

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

[K4] Evidence review on support for confirmed bacterial meningitis or meningococcal disease

NICE guideline number tbc

Evidence review underpinning recommendations 1.11.1, 1.11.3, 1.11.4, 1.12.14, 1.12.15, 1.13.1 to 1.13.3 and 1.13.6 in the NICE guideline

September 2023

Draft for consultation

This evidence review was developed by NICE

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1 Support for confirmed bacterial meningitis 2 or meningococcal disease

3 Review question

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

6 Introduction

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

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

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

13 Summary of the protocol

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

16 **Table 1: Summary of the protocol (PPC table)**

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

17 *OECD: Organisation for Economic Co-operation and Development*

18 For further details see the review protocol in appendix A.

1 **Methods and process**

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

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

7 **Qualitative evidence**

8 **Included studies**

9 Four studies were included in this review, 2 mixed-methods studies (Clark 2013, Wisemantel
10 2018), and 2 qualitative studies (Haines 2005, Sweeney 2013).

11 The included studies are summarised in Table 2.

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

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

16 One study was from the UK and Ireland (Clark 2013), 1 study was from England (Haines
17 2005), 1 study was from the UK (Sweeney 2013), and 1 study was from Australia
18 (Wisemantel 2018).

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

20 **Excluded studies**

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

23 **Summary of included studies**

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

25 **Table 2: Summary of included studies**
26

| Study | Population | Methods | Themes applied after thematic synthesis |
|---|---|--|---|
| Clark 2013 Grounded theory UK & Ireland | N=194; n=18 invited for interview Parent/legal guardian of children who survived meningitis and/or septicaemia. Only, those parents reporting permanent after-effects, and who | Setting: Purposive sampling from Meningitis Research Foundation members in the UK & Ireland Data collection and analysis: Semi-structured interviews (face-to-face or over the phone), analysed using the constant comparison method from grounded theory | <ul style="list-style-type: none">• Access to support• Type of support |

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

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

3 See the full evidence tables in appendix D.

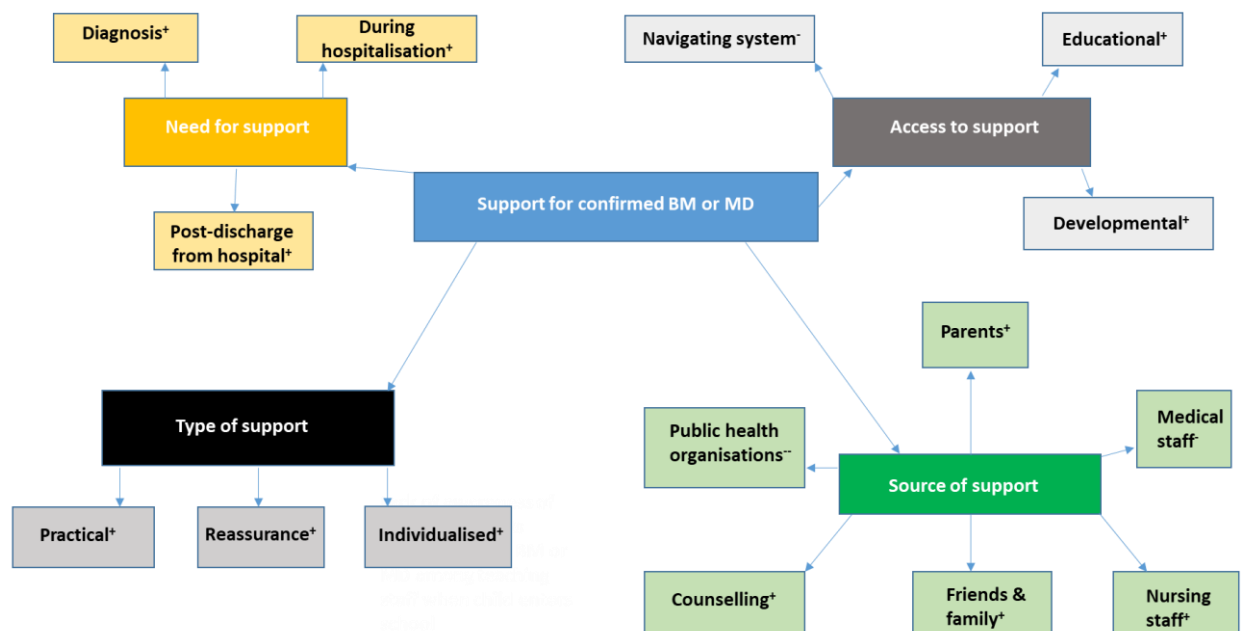
4 This was a qualitative meta-synthesis, so no quantitative meta-analysis was conducted (and
5 there are no forest plots in appendix E).

6 Summary of the evidence

7 The evidence generated 4 main themes in relation to the support valued by parents, their
8 families and carers when bacterial meningitis or meningococcal disease is confirmed. Three

1 studies provided the evidence relating to need for support, which had 3 subthemes
2 (diagnosis, during hospitalisation and post-discharge from hospital). Three studies provided
3 the evidence relating to access to support, which had 3 subthemes (navigating the system,
4 educational and developmental). Three studies provided the evidence relating to source of
5 support, which had 6 subthemes (parents, medical staff, nursing staff, friends and family,
6 counselling and public health bodies). Two studies provided the evidence relating to type of
7 support, which had 3 subthemes (individualised to child, practical and reassurance). The
8 overarching themes and subthemes were developed to allow subthemes on a common topic
9 to be grouped to aid presentation of results, without obscuring the detail included within the
10 individual subthemes. For example, the subthemes on source of support all related to
11 different sources of support that parents and carers had reported using and what their views
12 about these different sources were. The theme map (Figure 1) illustrates these overarching
13 themes and related subthemes.

14 **Figure 1: Theme map**



15

16

17 *BM: Bacterial Meningitis; MD: Meningococcal disease*

18 *+ = moderate quality evidence; - = low quality evidence; -- = very low quality evidence*

19 Whilst there was not a specific theme or subtheme about availability of support, the evidence
20 on the theme about source of support was identified. No evidence emerged relevant to the
21 theme of timing of support, that was included as a phenomenon of interest in the protocol.

22 A summary of the strength of evidence, assessed using GRADE-CERQual, is presented
23 according to the themes in the theme map above. The main reasons for downgrading were
24 due to concerns about the methodological limitations of the primary studies (for example,
25 because of a lack of consideration of the relationship between researcher and participants,
26 no justification for data collection methods as it relates to data saturation and potential for
27 recruitment bias), concerns about relevance (for example, because studies restricted the
28 population to meningococcal disease, thereby under-representing less severe forms of the
29 disease), and concerns about adequacy (for example, for review findings when evidence
30 offered no or only some or moderately rich data).

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

1 **Economic evidence**

2 **Included studies**

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

6 **Economic model**

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

10 **The committee's discussion and interpretation of the evidence**

11 **The outcomes that matter most**

12 The review focused on the views and experiences of the support provided when bacterial
13 meningitis or meningococcal disease is confirmed. The committee identified a number of
14 potential themes as illustrative of the main themes to guide the review. These themes were
15 type of support, timing of support, and availability of support. However, the potential themes
16 were not exhaustive, as the committee did not want to constrain the evidence, and an
17 emergent approach was taken to the thematic synthesis.

18 **The quality of the evidence**

19 The evidence was assessed using GRADE-CERQual methodology and the overall
20 confidence in the findings ranged from very low to moderate. Assessments of the potential
21 methodological limitations of the primary studies were undertaken using the CASP checklist,
22 and overall concerns regarding methodological limitations were rated as "minor concerns for
23 all the review findings". The most common issues were lack of consideration of the
24 relationship between researcher and participants, no justification for data collection methods
25 as it relates to data saturation and potential for recruitment bias. Concerns about relevance
26 ranged from "minor" to "serious". Minor concerns were due to studies restricting population to
27 meningococcal disease with the potential to under-represent less severe forms of the
28 disease. Serious concerns were due to the study population as well as a representation that
29 Public Health England can be contacted by the public for advice which may not be obtainable
30 in the UK. Concerns about coherence were "no or very minor" for all the review findings, as
31 there was no data that contradicted the findings nor was there ambiguous data. Concerns
32 about adequacy ranged from "no or very minor" to "serious". There were serious concerns for
33 review findings when evidence offered no rich data, moderate concerns for review findings
34 when evidence offered some rich data and minor concerns for review findings that were
35 based on evidence offering moderately rich data. The number of studies contributing to each
36 subtheme ranged from 1 to 2.

37 No evidence was identified for the theme of timing of support.

38 **Benefits and harms**

39 All the evidence identified for this review focused on the views of parents or carers. However,
40 the committee agreed that the recommendations made should apply equally to people with
41 confirmed bacterial meningitis or meningococcal disease themselves. Although, they
42 acknowledged that there may be differences in the types and delivery of support that is
43 provided to people with confirmed bacterial meningitis or meningococcal disease and their
44 parents or carers due to factors such as the developmental age of the individual. The

1 committee noted that there were no differences in the emergent themes based on whether
2 the suspected diagnosis was bacterial meningitis or meningococcal disease.

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

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

14 There was moderate quality evidence from theme 1 (need for support) and theme 4 (type of
15 support) that showed that parents would like to seek support and understanding about
16 bacterial meningitis and meningococcal disease. Moderate quality evidence from sub-theme
17 1.1 (diagnosis) highlighted that parents would like access to emotional support at diagnosis,
18 and they felt that it might be helpful to talk to someone who had insight into the situation (for
19 example, parents having gone through a similar situation) and to have specific psychosocial
20 support as it could be a very traumatic and upsetting time. The committee therefore
21 recommended that emotional support and pastoral support should be provided for people
22 with bacterial meningitis or meningococcal disease and their families and carers during
23 hospitalisation. Based on the evidence, and their clinical knowledge and experience, the
24 committee recommended that referral to psychological interventions should be considered
25 for people with bacterial meningitis or meningococcal disease who are in distress and who
26 need more specialist psychological support. The committee acknowledged that these were
27 good practice points but were aware that these needs were often unmet.

28 The evidence (sub-theme 1.3: post-discharge from hospital) showed that parents also found
29 the events following diagnosis of bacterial meningitis or meningococcal disease distressing
30 and would like emotional support after their child was discharged from hospital. Based on
31 this evidence, and their clinical knowledge and experience, the committee recommended that
32 referral to psychosocial support should be considered as part of preparing for discharge and
33 arranged for after discharge if needed.

34 The committee discussed that, based on their experience and on evidence reviewed in
35 evidence reports I1 and I2, bacterial meningitis and meningococcal disease could increase
36 the risk of poor educational outcomes. The committee reflected that this might be due to a
37 wide range of other potential long-term complications, such as cognitive deficits,
38 psychological and behavioural problems, and sensory impairment. In this review (sub-theme
39 2.2: educational), parents reported difficulties in accessing educational support for their child
40 with cognitive impairment, visual impairment, and psychosocial impairments. Therefore, the
41 committee recommended that the need for educational support should be considered as part
42 of planning for discharge, and discussions should be had with the patient's GP (and school,
43 where appropriate) to facilitate post-discharge access to educational support where this is
44 needed.

45 The committee discussed follow-up care after discharge and acknowledged that long-term
46 monitoring is required to identify latent or evolving sequelae that may not be apparent at
47 discharge (see evidence reviews I1 and I2). Sub-theme 2.1 (Navigating the system) showed
48 that parents had difficulties in accessing sufficient or timely care for their child after discharge
49 from hospital. Sub-theme 2.2 (educational) and 2.3 (developmental) also highlighted that
50 parents felt that the risk of long-term complications, including developmental impairment,
51 after bacterial meningitis were poorly understood and addressed by the health and social
52 care system, making accessing services harder. The committee agreed that people with

1 bacterial meningitis or meningococcal disease should have appropriate follow-up care with
2 appropriate services so that they receive optimal care. This was also supported by evidence
3 from sub-theme 4.1 (individualised to child) and 4.3 (reassurance), which showed that
4 parents valued support that was tailored to their child's needs and felt that appropriate follow-
5 up care would provide them with reassurance in terms of their coping skills or their child's
6 recovery. Based on this evidence, the evidence on long-term complications (evidence
7 reviews I1 and I2), and their clinical knowledge and experience, the committee
8 recommended that follow-up reviews should be arranged; at 4-6 weeks after discharge for
9 people with bacterial meningitis or meningococcal disease of any age; and at 1 year after
10 discharge for neonates and babies. These reviews should cover the neurodevelopmental,
11 orthopaedic (for meningococcal disease), sensory and psychosocial complications that were
12 identified by evidence reviews I1 and I2 to be associated with bacterial meningitis and
13 meningococcal disease.

14 **Cost effectiveness and resource use**

15 This qualitative review question did not consider decisions between competing alternatives
16 and therefore is not directly relevant to the tools of economic evaluation. Nevertheless, the
17 support recommendations made for confirmed bacterial meningitis and meningococcal
18 disease do involve the use of scarce NHS resources and the committee made a qualitative
19 assessment of their recommendations.

20 The committee considered that it would be cost-effective to arrange a review 4-6 weeks after
21 discharge from hospital in order that any complications arising from bacterial meningitis or
22 meningococcal disease could be identified to facilitate future management. The committee
23 considered that these recommendations reflected good practice and would not represent a
24 significant resource impact to the NHS. Likewise, they considered further review and follow-
25 up would be cost-effective for babies (including newborn babies), children and young people
26 as there are potential long-term complications that may not be apparent at an earlier stage.

27 **Recommendations supported by this evidence review**

28 This evidence review supports recommendations 1.11.1, 1.11.3, 1.11.4, 1.12.14, 1.12.15,
29 1.13.1 to 1.13.3 and 1.13.6. Other evidence supporting these recommendations can be
30 found in evidence reviews on information for confirmed bacterial meningitis or meningococcal
31 disease (see evidence review K3) and long-term complications and follow-up for bacterial
32 meningitis and meningococcal disease (see evidence reviews I1 and I2).

33

1 **References – included studies**

2 **Clark 2013**

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

6 **Haines 2005**

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

9 **Sweeney 2013**

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

12 **Wisemantel 2018**

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

16 **Economic**

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

18

1 Appendices

2 Appendix A Review protocols

3 Review protocol for review question: What support is valued by patients with confirmed bacterial meningitis or 4 meningococcal disease, and their families or carers?

5 **Table 3: Review protocol**

| Field | Content |
|------------------------------|---|
| PROSPERO registration number | CRD42020221151 |
| Review title | Support for confirmed bacterial meningitis or meningococcal disease |
| Review question | What support is valued by patients with confirmed bacterial meningitis or meningococcal disease, and their families or carers? |
| Objective | To determine what support is valued by patients with confirmed bacterial meningitis or meningococcal disease and their families or carers. |
| Searches | <p>The following databases will be searched:</p> <ul style="list-style-type: none">Cochrane Central Register of Controlled Trials (CENTRAL)Cochrane Database of Systematic Reviews (CDSR)EmbaseMEDLINEPsycInfoEmcare or Cinahl <p>Searches will be restricted by:</p> <ul style="list-style-type: none">Date limitations: studies after 2000English languageHuman studies <p>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 using an adaptation of the PRESS 2015</p> |

| Field | Content |
|---|--|
| | Guideline Evidence-Based Checklist. |
| Condition or domain being studied | People with confirmed bacterial meningitis or meningococcal disease |
| Population | <p>Inclusion:</p> <ul style="list-style-type: none"> • People with confirmed bacterial meningitis or meningococcal disease. • Parents or carers of babies, children, and young people with confirmed bacterial meningitis or meningococcal disease. • Families or carers of adults with confirmed bacterial meningitis or meningococcal disease. <p>Exclusion:</p> <p>People and families or carers of people:</p> <ul style="list-style-type: none"> • with known immunodeficiency. • who have brain tumours, pre-existing hydrocephalus, intracranial shunts, previous neurosurgical procedures, or known cranial or spinal anomalies that increase the risk of bacterial meningitis. • with confirmed viral meningitis or viral encephalitis. • with confirmed tuberculous meningitis. • with confirmed fungal meningitis • suspected bacterial meningitis or meningococcal disease <p>The views of staff caring for people with suspected or confirmed bacterial meningitis or meningococcal disease.</p> |
| Phenomenon of interest | Views and experiences of support available when bacterial meningitis and/or meningococcal disease is confirmed. |
| Comparator/Reference standard/Confounding factors | Not applicable |
| Types of study to be included | <p>Qualitative methods: systematic reviews of qualitative studies and primary qualitative studies, including semi-structured and structured interviews, focus groups, observations and surveys with open-ended questions.</p> <p>Exclusions:</p> <ul style="list-style-type: none"> • Quantitative studies (including surveys reporting only quantitative data) • Surveys which quantify open-ended answers for analysis • Conference abstracts |
| Other exclusion criteria | <p>Countries other than OECD high income European countries, Australia, New Zealand and Canada.</p> <p>Studies conducted prior to 2000 as microbiology has not changed much since 2000 and most relevant interventions (for</p> |

| Field | Content |
|---|---|
| | example, steroids) were available by then. Studies published not in English-language |
| Context | This guidance will fully update the following: Meningitis (bacterial) and meningococcal septicaemia in under 16s: recognition, diagnosis and management (CG102) |
| Primary outcomes (critical outcomes) | 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): <ul style="list-style-type: none"> • Type of support • Timing of support • Availability of support |
| Secondary outcomes (important outcomes) | Not applicable |
| Data extraction (selection and coding) | All references identified by the searches and from other sources will be uploaded into STAR and de-duplicated. Titles and abstracts of the retrieved citations will be screened to identify studies that potentially meet the inclusion criteria outlined in the review protocol. Dual sifting will not be undertaken for this question. Full versions of the selected studies will be obtained for assessment. Studies that fail to meet the inclusion criteria once the full version has been checked will be excluded at this stage. Each study excluded after checking the full version will be listed, along with the reason for its exclusion. A standardised form will be used to extract data from studies. The following data will be extracted: study details (reference, country where study was carried out, type and dates), recruitment strategy, participant characteristics, setting, methods of data collection and analysis, relevant findings and source of funding. One reviewer will extract relevant data into a standardised form, and this will be quality assessed by a senior reviewer. |
| Risk of bias (quality) assessment | Quality assessment of individual studies will be performed using the following checklists: <ul style="list-style-type: none"> • 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 |

| Field | Content | | |
|--|--|-------------------------------------|-------------------------------------|
| | of richness and quantity of findings | | |
| Analysis of sub-groups | <p>Formal subgroup analyses are not appropriate for this question due to qualitative data, but the views and experiences of the following groups will be considered separately, where possible: Confirmed diagnosis (Bacterial meningitis or meningococcal disease). Population.</p> <ul style="list-style-type: none"> • Patients aged 18 years or over and their families or carers • Patients aged under 18 years • Parents or carers of patients under 18 years | | |
| Type and method of review | <input type="checkbox"/> | Intervention | |
| | <input type="checkbox"/> | Diagnostic | |
| | <input type="checkbox"/> | Prognostic | |
| | <input checked="" type="checkbox"/> | Qualitative | |
| | <input type="checkbox"/> | Epidemiologic | |
| | <input type="checkbox"/> | Service Delivery | |
| | <input type="checkbox"/> | Other (please specify) | |
| 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 | <input checked="" type="checkbox"/> | <input checked="" type="checkbox"/> |
| | Piloting of the study selection process | <input checked="" type="checkbox"/> | <input checked="" type="checkbox"/> |
| | Formal screening of search results against eligibility criteria | <input checked="" type="checkbox"/> | <input checked="" type="checkbox"/> |
| | Data extraction | <input checked="" type="checkbox"/> | <input checked="" type="checkbox"/> |

| Field | Content | | | | | | |
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| | <table border="1"> <tr> <td>Risk of bias (quality) assessment</td> <td><input checked="" type="checkbox"/></td> <td><input checked="" type="checkbox"/></td> </tr> <tr> <td>Data analysis</td> <td><input checked="" type="checkbox"/></td> <td><input checked="" type="checkbox"/></td> </tr> </table> | Risk of bias (quality) assessment | <input checked="" type="checkbox"/> | <input checked="" type="checkbox"/> | Data analysis | <input checked="" type="checkbox"/> | <input checked="" type="checkbox"/> |
| Risk of bias (quality) assessment | <input checked="" type="checkbox"/> | <input checked="" type="checkbox"/> | | | | | |
| Data analysis | <input checked="" type="checkbox"/> | <input checked="" type="checkbox"/> | | | | | |
| Named contact | <p>Named contact: National Guidelines Alliance</p> <p>Named contact e-mail: meningitis&meningococcal@nice.org.uk</p> <p>Organisational affiliation of the review: National Institute for Health and Care Excellence (NICE) and National Guideline Alliance</p> | | | | | | |
| 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=CRD42020221151 | | | | | | |
| Dissemination plans | NICE may use a range of different methods to raise awareness of the guideline. These include standard approaches such as: <ul style="list-style-type: none"> 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, support, qualitative | | | | | | |

| Field | Content | |
|--|--|--|
| Details of existing review of same topic by same authors | None | |
| Current review status | <input type="checkbox"/> | Ongoing |
| | <input checked="" type="checkbox"/> | Completed but not published |
| | <input type="checkbox"/> | Completed and published |
| | <input type="checkbox"/> | Completed, published and being updated |
| | <input type="checkbox"/> | Discontinued |
| Additional information | None | |
| Details of final publication | www.nice.org.uk | |

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

1 Appendix B Literature search strategies

2 Literature search strategies for review question: What support is valued by
3 patients with confirmed bacterial meningitis or meningococcal disease, and
4 their families or carers?
5

6 Clinical Search

7
8 This was a combined search to cover this review (K4), evidence review K3 on information for
9 confirmed bacterial meningitis and/or meningococcal disease, and evidence reviews K1 and
10 K2 on information for suspected bacterial meningitis and/or meningococcal disease and
11 support for suspected bacterial meningitis and/or meningococcal disease.
12

13 **Database(s): Medline, Embase & PsycINFO (Multifile) – OVID interface**
14 **Embase Classic+Embase** 1947 to 2021 July 13, **Ovid MEDLINE(R) ALL** 1946 to July 13,
15 2021, **APA PsycINFO** 1806 to July Week 1 2021
16 Date of last search: 14 July 2021
17 *Multifile database codes: emczd = Embase Classic+Embase; ppez = MEDLINE(R) ALL; psych =*
18 *PsycINFO*

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

| # | 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 psych |
| 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-look* or healthcareseek* or healthcare-look* or healthseek* or health-look* or care-look* 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 caregiver* 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 psych |
| 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 psych |
| 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 |

1

2

Database(s): Cochrane Library – Wiley interface

3

Cochrane Database of Systematic Reviews, Issue 7 of 12, July 2021, Cochrane Central Register of Controlled Trials, Issue 7 of 12, July 2021

4

Date of last search: 14 July 2021

5

| # | Searches |
|----|---|
| #1 | MeSH descriptor: [Meningitis] this term only |
| #2 | MeSH descriptor: [Meningitis, Bacterial] this term only |

| # | Searches |
|-----|---|
| #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 influenza*" or "hemophilus influenza*" or "h influenza*" 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 influenza*" or "hemophilus influenza*" or "h influenza*" 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] |
| #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 |

| # | Searches |
|-----|---|
| #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 caregiver* or "care giv*") NEAR/3 (advice or inform* or support* or guidance)):ti,ab,kw |
| #73 | ((information* NEAR/3 (model* or program* or need* or require* or seek* or access* or dissem* or shar* or provid* or provision))):ti,ab,kw |
| #74 | ((inform* or support*) NEAR/3 (help* or support* or benefi* or hinder* or hindran* or barrier* or facilitate* or practical* or clear* or accurate*)):ti,ab,kw |
| #75 | ((information* or support* or advice or guidance) NEAR/3 (type* or content* or method* or quality or format*)):ti,ab,kw |
| #76 | ("information sheet"):ti,ab,kw |
| #77 | ("patient guidance"):ti,ab,kw |
| #78 | #19 OR #20 OR #21 OR #22 OR #23 OR #24 OR #25 OR #26 OR #27 OR #28 OR #29 OR #30 OR #31 OR #32 OR #33 OR #34 OR #35 OR #36 OR #37 OR #38 OR #39 OR #40 OR #41 OR #42 OR #43 OR #44 OR #45 OR #46 OR #47 OR #48 OR #49 OR #50 OR #51 OR #52 OR #53 OR #54 OR #55 OR #56 OR #57 OR #58 OR #59 OR #60 OR #61 OR #62 OR #63 OR #64 OR #65 OR #66 OR #67 OR #68 OR #69 OR #70 OR #71 OR #72 OR #73 OR #74 OR #75 OR #76 OR #77 |
| #79 | #18 AND #78 |
| #80 | MeSH descriptor: [Acute Disease] this term only |
| #81 | MeSH descriptor: [Fever] this term only |
| #82 | MeSH descriptor: [Sepsis] this term only |
| #83 | MeSH descriptor: [Bacterial Infections] this term only |
| #84 | ((acute* NEAR/2 (ill or illness)) or fever or sepsis or bacter?emia or (bacteria* adj infection*)):ti |
| #85 | #80 or #81 or #82 or #83 or #84 |
| #86 | #78 AND #85 |
| #87 | ((appropriat* NEXT informat*)):ti,ab,kw |
| #88 | (#18 OR #85) AND #87 |
| #89 | #79 OR #86 OR #88 |

1

2 **Database(s): Emcare – OVID interface**3 **Emcare 1995 to present**4 **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 meningoenzephalitis/ |
| 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 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 health 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/ |
| 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 |

| # | Searches |
|----|---|
| | 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 caregiver* or care giv*) adj3 (advice or inform* or support* or guidance)).tw. |
| 20 | (information* adj3 (model* or program* or need* or require* or seek* or access* or dissem* or shar* or provid* or provision)).tw. |
| 21 | ((inform* or support*) adj3 (help* or support* or benefi* or hinder* or hindran* or barrier* or facilitate* or practical* or clear* or accurate)).tw. |
| 22 | ((information* or support* or advice or guidance) adj3 (type* or content* or method* or quality or format)).tw. |
| 23 | information sheet.tw. |
| 24 | patient guidance.tw. |
| 25 | or/12-24 |
| 26 | Qualitative Research/ or exp interview/ |
| 27 | interview*.tw. |
| 28 | thematic analysis/ |
| 29 | (theme* or thematic).mp. |
| 30 | qualitative.af. |
| 31 | questionnaire\$.mp. |
| 32 | ethnological research.mp. |
| 33 | ethnograph*.mp. |
| 34 | ethnonursing.af. |
| 35 | phenomenol*.af. |
| 36 | (life stor* or women* stor*).mp. |
| 37 | (grounded adj (theor* or study or studies or research or analys?s)).af. |
| 38 | ((data adj1 saturat\$) or participant observ\$).tw. |
| 39 | (field adj (study or studies or research)).tw. |
| 40 | biographical method.tw. |
| 41 | theoretical sampl\$.af. |
| 42 | ((purpos\$ adj4 sampl\$) or (focus adj group\$)).af. |
| 43 | open ended questionnaire/ |
| 44 | ((open end* or openend*) adj3 questionnaire*).tw. |
| 45 | (account or accounts or unstructured or openended or open ended or text\$ or narrative\$.mp. |
| 46 | (life world or life-world or conversation analys?s or personal experience\$ or theoretical saturation).mp. |
| 47 | ((lived or life) adj experience\$.mp. |
| 48 | narrative analys?s.af. |
| 49 | parental attitude/ or patient satisfaction/ or patient preference/ or personal experience/ |
| 50 | (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/ |
| 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/ |

| # | Searches |
|----|----------------------|
| 80 | exp rodent/ |
| 81 | Animals, Laboratory/ |
| 82 | exp Animal Studies/ |
| 83 | exp RODENTS/ |
| 84 | or/62-83 |
| 85 | 61 not 84 |

1

2 **Economic Search**

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

4

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

7 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 |

8

9 **Database(s): Medline & Embase (Multifile) – OVID interface**10 **Embase Classic+Embase 1947 to 2021 March 10, Ovid MEDLINE(R) and Epub Ahead of**
11 **Print, In-Process & Other Non-Indexed Citations and Daily 1946 to March 09, 2021**

12 Date of last search: 11 March 2021

13 *Multifile database codes: emczd = Embase Classic+Embase; ppez= MEDLINE(R) and Epub Ahead of*
14 *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. |
| 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 |

| # | Searches |
|----|--|
| 14 | (meningococc* adj3 (sepsis* or septic* or toxic* or endotoxic* or disease? or infection?)).ti,ab. |
| 15 | (meningococcus* or meningococci* or meningococc?emi?).ti,ab. |
| 16 | (Neisseria* mening* or n mening*).ti,ab. |
| 17 | or/11,13-16 |
| 18 | Economics/ use ppez |
| 19 | Value of life/ use ppez |
| 20 | exp "Costs and Cost Analysis"/ use ppez |
| 21 | exp Economics, Hospital/ use ppez |
| 22 | exp Economics, Medical/ use ppez |
| 23 | Economics, Nursing/ use ppez |
| 24 | Economics, Pharmaceutical/ use ppez |
| 25 | exp "Fees and Charges"/ use ppez |
| 26 | exp Budgets/ use ppez |
| 27 | health economics/ use emczd |
| 28 | exp economic evaluation/ use emczd |
| 29 | exp health care cost/ use emczd |
| 30 | exp fee/ use emczd |
| 31 | budget/ use emczd |
| 32 | funding/ use emczd |
| 33 | budget*.ti,ab. |
| 34 | cost*.ti. |
| 35 | (economic* or pharmaco?economic*).ti. |
| 36 | (price* or pricing*).ti,ab. |
| 37 | (cost* adj2 (effective* or utilit* or benefit* or minimi* or unit* or estimat* or variable*)).ab. |
| 38 | (financ* or fee or fees).ti,ab. |
| 39 | (value adj2 (money or monetary)).ti,ab. |
| 40 | or/18-39 |
| 41 | Quality-Adjusted Life Years/ use ppez |
| 42 | Sickness Impact Profile/ |
| 43 | quality adjusted life year/ use emczd |
| 44 | "quality of life index"/ use emczd |
| 45 | (quality adjusted or quality adjusted life year*).tw. |
| 46 | (qaly* or qal or qald* or qale* or qtime* or qwb* or daly).tw. |
| 47 | (illness state* or health state*).tw. |
| 48 | (hui or hui2 or hui3).tw. |
| 49 | (multiattribute* or multi attribute*).tw. |
| 50 | (utilit* adj3 (score*1 or valu* or health* or cost* or measur* or disease* or mean or gain or gains or index*)).tw. |
| 51 | utilities.tw. |
| 52 | (eq-5d* or eq5d* or eq-5* or eq5* or euroqual* or euro qual* or euroqual 5d* or euro qual 5d* or euro qol* or euroqol* or euro quol* or 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. |
| 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/ |

| # | Searches |
|-----|--|
| 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 |

1

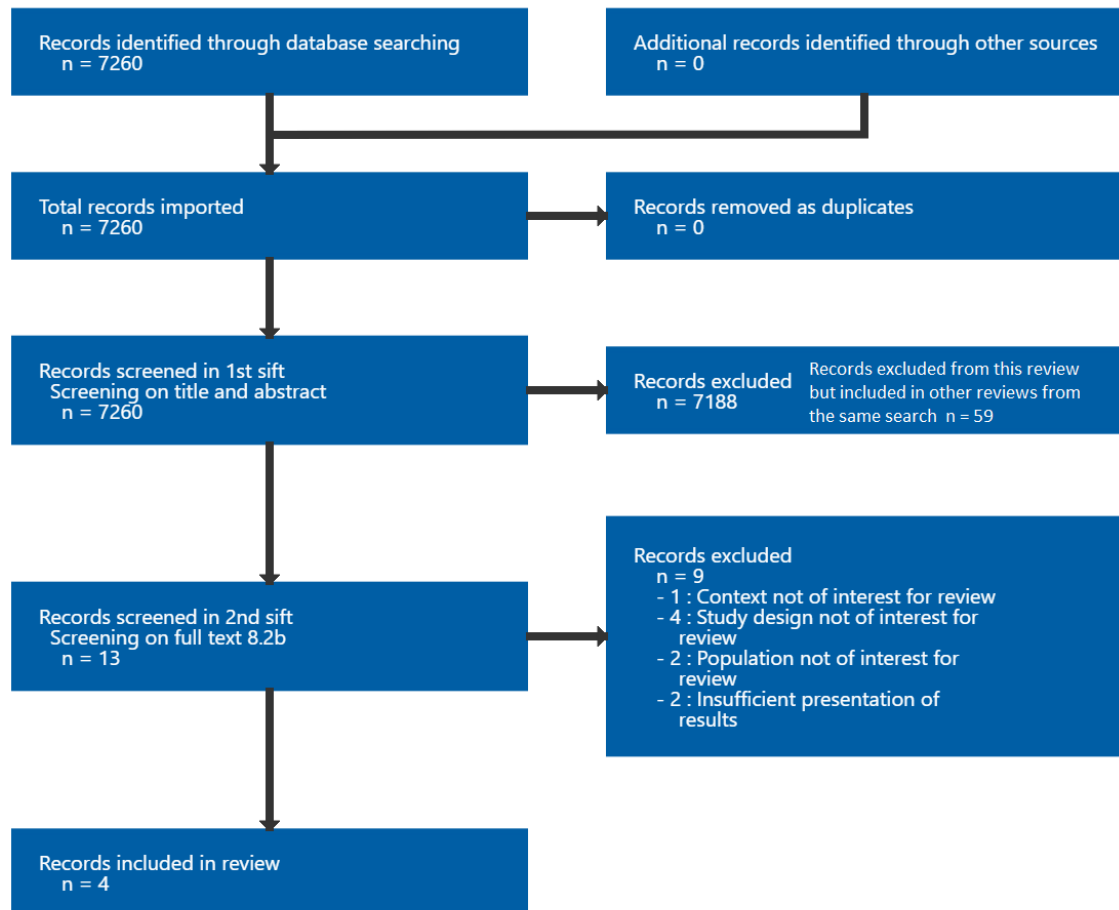
2

1 Appendix C Qualitative evidence study selection

2 Study selection for: What support is valued by patients with confirmed 3 bacterial meningitis or meningococcal disease, and their families or carers?

4 Figure 2: Study selection flow chart

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1 Appendix D Evidence tables

2 Evidence tables for review question: What support is valued by patients with confirmed bacterial meningitis or 3 meningococcal disease, and their families or carers?

4 Table 4: Evidence tables – qualitative evidence

5 Clark, 2013

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

6

7 Study Characteristics

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

| | |
|------------------------------------|---|
| | the disease in the last six months. |
| Sample size | Survey n=194 Interviews n = 18 |
| Participant characteristics | Survey n = 194 Meningitis n= 76 Septicaemia n = 16 Both meningitis and septicaemia n = 102 Mean age of children at the time of illness = 3.83 years Median time since illness = 5 years |
| Results | <p>Themes (information in bullet points are theme(s) applied after thematic synthesis)</p> <p>Original theme: Accessing appropriate support and follow-up care: Navigating the system.</p> <ul style="list-style-type: none"> • Information on discharge from hospital <ul style="list-style-type: none"> ○ Navigating the system <ul style="list-style-type: none"> ▪ P1: “Because her needs are so complicated and they’re in so many different areas... there is physio, speech and language, OT, neurology...so many different people for us to learn, to keep up with and to learn the language, we didn’t know what to ask...we’re just completely ... overwhelmed.” page 4 • Access to support <ul style="list-style-type: none"> ○ Navigating the system <ul style="list-style-type: none"> ▪ P8: “He’s now gone into a specialist educational provision and now because they’re on-site he’s kind of accessing all those services again on a really regular basis.” page 4 <p>Original theme: Accessing appropriate support and follow-up care: Poorly appreciated link between meningitis and sequelae</p> <ul style="list-style-type: none"> • Access to support <ul style="list-style-type: none"> ○ Educational <ul style="list-style-type: none"> ▪ P2: “You look at him against all his other class and you wouldn’t straight away say this is the child |

who's had meningitis, this is the child who can't hear in one ear, this is the child who struggles in these areas of social behaviour ...so just trying to access any extra help in school is like pulling teeth." page 5

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

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

Original theme: Communication: Debrief before discharge

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

Original theme: Communication: Involving parents

- Communication
 - Standardised
 - P3: "[Hospital] said, 'he might be ok you know he might have problems, but you won't know at the moment' ...which I felt wasn't really helpful either because it was kind of like well you have to go home and you just wait and see how he turns out...I don't think I had the right support for that." page 5-6

| | |
|--|---|
| | <ul style="list-style-type: none"> ○ Involving parents <ul style="list-style-type: none"> ▪ P7: “The fact that he’d had an assessment [at school] and I don’t know what the outcome is... I don’t know if that’s in anyway had any bearing on what’s happening with him now.” page 6 <p>Original theme: Communication: Healthcare professionals</p> <ul style="list-style-type: none"> • Communication <ul style="list-style-type: none"> ○ Enhanced communication between healthcare professionals <ul style="list-style-type: none"> ▪ P15: “They’ve just given her some words to practise, she doesn’t say the endings of any of the words ... probably because she can’t hear them...speech and language can’t sort her hearing out, they can just try and help her with pronouncing the words, but if she can’t hear them then they’re hitting their heads against a brick wall.” Page 6 ▪ P13: “... and nothing was ever planned without [consultant]’s say so...to me that said we have got your son’s best interests at heart we have a plan and we know what we’re doing.” page 6 |
|--|---|

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2 **Critical appraisal**

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

3

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5 **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 |
|--------------------------------|--|

6

7 **Study Characteristics**

| | |
|-------------------|------------------|
| 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 | 7 parents |
| Participant characteristics | Parents n = 7 No further details reported |
| Results | <p>Themes (information in bullet points are theme(s) applied after thematic synthesis)</p> <p>Original theme: Complications/side effects of the disease</p> <ul style="list-style-type: none"> • Information during hospitalisation <ul style="list-style-type: none"> ○ Complications of the disease <ul style="list-style-type: none"> ▪ 'It was such a shock, I thought children with meningitis they either lived or they died. I didn't think that they survived with problems . . . and if they lived it was just a course of antibiotics like you, perhaps you'd even have them at home or something and umm. . . it would be fine'. Isabelle page 81 ▪ 'I watched the rash turn black, the areas of tissue dying and turning black and hard scabs forming on the surface, and I thought that was it. I didn't realize that those wounds went so deep underneath . . . and I watched that, those areas happen and uhhh with all the weeping and the blisters appearing and all these horrid things that happen after the bug umm . . . you know stops killing the tissue and I |

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

Original theme: Child's physical appearance

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

Original theme: Need for support and understanding

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

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

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

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

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

2 **Critical appraisal**

| Section | Question | Answer |
|------------------------------------|----------------------|--|
| Overall risk of bias and relevance | Overall risk of bias | Minor concerns <i>(Concerns around data saturation not discussed)</i> |

3

4 **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

5 **Study Characteristics**

| | |
|--|---|
| 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 | 244 parents |
| Participant characteristics | No details reported |
| Results | <p>Themes (information in bullet points are theme(s) applied after thematic synthesis)</p> <p>Original theme: Medical follow-up care</p> <ul style="list-style-type: none"> • Access to support <ul style="list-style-type: none"> ○ Developmental <ul style="list-style-type: none"> ▪ 'more follow ups for the next 18 months to check how the child progresses. Maybe every 3 months to see if child progresses normally'. page e128 ▪ 'I wouldn't say he was a really naughty child but at home he seems not to listen or pay attention. I am not sure if he has behavioural problems... I would like to know about that'. page e128 <p>Original theme: Recognition of and provision for additional needs: emotional</p> <ul style="list-style-type: none"> • Need for support <ul style="list-style-type: none"> ○ Diagnosis <ul style="list-style-type: none"> ▪ 'It is very traumatic, it's a very upsetting time...it might be helpful to have counselling. I had been told that there was a chance that [child] could die'. page e128 ○ Post-discharge from hospital <ul style="list-style-type: none"> ▪ 'It is haunting now and I still feel very sad as I feel there are two [child's name]...before and after the illness and two me's. I don't know what support I need...it's with me every day and it fuels every |

aspect of how I parent her. It feels like I've taken a deep breath and never exhaled" page e128

- Sources of support
 - Parents
 - No quotes
 - Counselling
 - 'It is very traumatic, it's a very upsetting time...it might be helpful to have counselling. I had been told that there was a chance that [child] could die'. page e128
 - 'It is haunting now and I still feel very sad as I feel there are two [child's name]...before and after the illness and two me's. I don't know what support I need...it's with me every day and it fuels every aspect of how I parent her. It feels like I've taken a deep breath and never exhaled'. page e128

Original theme: Recognition of and provision for additional needs: Practical

- Type of support
 - Practical
 - 'some information or a leaflet about what to do financially if your child is hospitalized' page e128
 - 'her home has still not been adapted for a wheelchair-bound, visually impaired child with severe learning difficulties. We still require someone to help us to access the services she needs'. page e128

Original theme: Recognition and provision of additional needs: Educational

- Access to support
 - Educational
 - No quotes

Original theme: Reassurance

- Type of support
 - Reassurance
 - 'For two years I was completely changed - my nerves - I was like a woman possessed. I would've liked someone to talk to and reassure us about things'. page e128

1 *MOSAID: meningococcal outcome study in adolescents and in children*

2 **Critical appraisal**

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

1
23 **Wisemantel, 2018**

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

4 **Study Characteristics**

| | |
|--|--|
| Study type | General qualitative inquiry |
| Country/ies where study was carried out | Australia |
| Setting | A regional area of northern New South Wales, Australia that includes a large city, regional centres, and rural and remote areas. |
| Data collection and analysis | Semi structured interviews (range from 20 to 50 minutes, average 45 minutes) conducted in families homes or workplace. Parents were asked who provided support during the illness, what worked, and their opinions on what could have been done differently to make the experience with the illness easier during admissions. Data analysed using thematic analysis with inductive and deductive techniques. |
| Recruitment strategy | A convenience sample of parents who had experienced a child or young person with an invasive Meningococcal Disease (IMD) within the previous 5-6 years. Parents were selected based on the outcome for the child to include only families who did not experience their child dying, being revived, or ventilated. |
| Study dates | 2010-2012 |
| Sources of funding | Not industry funded |
| Inclusion criteria | <ul style="list-style-type: none"> • IMD admissions within the 2010–2012 period recorded in the study region • parents were selected based on the outcome for the child to include only families who did not experience their child |

| | |
|------------------------------------|--|
| | dying, being revived, or ventilated |
| Exclusion criteria | Not reported |
| Sample size | n = 6 |
| Participant characteristics | Parents n=6 |
| Results | <p>Themes (information in bullet points are theme(s) applied after thematic synthesis)</p> <p>Original theme: Support Needs: Support During and After; Support as a Coping Strategy; Support from Hospital Staff; and Follow-up Support</p> <ul style="list-style-type: none"> • Need for support <ul style="list-style-type: none"> ○ During hospitalisation <ul style="list-style-type: none"> ▪ No quotes ○ Post-discharge from hospital <ul style="list-style-type: none"> ▪ "Maybe a counselling session for parents and grandparents or whoever...to go in and sit down and talk to somebody...afterwards, after you get that breath and you go right ...“Wow! That was huge”. More so after what you have just been through, that would have been really helpful". page 483 • Access to support <ul style="list-style-type: none"> ○ Developmental <ul style="list-style-type: none"> ▪ "It would have been good to have the specialist or someone to go over and do a few tests...just to give you a little peace of mind...just to definitely check that nothing else, side effects have happened because of it". page 483 • Source of support <ul style="list-style-type: none"> ○ Nursing staff <ul style="list-style-type: none"> ▪ “The nurses say, ‘Are you alright?’ and you say ‘yeah’, you know you are not really, but you don’t know what else to say because you have got to be strong”. page 484 ▪ "The nurses were great. You know he [son] wouldn’t let me leave the room and I really needed coffee...and there were a couple of nurses that were really, really good...and there was a nurse who ended sitting with my son so I could have a coffee and just go away for ten minutes. page 484 ○ Friends and family <ul style="list-style-type: none"> ▪ My husband was with [him] most of the time...we were doing the shifts...we sort of took it in turn...and my mum was coming up as well and helping”. Another mother described how they were just hanging on through the stress “like it was sort of one go home and sleep, one stay over...I actually shut |

down...and you are just holding on". page 483

- Family and friends come nearly every day and every night...some would bring me dinner, stay with my son while I went and had a shower or sleep...so there were forever people around me...when people came in, they would ask how he is going today...but then it would just carry on...so there wasn't a lot of conversation on the disease. page 483
- Counselling
 - "Maybe a counselling session for parents and grandparents or whoever...to go in and sit down and talk to somebody...afterwards, after you get that breath and you go right ...“Wow! That was huge”. More so after what you have just been through, that would have been really helpful". page 483
- Public Health bodies
 - "The [Population Health nurse consultant] I had originally spoken to, he knew more about it [IMD] than what the doctors did so I just called him if I wasn't sure about something". page 484

1 *IMD: invasive meningococcal disease*

2 **Critical appraisal**

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

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

1

2 **Appendix E Forest plots**

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

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

1 Appendix F GRADE-CERQual tables

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

4 Table 5: Evidence summary profile for theme 1 (Need for support)

| Study information | | | CERQual assessment of the evidence | | |
|--|--|--|------------------------------------|---|-----------------|
| Number of studies | Design | Description of theme or finding | Criteria | Level of concern | Overall quality |
| Sub-theme 1.1: Diagnosis | | | | | |
| 1 (Sweeney 2013) n=244 | Qualitative study using structured interviews (over the phone) | Parents reported that they would have liked access to emotional support at diagnosis. Parents mentioned that talking to somebody who had insight into the situation, for example parents having gone through a similar situation or specific counselling services. <i>'It is very traumatic, it's a very upsetting time...it might be helpful to have counselling. I had been told that there was a chance that [child] could die'.</i> (Sweeney 2013, page e128) | Methodological limitations | Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist | Moderate |
| | | | Relevance | Minor concerns. Population restricted to MD. Less severe forms of disease under represented | |
| | | | Coherence | None or very minor concerns | |
| | | | Adequacy | Moderate concerns. Studies together offered some rich data | |
| Sub-theme 1.2: During hospitalisation | | | | | |
| 2 (Haines 2005; Wisemantel 2018) | Qualitative studies using semi-structured | Parents reported that they sought support and understanding from different sources during the hospitalisation period, for example nursing staff, other parents, and family and friends. | Methodological limitations | Minor concerns about methodological limitations of the | Moderate |

| Study information | | Description of theme or finding | CERQual assessment of the evidence | | | |
|--|---|---|------------------------------------|---|-----------------|---|
| Number of studies | Design | | Criteria | Level of concern | Overall quality | |
| n=14 | interviews (face-to-face) | <i>'They'd try (other parents) and cheer you up a bit if they saw you going past in a bit of state.'</i> (Haines 2005, Molly page 84) | | evidence as per CASP qualitative checklist | | |
| | | | Relevance | Minor concerns. Population restricted to MD. Less severe forms of disease under represented | | |
| | | | Coherence | None or very minor concerns | | |
| | | | Adequacy | Minor concerns. Studies together offered moderately rich data | | |
| Sub-theme 1.3: Post-discharge from hospital | | | | | | |
| 2 (Sweeney 2013; Wisemantel 2018) | Qualitative studies using structured and semi-structured interviews (over the phone and face-to-face) | Parents reported that it would have been helpful to have emotional support after their child was discharged from hospital. Parents reported that the events following diagnosis of meningitis and meningococcal disease were distressing and they often didn't process what had happened until after their child was at home. <i>'It is haunting now and I still feel very sad as I feel there are two [child's name]...before and after the illness and two me's. I don't know what support I need...it's with me every day and it fuels every aspect of how I parent her. It feels like I've taken a deep breath and never exhaled'</i> (Sweeney, page e128) <i>'Maybe a counselling session for parents and grandparents or whoever...to go in and sit down and talk to somebody...afterwards, after you get that breath and you go right ..."Wow! That was huge". More so after what you have just been through, that would have been really helpful'</i> . (Wisemantel 2018, page 483) | Methodological limitations | Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist | Moderate | |
| n=250 | | | | Relevance | | Minor concerns. Population restricted to MD. Less severe forms of disease under represented |
| | | | | Coherence | | None or very minor concerns |
| | | | | | | |

| Study information | | | CERQual assessment of the evidence | | |
|-------------------|--------|---------------------------------|------------------------------------|---|-----------------|
| Number of studies | Design | Description of theme or finding | Criteria | Level of concern | Overall quality |
| | | | Adequacy | Minor concerns. Studies together offered moderately rich data | |

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

2 **Table 6: Evidence summary profile for theme 2 (Access to support)**

| Study information | | | CERQual assessment of the evidence | | |
|---|---|--|--|--|-----------------|
| Number of studies | Design | Description of theme or finding | Criteria | Level of concern | Overall quality |
| Sub-theme 2.1: Navigating the system | | | | | |
| 1 (Clark 2013) n=18 | Qualitative study using semi-structured interviews (face-to-face or over the phone) | Parents reported difficulties in accessing sufficient or timely care for their child after discharge from hospital. Parents reported that where the child had a statement of educational needs the school could prove extremely useful in provision of services, making access to aftercare and support more frequent, with fewer delays. <i>“He’s now gone into a specialist educational provision and now because they’re on-site he’s kind of accessing all those services again on a really regular basis.”</i> (Clark 2013, P8 page 4) | Methodological limitations Relevance Coherence Adequacy | Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist Minor concerns. Less severe forms of disease under represented None or very minor concerns Serious concerns. Studies together did not offer rich data | Low |
| Sub-theme 2.2: Educational | | | | | |
| 2 (Clark 2013; Sweeney 2013) | Qualitative studies using structured and | Parents reported difficulties in accessing educational support for their child with less visible, psychosocial and cognitive impairment after meningitis. Parents highlighted that the link between acute meningitis and long-term complications | Methodological limitations | Minor concerns about methodological | Moderate |

| Study information | | Description of theme or finding | CERQual assessment of the evidence | | |
|--|---|---|---|--|-----------------|
| Number of studies | Design | | Criteria | Level of concern | Overall quality |
| n=262 | semi-structured interviews (over the phone and face-to-face) | <p>were poorly understood and addressed by the health and social care system, making accessing services harder.</p> <p><i>“You look at him against all his other class and you wouldn’t straight away say this is the child who’s had meningitis, this is the child who can’t hear in one ear, this is the child who struggles in these areas of social behaviour ...so just trying to access any extra help in school is like pulling teeth.”</i> (Clark 2013, P2 page 5)</p> | <p>Relevance</p> <p>Coherence</p> <p>Adequacy</p> | <p>limitations of the evidence as per CASP qualitative checklist</p> <p>Minor concerns. Less severe forms of disease under represented</p> <p>None or very minor concerns</p> <p>Minor concerns. Studies together offered moderately rich data</p> | |
| Sub-theme 2.3: Developmental | | | | | |
| 2 (Sweeney 2013; Wisemantel 2018) n=250 | Qualitative studies using structured and semi-structured interviews (over the phone and face-to-face) | <p>Parents reported that developmental impairment in their child was a concern and that they had difficulty accessing specific developmental follow-up. Parents reported that they felt worried and confused due to the lack of developmental follow-up. Parents reported that that they would have liked a specific follow-up plan, however the specific amount and type of contact varied.</p> <p><i>‘more follow ups for the next 18 months to check how the child progresses. Maybe every 3 months to see if child progresses normally’.</i> (Sweeney 2013, page e128)</p> <p><i>‘I wouldn’t say he was a really naughty child but at home he seems not to listen or pay attention. I am not sure if he has behavioural problems... I would like to know about that’.</i> (Sweeney 2013, page e128)</p> <p><i>“It would have been good to have the specialist or someone to go over and do a few tests...just to give you a little peace of mind...just to definitely check that nothing else, side effects have happened because of it”.</i> (Wisemantel 2018, page 483)</p> | <p>Methodological limitations</p> <p>Relevance</p> <p>Coherence</p> <p>Adequacy</p> | <p>Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist</p> <p>Minor concerns. Population restricted to MD. Less severe forms of disease under represented</p> <p>None or very minor concerns</p> <p>Minor concerns. Studies together offered</p> | Moderate |

| Study information | | | CERQual assessment of the evidence | | |
|-------------------|--------|---------------------------------|------------------------------------|----------------------|-----------------|
| Number of studies | Design | Description of theme or finding | Criteria | Level of concern | Overall quality |
| | | | | moderately rich data | |

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

2 **Table 7: Evidence summary profile for theme 3 (Source of support)**

| Study information | | | CERQual assessment of the evidence | | | |
|--|---|---|------------------------------------|---|-----------------|---|
| Number of studies | Design | Description of theme or finding | Criteria | Level of concern | Overall quality | |
| Sub-theme 3.1: Parents | | | | | | |
| 2 (Haines 2005, Sweeney 2013) n=252 | Qualitative studies using structured and semi-structured interviews (over the phone and face-to-face) | Parents reported that other parents who had the experience of a child with meningitis or meningococcal disease, or a child on the intensive care unit were a source of support during hospitalisation. <i>'They'd try (other parents) and cheer you up a bit if they saw you going past in a bit of state.'</i> (Haines 2005, Molly page 84) | Methodological limitations | Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist | Moderate | |
| | | | Relevance | | | Minor concerns. Population restricted to MD. Less severe forms of disease under represented |
| | | | Coherence | | | None or very minor concerns |
| | | | Adequacy | | | Minor concerns. Studies together offered moderately rich data |
| Sub-theme 3.2: Medical staff | | | | | | |
| 1 (Haines 2006) n=8 | Qualitative study using semi-structured interviews | Parents reported that the medical and nursing staff were a source of support when their child was on the intensive care unit. <i>'... and I'd also just sit there and just...notice just all the care and attention</i> | Methodological limitations | Minor concerns about methodological limitations of the evidence as per | Low | |

| Study information | | Description of theme or finding | CERQual assessment of the evidence | | |
|--|---|---|------------------------------------|---|-----------------|
| Number of studies | Design | | Criteria | Level of concern | Overall quality |
| | (face-to-face) | <i>each child was having . . . , it was just overwhelming really, I didn't feel frightened'. (Haines 2006, Olivia page 85)</i> | | CASP qualitative checklist | |
| | | | Relevance | Minor concerns. Population restricted to MD. Less severe forms of disease under represented | |
| | | | Coherence | None or very minor concerns | |
| | | | Adequacy | Serious concerns. Studies together do not offer rich data | |
| Sub-theme 3.3: Nursing staff | | | | | |
| 2 (Haines 2005; Wisemantel 2018) n=14 | Qualitative studies using semi-structured interviews (face-to-face) | Parents valued the support provided by the nursing staff, in particular the relationships which nursing staff developed with the parents. 'and the nurses I found were brilliant, I mean they were such, . . . I feel like they were my friends really, that they befriended me, they gave me support'. (Haines 2006, Isabelle page 85) 'The nurses were great. You know he [son] wouldn't let me leave the room and I really needed coffee...and there were a couple of nurses that were really, really good...and there was a nurse who ended sitting with my son so I could have a coffee and just go away for ten minutes'. (Wisemantel 2018, page 484) | Methodological limitations | Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist | Moderate |
| | | | Relevance | Minor concerns. Population restricted to MD. Less severe forms of disease under represented | |
| | | | Coherence | None or very minor concerns | |
| | | | Adequacy | Minor concerns. Studies together | |

| Study information | | Description of theme or finding | CERQual assessment of the evidence | | |
|--|---|---|---|--|-----------------|
| Number of studies | Design | | Criteria | Level of concern | Overall quality |
| | | | | offered moderately rich data | |
| Sub-theme 3.4: Friends and family | | | | | |
| 1 (Wisemantel 2018) n=6 | Qualitative study using semi-structured interviews (face-to-face) | <p>Parents reported that the support provided by friends and family was invaluable. Parents also highlighted that the support offered by friends was important for their own self-care needs and allowed them to have other conversations that weren't about meningococcal disease.</p> <p><i>'Family and friends come nearly every day and every night...some would bring me dinner, stay with my son while I went and had a shower or sleep...so there were forever people around me...when people came in, they would ask how he is going today...but then it would just carry on...so there wasn't a lot of conversation on the disease'. (Wisemantel 2018, page 483)</i></p> | <p>Methodological limitations</p> <p>Relevance</p> <p>Coherence</p> <p>Adequacy</p> | <p>Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist</p> <p>Minor concerns. Population restricted to MD. Less severe forms of disease under represented</p> <p>None or very minor concerns</p> <p>Moderate concerns. Studies together offered some rich data</p> | Moderate |
| Sub-theme 3.5: Counselling | | | | | |
| 2 (Sweeney 2013; Wisemantel 2018) n=250 | Qualitative studies using structured and semi-structured interviews (over the phone and face-to-face) | <p>Parents reported that they would have liked access to emotional support via counselling at diagnosis and after discharge from hospital. Parents reported that the events associated with meningitis and meningococcal disease were distressing and they often didn't process what had happened until after their child was at home.</p> <p><i>'It is very traumatic, it's a very upsetting time...it might be helpful to have counselling. I had been told that there was a chance that [child] could die'. (Sweeney 2013, page e128)</i></p> | <p>Methodological limitations</p> <p>Relevance</p> | <p>Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist</p> <p>Minor concerns. Population</p> | Moderate |

| Study information | | Description of theme or finding | CERQual assessment of the evidence | | |
|--|---|---|------------------------------------|---|-----------------|
| Number of studies | Design | | Criteria | Level of concern | Overall quality |
| | | <p><i>'It is haunting now and I still feel very sad as I feel there are two [child's name]...before and after the illness and two me's. I don't know what support I need...it's with me every day and it fuels every aspect of how I parent her. It feels like I've taken a deep breath and never exhaled'. (Sweeney 2013, page e128)</i></p> <p><i>'Maybe a counselling session for parents and grandparents or whoever...to go in and sit down and talk to somebody...afterwards, after you get that breath and you go right ..."Wow! That was huge". More so after what you have just been through, that would have been really helpful'.(Wisemantel 2018, page 483)</i></p> | | restricted to MD. Less severe forms of disease under represented | |
| | | | Coherence | None or very minor concerns | |
| | | | Adequacy | Minor concerns. Studies together offered moderately rich data | |
| Sub-theme 3.6: Public health bodies | | | | | |
| 1 (Wisemantel 2018) | Qualitative study using semi-structured interviews (face-to-face) | <p>One parent reported that they valued the information and support provided from the population health unit.</p> <p><i>'The [Population Health nurse consultant] I had originally spoken to, he knew more about it [IMD] than what the doctors did so I just called him if I wasn't sure about something'. (Wisemantel 2018, page 484)</i></p> <p>.</p> | Methodological limitations | Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist | Very low |
| n=6 | | | Relevance | Serious concerns. Unclear if there is a public helpline for the health protection team in the UK. Population restricted to MD. Less severe forms of disease under represented | |
| | | | Coherence | None or very minor concerns | |
| | | | Adequacy | Serious 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 did not offer rich data | |

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

2 **Table 8: Evidence summary profile for theme 4 (Type of support)**

| Study information | | | CERQual assessment of the evidence | | |
|---|---|--|--|--|-----------------|
| Number of studies | Design | Description of theme or finding | Criteria | Level of concern | Overall quality |
| Sub-theme 4.1: Individualised to child | | | | | |
| 1 (Clark 2013) n=18 | Qualitative study using semi-structured interviews (face-to-face or over the phone) | Parents reported that they valued support that was individualised and tailored to their child's needs. Parents reported that they were unhappy with support when it was perceived as not fit for purpose. <i>'... she has a helmet from orthopaedics because of her epilepsy...it fits poorly and she pushed it back so the bit of the head it's supposed to protect, it doesn't protect. I went back and said, 'is there something better we can do with it?', and she said, 'no that's it'. Really, she cannot be the only child to be doing this.'</i> (Clark 2013, P1 page 5) <i>'They spent a lot of time on his spatial awareness, and those types of things because he does seem to be quite clumsy...they picked up this constant need he has of stimulation to the head, which I hadn't noticed.'</i> (Clark 2013, P2 page 5) | Methodological limitations Relevance Coherence Adequacy | Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist Minor concerns. Less severe forms of disease under represented None or very minor concerns Moderate concerns. Studies together offered some rich data | Moderate |
| Sub-theme 4.2: Practical | | | | | |
| 1 (Sweeney 2013) n=244 | Qualitative study using structured interviews (over the | Parents reported that they valued practical support accessing different services during hospitalisation and after discharge. Some parents would have liked help accessing financial support during hospitalisation and accessing support services after discharge. | 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 |
| | phone) | <p><i>'some information or a leaflet about what to do financially if your child is hospitalized'. (Sweeney 2013, e128)</i></p> <p><i>'her home has still not been adapted for a wheelchair-bound, visually impaired child with severe learning difficulties. We still require someone to help us to access the services she needs'. (Sweeney 2013, e128)</i></p> | Relevance | CASP qualitative checklist Minor concerns. Population restricted to MD. Less severe forms of disease under represented | |
| | | | Coherence | None or very minor concerns | |
| | | | Adequacy | Moderate concerns. Studies together offered some rich data | |
| | | | | | |
| Sub-theme 4.3: Reassurance | | | | | |
| 1 (Sweeney 2013) n=244 | Qualitative study using structured interviews (over the phone) | <p>Parents reported the importance of reassurance as an integral part of support. Parents highlighted how receiving more information, emotional support or follow-up care would provide them with reassurance regarding their coping skills or their child's recovery.</p> <p><i>'For two years I was completely changed - my nerves - I was like a woman possessed. I would've liked someone to talk to and reassure us about things'. (Sweeney 2013, e128)</i></p> | Methodological limitations | Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist | Moderate |
| | | | Relevance | Minor concerns. Population restricted to MD. Less severe forms of disease under represented | |
| | | | Coherence | None or very minor concerns | |
| | | | Adequacy | Moderate concerns. | |

| 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 | |

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

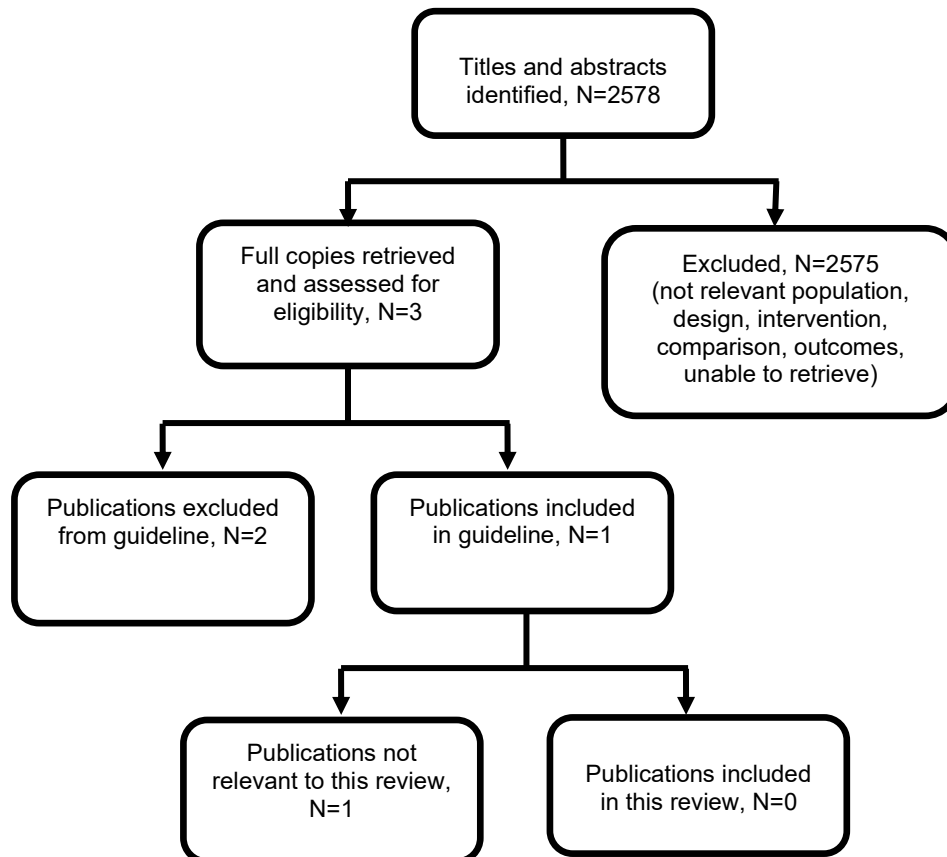
1 Appendix G Economic evidence study selection

2 Study selection for: What support is valued by patients with confirmed 3 bacterial meningitis or meningococcal disease, and their families or carers?

4 A global economic search was undertaken for the whole guideline, but no economic
5 evidence was identified which was applicable to this review question (see Figure 3).

6 **Figure 3: Study selection flow chart**

7



8

9

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1 **Appendix H Economic evidence tables**

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

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

6

7

1 **Appendix I Economic model**

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

5 No economic analysis was conducted for this review question.

6

7

1 Appendix J Excluded studies

2 Excluded studies for review question: What support is valued by patients with 3 confirmed bacterial meningitis or meningococcal disease, and their families or 4 carers?

5 Excluded qualitative studies

6 The excluded studies table only lists the studies that were considered and then excluded at
7 the full-text stage for this review (N=9) and not studies (N=59) that were considered and then
8 excluded from the search at the full-text stage as per the PRISMA diagram in Appendix C for
9 the other review questions in the same search.

10 **Table 9: Excluded studies and reasons for their exclusion**

| Study | Code [Reason] |
|--|---|
| Carter, B, Roland, D, Bray, L et al. (2020) A systematic review of the organizational, environmental, professional and child and family factors influencing the timing of admission to hospital for children with serious infectious illness. 15(7): e0236013 | - Study design not of interest for review A systematic review study; individual included studies have been assessed and none meet the inclusion criteria |
| Davie, S; Glennie, L; Rowland, K. (2012) Towards a meningitis free world-Can we eliminate meningococcal meningitis?. Contribution of the meningitis patient groups. Vaccine 30(suppl2): B98-B105 | - Study design not of interest for review Overview of research and other activities by meningitis patient groups. No qualitative data presented |
| Duramaz, B. B, Kihtir, H. S, Petmezci, M. T et al. (2020) Analysis of meningitis cases in pediatric intensive care unit: 8-year single center experience. Medical Journal of Bakirkoy 16(1): 26-32 | - Study design not of interest for review Quantitative study. No qualitative data presented |
| Shevlin, Mark, Coen, Pietro G; Borg, Jennie, Booy, Robert, Viner, Russell M; Christie, Deborah, Apajasalo, Arnau Aspesberro Baraff Beck Bellamy Borg Bowling Chin Christie de Winter Deyo Eiser Erickson Fellick Garratt Gill Guyatt Harrison Jenkinson Jenkinson Jones Joreskog Khan Krefetz Linstone Mobily Naess Nunnally Oranga Raphael Ridley Sander Starfield Steiger Viner Ware Ware (2016) Development of a health related quality of life measure for adolescents and young adults following invasive meningococcal disease. Applied Research in Quality of Life 11(3): 971-982 | - Insufficient presentation of results Describes using focus groups of IMD survivors to develop questionnaire, but no presentation of qualitative data |
| 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 None of the respondents had suspected or confirmed meningitis or IMD |

| Study | Code [Reason] |
|---|---|
| van Elsland, S. L, Springer, P, Steenhuis, I. H et al. (2012) Tuberculous meningitis: barriers to adherence in home treatment of children and caretaker perceptions. <i>Journal of Tropical Pediatrics</i> 58(4): 275-9 | - Not a high-income OECD country Study set in South Africa |
| Vermunt, L. C, Buysse, C. M, Joosten, K. F et al. (2011) Survivors of septic shock caused by <i>Neisseria meningitidis</i> in childhood: Psychosocial outcomes in young adulthood. <i>Pediatric Critical Care Medicine</i> 12(6): e302-e309 | - Insufficient presentation of results No thematic analysis conducted. Responses to free-text questions and focus groups presented as quantitative outcomes |
| Williams, C. N, Eriksson, C, Piantino, J et al. (2018) Long-term Sequelae of Pediatric Neurocritical Care: The Parent Perspective. <i>Journal of Pediatric Intensive Care</i> 7(4): 173-181 | - Population not of interest for review Mixed population: Parents of children admitted to neurocritical care. Only 22% admitted for meningitis or encephalitis (67% admitted for TBI, 22% admitted for stroke. Results not presented or analysed separately for target population. |

1 **Excluded economic studies**

2 No economic evidence was identified for this review.

3

1 **Appendix K Research recommendations – full details**

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

5 No research recommendation was made for this review.