health Information Using Real-Time Observations: A Mixed-Methods Approach. Journal of Medical Internet Research 17(7): e173	- Population not of interest for review Participants did not have suspected BM or MD but responded to clinical scenario of BM
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
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 under-five 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 Child Health (Canada) 19(6): e92	- Study design not of interest for review Systematic review of quantitative studies
Taylor-Robinson, D, Elders, K, Milton, B et al. (2010) Students' attitudes to the communications employed during an outbreak of meningococcal disease in a UK school: A qualitative study. 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	- Study design not of interest for review systematic review study, included studies have

Study	Code [Reason]
review. Patient education and counseling 103(4): 750-763	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. (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 Literature review
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	- Study design not of interest for review Literature review. Studies included were checked and none met the inclusion criteria

Study	Code [Reason]
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	
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 IMD 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 information 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.