National Institute for Health and Care Excellence

Final

Otitis media with effusion in under 12s

[N] Evidence reviews for information for suspected or confirmed OME

NICE guideline number NG233

Evidence reviews underpinning recommendations 1.1.1 to 1.1.9 in the NICE guideline

August 2023

Final

This evidence review was developed by NICE

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Contents

Information for suspected or confirmed OME

Review question

What information is valued by children under 12 years with suspected or confirmed otitis media with effusion (OME) and their parents and carers?

Introduction

The aim of this review is to identify what information is valued by children under 12 years with suspected or confirmed otitis media with effusion (OME) and their parents and carers.

Summary of the protocol

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

Table 1: Summary of the protocol (PPC table)

Population	All children under 12 years with suspected or confirmed otitis media with effusion (OME) and their parents and carers.
Phenomenon of interest	Views and preferences about information provided in suspected or confirmed OME. Themes will be identified from the literature. The committee identified the following potential themes (however, not all of these themes may be found in the literature, and additional themes may be identified): • Information content • Information format • Language • Communication
Context	Studies sought will be those published in the English language from European high-income countries, Australia, New Zealand, and Canada from 2000 until the date the searches are run.

OME: Otitis media with effusion

For further details see the review protocol in appendix A.

Methods and process

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

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

Qualitative evidence

Included studies

Two studies were included for this review (Gkiousias 2016; Tierney 2013).

The included studies are summarised in Table 2.

One study reported on the views and experiences of parents of children diagnosed with OME, excluding those with craniofacial anomalies, (Gkiousias 2016) and the other study reported on the views and experiences of parents of children with cleft palate diagnosed with OME (Tierney 2013).

Participants in 1 study (Gkiousias 2016) were parents of children who were receiving oral steroids as part of an ongoing trial, and participants in the other study (Tierney 2013) were parents of children who had received watchful waiting, or grommets and/or hearing aids.

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

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

Excluded studies

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

Summary of included studies

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

Table 2: Summary of included studies.

Study	Population	Methods	Themes applied after thematic synthesis
Gkiousias 2016 General qualitative inquiry United Kingdom	N=12 parents of children OME who attended an ENT outpatient clinic and had been recruited as part of the OSTRICH Study Participating parents: Age in years, mean (SD): NR Sex (male/female): 1/11 Children of participants: Age in years, mean (SD): NR, range: 3-7 Sex (male/female): 6/5	**Setting:** Convenience sampling of parents at a single site of the OSTRICH study, a hospital in South Wales, UK **Data collection:** Semi-structured interviews	• Information sources • Information format • Information content • Communication
Tierney 2013	N= 43 parents of children with OME and non-syndromic cleft palate (with or without	**Setting:** Purposive sampling of parents from two cleft centres in Northern England	• Information sources • Information format • Information content

Study	Population	Methods	Themes applied after thematic synthesis
General qualitative inquiry United Kingdom	cleft lip) who were able to converse in English Participating parents: Age in years, mean (SD): 34.9 (6.7) Sex (male/female): 7/36 Children of participants: Age in years, mean (SD): 6.5 (3.4) Sex (male/female): 21/16	**Data collection:** Semi-structured interviews	• Communication

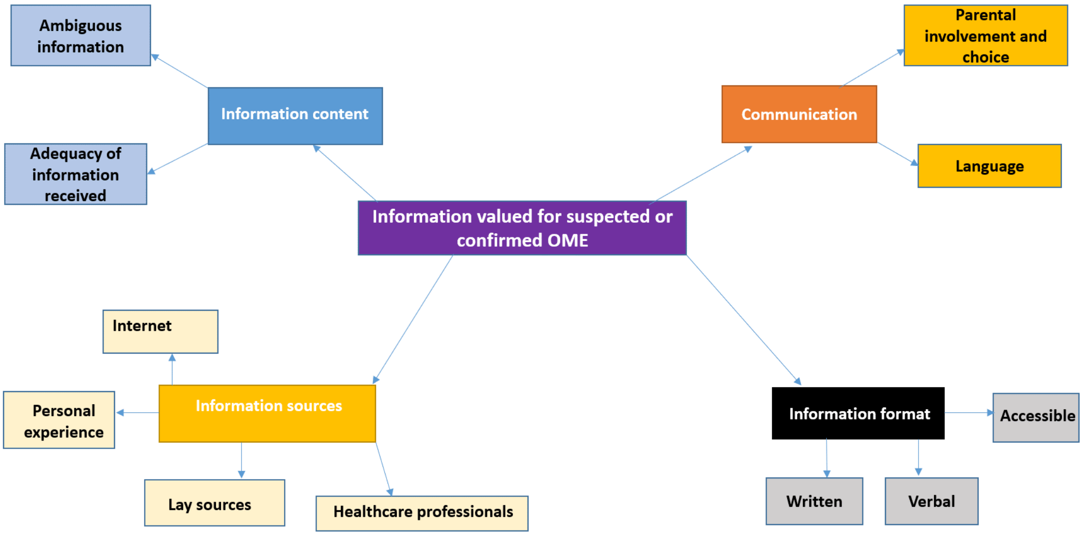
ENT: ears, nose and throat; NR: not reported; OME: otitis media with effusion; OSTRICH: Oral STeroids for Resolution of otitis media with effusion In Children; SD: standard deviation

See the full evidence tables in appendix D. No meta-analysis was conducted (and so there are no forest plots in appendix E).

Summary of the evidence

The evidence generated 4 main themes in relation to the information valued by parents of children with confirmed OME. Two studies provided the evidence relating to information sources, which had 4 sub-themes (healthcare professionals, internet, personal experiences and lay sources). Two studies provided the evidence relating to information format, which had 3 subthemes (verbal, written and accessible). Two studies provided the evidence relating to information content, which had 2 subthemes (adequacy of information received and ambiguous information). Two studies provided the evidence relating to Communication, which had 2 subthemes (parental involvement and choice, and language). Figure 1 shows the themes and the subthemes.

Figure 1: Theme map



OME: Otitis media with effusion

A summary of the strength of evidence, assessed using GRADE-CERQual, is presented for each of the sub-themes. The main reasons for downgrading were due to concerns about methodological limitations of the primary studies (e.g., because of a lack of consideration of the relationship between researcher and participants and no justification for data collection methods as it relates to data saturation), and concerns about adequacy (e.g., for review findings when evidence offered no or moderate or only some rich data). For each of the sub-themes, the overall quality of the evidence was judged to be:

Main theme 1: Information sources

- Subtheme 1.1: Healthcare professionals. The overall confidence in this sub-theme was judged to be moderate.
- Subtheme 1.2: Internet. The overall confidence in this sub-theme was judged to be moderate.
- Subtheme 1.3: Personal experiences. The overall confidence in this sub-theme was judged to be low.
- Subtheme 1.4: Lay sources. The overall confidence in this sub-theme was judged to be moderate.

Main theme 2: Information format

- Subtheme 2.1: Verbal. The overall confidence in this sub-theme was judged to be moderate.
- Subtheme 2.2: Written. The overall confidence in this sub-theme was judged to be moderate.
- Subtheme 2.3: Accessible. The overall confidence in this sub-theme was judged to be low.

Main theme 3: Information content

- Subtheme 3.1: Adequacy of information received. The overall confidence in this sub-theme was judged to be moderate.
- Subtheme 3.2: Ambiguous information. The overall confidence in this sub-theme was judged to be low.

Main theme 4: Communication

- Subtheme 4.1: Parental involvement and choice. The overall confidence in this sub-theme was judged to be high.
- Subtheme 4.2: Language. The overall confidence in this sub-theme was judged to be low.

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

Economic evidence

Included studies

A systematic review of the economic literature was conducted but no economic studies were identified which were applicable to this review question.

Economic model

No economic modelling was undertaken for this review because the committee agreed that other topics were higher priorities for economic evaluation as this review question did not explicitly address a decision between competing alternatives.

The committee's discussion and interpretation of the evidence

The outcomes that matter most

The review focused on the views and preferences about information provided when OME is suspected or confirmed. The committee did not pre-specify themes as they did not want to constrain the evidence. However, they identified a few potential themes as illustrative of the main themes to guide the review. These themes were information content, information format, language, and communication. The potential themes were not exhaustive, and an emergent approach was taken to the thematic synthesis.

The quality of the evidence

The evidence was assessed using GRADE-CERQual methodology and the overall quality ranged from low to high. Concerns about the methodological limitations of the primary studies were assessed with the CASP checklist was "minor concerns" for all the review findings. The issues identified were lack of consideration of the relationship between researcher and participants and no justification for data collection methods as it relates to data saturation. Concerns about relevance ranged from "no or very minor" to "minor". The minor concerns were due to study focusing only on children with cleft palate as the population of the study. Concerns about coherence ranged from "no or very minor" to "minor". Minor concerns were due to some ambiguity of findings across studies without a credible explanation of the difference. Concerns about adequacy ranged from "no or very minor" to "serious". There were serious concerns for review findings when evidence offered no rich data, moderate concerns for review findings when evidence offered some rich data and minor concerns for review findings that were based on evidence offering moderately rich data. The number of studies used for each review finding ranged from 1 to 2.

Benefits and harms

There was high quality evidence from sub-theme 4.1 showing that parents felt that their views about their child's illness were not taken into consideration by healthcare professionals and they were not given a choice about their child's treatment but felt coerced into a decision. The committee considered the impact OME may have on children and their families and emphasised that the experience of OME is often different for each child. For example, for some children OME may have no or very minimal impact, while others may have a higher level of frustration, tiredness and behavioural concerns. As a result, any treatment decisions should be made in the context of the child's experience of OME and any associated impact or concerns, the parents' or carers' knowledge and experience of their child, the family and their circumstances. Therefore, they agreed that it is crucial for health professionals to ask the child, their parents and/or carers about their experiences and listen to understand the impact of the illness on the child and the family and use this to inform treatment planning.

The committee considered the low quality evidence from sub-theme 3.2 of parents reporting that they receive conflicting and confusing information from healthcare professionals, as well as the low quality evidence from sub-theme 4.2 that information provided often included medical terms that were incomprehensible. The committee referred to the studies included in the review and recognised that although the participants could converse in English, they still found some information incomprehensible. The committee added that, based on their experience, this may be a particular problem for people who have English as a second language. The committee recognised the importance of parents and carers understanding the information they are given about their child's illness so that they are aware of potential management options for OME and actions that can be taken to support a child with OME prior to an intervention, and to help empower them to make an informed decision and support their child throughout the process. Additionally, this understanding will help enable parents or carers to explain information to their children, as discussed below in relation to easy read formats. Therefore, the committee agreed that this information should be provided to parents and carers and should be clear, possibly in different languages and without medical terminology. The committee discussed the importance of information being consistent, and made a recommendation in support of this, but acknowledged that there are very few resources that present concise information on OME of varying degrees. For example, the National Deaf Children’s Society (NDCS) website contains information on OME and hearing loss, but there are barriers to accessing some of the information, such as having to join NDCS as a member.

There was moderate quality evidence from sub-theme 3.1 that parents were generally satisfied with information received about OME and different treatment options but there was little detail provided about the exact content of information that should be provided to parents and carers. The committee considered the need for parents or carers to be fully equipped with relevant information about their child’s illness in order to reduce anxiety, make informed choices about management options, and aid shared decision-making. This would also help parents or carers prepare their child for any interventions and for transition to school, including enabling the sharing of information with teachers. Additionally, the committee reiterated that the impact of OME on a child’s wellbeing is a major consideration as it impacts on their hearing, listening, anxiety, emotional, behavioural and social wellbeing. The committee agreed that parents need to understand that their child may not hear properly, and that this can affect their speech, language, social skills and behaviours. Understanding the impacts of OME will help parents understand what has been happening with their child and the potential need for intervention. The committee explained that unless parents understand OME and its impacts, they may not be receptive to potential management options. Therefore, the committee agreed that children, parents and carers need to be provided with comprehensive information about what OME is, its causes, its fluctuating nature and the potential impact on the child’s hearing, listening, wellbeing and development, as well as the different management options (including the option of no active treatment).

It is not current practice to intervene for OME unless there is an associated hearing loss. The committee agreed, based on their experience, that parents can find it distressing to be told that children with OME and no related hearing loss do not usually get treatment. Therefore, it is important to explain why treatment is unnecessary while there is no associated hearing loss, and to reassure parents that OME usually clears up by itself. However, the committee agreed it was also important to ensure that parents remained attentive to their child’s hearing and general behaviour in case hearing problems do develop. It is important that parents are aware that they should seek advice if they develop concerns about their child’s hearing, to reduce the risk of hearing problems being overlooked if they develop after an initial assessment.

The committee considered their experiences in caring for children with OME and agreed that involving children and their parents/ carers in discussions about their condition and care may help improve adherence to interventions and empower them to provide feedback about interventions and changes in their condition that can be used to inform ongoing management. Additionally, evidence from sub-theme 4.1 showed that parents wanted to be more involved in decisions made about their child’s care and were frustrated when they felt they had been coerced into a decision. The committee agreed that, in order to support shared decision-making, healthcare professionals should discuss different treatment and management options with children with OME and their parents/ carers. They agreed that this would empower people to feel supported in the decisions made about the child’s care. Discussing supportive strategies would also enable parents to support their children outside of healthcare environments, thereby aiding the child’s development and reducing the risk of behavioural problems and distress. The committee discussed information suitable for children, which can also be used by parents to support their child in understanding OME and mitigating its impacts. The committee gave particular consideration to children with learning disabilities such as children with Down’s syndrome, and therefore emphasised the need for information that is age and developmentally appropriate for children, especially considering the hearing difficulty the children may be experiencing. The committee discussed that information for parents or carers may not be age or developmentally appropriate for children and agreed that information will need to be tailored differently for children. Therefore, the committee agreed that information should also be provided using visually aided formats such as pictures, captioned videos and animations to make it easier for children to understand. The committee were aware that the 2021 NICE guideline on babies, children and young people's experience of healthcare includes more general recommendations about caring for children and young people and how to provide information to children. Therefore, they agreed to include a cross-reference to this guideline to provide more detailed guidance on communicating information to children in the most appropriate ways.

There was low quality evidence from sub-theme 2.3 expressing parents' needs for detailed information in accessible ways. The committee considered the different formats of providing information for parents that were highlighted in theme 2 of the evidence, along with other formats encountered in their experience and practice that were beneficial to parents, and deliberated on the most appropriate formats of information that parents will find useful. The committee discussed the benefit of providing information in easy read formats, without medical terminology, in order to ensure that the information is easily understood by parents or carers, and can also be used to explain information to their children. Similarly, the accessibility and convenience of getting adequate information was discussed. The committee explained that in their experience, some parents or carers are more able to access digital information than others. Therefore, the committee agreed that information should be provided to parents and carers in both digital and non-digital formats to cater for the varying proficiencies and requirements of parents and carers. Additionally, the committee considered the moderate quality evidence from subtheme 1.1 where parents reported a preference for receiving face-to-face information from health professionals. However, the moderate quality evidence from subtheme 2.2 also showed parents valued written information as a useful aid when discussing OME with their family members. The committee explained that in their experiences, information is mostly provided verbally face-to-face but recognised that parents and carers may not be able to take in all the information offered verbally and may have additional questions after leaving the healthcare professional. Therefore, the committee agreed that in addition to offering information verbally, having written information that parents could refer to later will be helpful in answering some of the parents' and carers' questions that arise, as well as explaining OME to other family members, schools and nurseries.

The committee agreed, based on their experience, that the timing of when information is shared with children, parents and carers is also important. They discussed that children and their families may feel anxiety when there in a lack of information. However, the committee agreed that parents should not be overloaded with information when OME has not been confirmed. Therefore, the committee agreed that this information should be shared with children, parents and carers as soon as OME is confirmed and before a management decision is made, to empower children, parents and carers to be involved in the management decision.

The committee drew on their experiences and considered parents' lack of understanding of OME and its impacts on their child's behaviours, speech and language and wellbeing. In addition to the importance of understanding the impact of OME in relation to management options described above, the committee agreed that parents or carers understanding the impact of OME is important for helping them to understand additional ways they can support their child while they are experiencing hearing loss in order to help mitigate the impact of OME. The committee described different scenarios where parents have expressed a lack of understanding about the impact of OME on the child's listening and hearing (for example, parents seeing their children respond to some sounds and not to others and think that their children are choosing what they respond to), emotions (for example being dependent on siblings to understand things that are happening around them and feeling anxious when on their own), behaviour (for example, children having tantrums as they are unable to comprehend their environments well, which could sometimes be a result of continuous background noise as well as listening fatigue and frustration with communication) and social wellbeing (for example being unable to socialise with peers because they are unable to comprehend the relationship, hear what is being said, or understand the emotion conveyed in what is being said). The committee agreed, based on their experience, that using visual aids, being close to and facing the child when speaking to them and limiting background noise may be beneficial to reduce the distractions from conflicting sounds and aid the child's hearing and understanding. These interventions were considered applicable in educational settings as well. The committee recognised that the biggest impact of hearing loss on children is having limited receptivity to education and agreed that support in the educational setting should be considered as part of the support to children with OME, their parents or carers. The committee highlighted that some educational settings, such as nurseries, have very limited knowledge of OME and being aware of OME would help them to be more aware of positive interventions that could support a child with OME.

The committee agreed that an important aspect of shared decision-making was ensuring that children with OME and their parents and carers understood the care and treatment options available, in order to promote confidence that the right decisions were being made. They agreed that people should always feel empowered to ask questions if they need more information to feel comfortable with any decisions being made, and therefore recommended that clinicians give children and their parents/ carers the time to ask questions and answer them in sufficient detail. The committee agreed this should lower the risk of parents feeling as though their information needs have not been met, and should improve service user satisfaction.

The committee also drew on their experiences and explained that parents may change their minds about a chosen management decision either because they want to try a different management option, or because they realise that a different option is better suited to their child. For example, in a situation where the child refuses to keep the hearing aid on, the parent may decide to try grommets instead. The committee therefore agreed that parents and carers should be aware that management decisions may need to be reviewed or changed depending on the child's needs, and the child, parents or carers should be supported through such changes.

The recommendation that parents and carers should be advised not to expose their children to tobacco smoke was based on the committee's knowledge and experience, as well as evidence from the review on modifiable risk factors for OME. See Evidence Review A for more information about why this recommendation was made.

There was moderate quality evidence from subtheme 1.2 and 1.4 that showed that parents used the internet and other lay sources for information. The committee considered this evidence and agreed that information could include signposting to relevant and appropriate resources such as NDCS website and shared stories. However, there were concerns that some shared stories may not be appropriate to share with parents because they could be more extreme examples (for example a published story of a child who had had grommets several times and was now awaiting surgery of his eardrum). The committee also discussed the difficulty in finding clear and succinct information that parents can be signposted to. Therefore, no recommendation was made about signposting children, parents and carers to internet resources. However, as indicated above, the committee agreed that parents should be provided with some written information that they could refer to after leaving the consultant and further suggested the possibility of developing clear and succinct information that parents can be signposted to.

Cost effectiveness and resource use

As no formal economic evaluation was undertaken the committee made a qualitative assessment of the likely cost effectiveness of their recommendations. The evidence reviewed was qualitative and therefore the effectiveness of information provision was not quantified but the committee noted that information provision is inexpensive and a requirement of health service interactions between healthcare professionals and parents and children. The committee considered that their recommendations on information and advice would be cost-effective as it was consistent with existing NICE guidance (Babies, children and young people's experience of healthcare [NG204]) and would promote treatment decisions that reflected the child's individual experience of OME.

Other factors the committee took into account

The committee referred to research conducted by the NDCS that showed children with mild and moderate hearing loss underachieve when compared to children with severe and profound hearing loss, possibly because the parents or carers were not very aware of the impacts as they were not as obvious. This was used to inform the recommendation that children, parents and carers should be provided with comprehensive information about OME, its fluctuating nature, and the potential impact on the child's hearing, listening, wellbeing and development.

Recommendations supported by this evidence review

This evidence review supports recommendations 1.1.1 to 1.1.9.

References – included studies

Qualitative

Gkiousias 2016

Gkiousias, Vasileios, Butler, Christopher Collett, Shepherd, Victoria et al. (2016) Parental perceptions and understanding of information provision, management options and factors influencing the decision-making process in the treatment of children with glue ear. International journal of pediatric otorhinolaryngology 89: 6-12

Tierney 2013

Tierney, S, O'Brien, K, Harman, N L et al. (2013) Risks and benefits of ventilation tubes and hearing aids from the perspective of parents of children with cleft palate. International journal of pediatric otorhinolaryngology 77(10): 1742-8

Other

NICE 2021

National Institute for Health and Care Excellence (2021). Babies, children and young people's experience of healthcare. Available at: https://www.nice.org.uk/guidance/ng204 [Accessed 31/05/2022]

Appendices

Appendix A Review protocols

Review protocol for review question: What information is valued by children under 12 years with suspected or confirmed OME and their parents and carers?

Table 3: Review protocol

Field	Content
PROSPERO registration number	CRD42022334029
Review title	Information for suspected or confirmed otitis media with effusion (OME)
Review question	What information is valued by children under 12 years with suspected or confirmed OME and their parents and carers?
Objective	To determine what information is valued by children under 12 years, their parents and carers when OME is suspected or confirmed
Searches	The following databases will be searched: • Cochrane Central Register of Controlled Trials (CENTRAL) • Cochrane Database of Systematic Reviews (CDSR) • Embase • MEDLINE • PsycInfo • CINAHL • Epistemonikos • International Health Technology Assessment (INAHTA) database Searches will be restricted by: • Date limitations: 2000 • English language

Field	Content
	- Human studies The full search strategies for MEDLINE database will be published in the final review. For each search, the principal database search strategy is quality assured by a second information scientist using an adaptation of the PRESS 2015 Guideline Evidence-Based Checklist.
Condition or domain being studied	Otitis media with effusion
Population	Inclusion: All children under 12 years with suspected or confirmed otitis media with effusion (OME) and their parents and carers.
Phenomenon of interest	Views and preferences about information provided in suspected or confirmed OME
Comparator/Reference standard/Confounding factors	Not applicable
Types of study to be included	Qualitative methods: systematic reviews of qualitative studies, primary qualitative studies including semi-structured and structured interviews, focus groups, observations and surveys with open-ended questions. Exclusions: - Quantitative studies (including surveys reporting only quantitative data) - Surveys which quantify open-ended answers for analysis - Conference abstracts
Other exclusion criteria	- Country limitations: Limit countries to European high-income countries, Australia, New Zealand, Canada - Date limitations: Exclude studies conducted prior to 2000 due to change in practice - Studies not published in the English Language
Context	This guidance will fully update the following NICE guideline: Otitis media with effusion in under 12s: surgery (2008; CG60)
Primary outcomes (critical outcomes)	Themes will be identified from the literature. The committee identified the following potential themes (however, not all of these themes may be found in the literature, and additional themes may be identified): - Information content

Field	Content
	• Information format • Language • Communication
Secondary outcomes (important outcomes)	Not applicable
Data extraction (selection and coding)	All references identified by the searches and from other sources will be uploaded into EPPI 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. Duplicate screening 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), participant characteristics, inclusion and exclusion criteria, details of the interventions if relevant, setting and follow-up, relevant outcome data and source of funding. One reviewer will extract relevant data into a standardised form, and this will be quality assessed by a senior reviewer.
Risk of bias (quality) assessment	Quality assessment of individual studies will be performed using the following checklists: • ROBIS tool for systematic reviews • CASP checklist for qualitative studies The quality assessment will be performed by one reviewer and this will be quality assessed by a senior reviewer.
Strategy for data synthesis	Secondary thematic analysis will be used to synthesise the evidence from individual studies. The GRADE-CERQual (Confidence in the Evidence from Reviews of Qualitative research; Lewin 2015) approach will be used to summarise the confidence in qualitative evidence. The overall confidence in evidence about each theme or sub-theme will be rated on four dimensions: methodological limitations, applicability, coherence and adequacy of data.

Field	Content	
	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. Adequacy of data will be assessed by looking at the degree of richness and quantity of findings.	
Analysis of sub-groups	Formal subgroup analyses are not appropriate for this question due to qualitative data, but the views and experiences of the following groups will be considered separately, where possible): • Status of OME ○ Suspected ○ Confirmed • Intervention status/timing ○ Without intervention ○ Before intervention ○ During intervention ○ Following intervention • Children vs parents/carers The guideline committee also noted that it may be appropriate to make separate recommendations for children with Down syndrome, cleft palate, or with complex needs and for children with a first episode or recurrent OME if there is sufficient evidence for each subgroup to allow it.	
Type and method of review	☐	Intervention
	☐	Diagnostic
	☐	Prognostic
	☒	Qualitative
	☐	Epidemiologic

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Named contact e-mail: otitis@nice.org.uk
Organisational affiliation of the review: National Institute for Health and Care Excellence (NICE) and National Guideline Alliance</td></tr>
<tr><td>Review team members</td><td colspan="3">National Guideline Alliance</td></tr>
<tr><td>Funding sources/sponsor</td><td colspan="3">This systematic review is being completed by National Guideline Alliance which receives funding from NICE.</td></tr>
</table>

Field	Content	
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-ng10193.	
Other registration details	None	
Reference/URL for published protocol	https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42022334029	
Dissemination plans	NICE may use a range of different methods to raise awareness of the guideline. These include standard approaches such as: • notifying registered stakeholders of publication • publicising the guideline through NICE's newsletter and alerts • issuing a press release or briefing as appropriate, posting news articles on the NICE website, using social media channels, and publicising the guideline within NICE.	
Keywords	Otitis media with effusion, glue ear information, qualitative	
Details of existing review of same topic by same authors	None	
Current review status	☐	Ongoing
	☒	Completed but not published
	☐	Completed and published

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

CASP: Critical Appraisal Skills Programme; CDSR: Cochrane Database of Systematic Reviews; CENTRAL: Cochrane Central Register of Controlled Trials; EPPI: Evidence for Policy and Practice Information; GRADE-CERQual: Grading of Recommendations Assessment, Development and Evaluation-Confidence in the Evidence from Reviews of Qualitative research; INAHTA: International Health Technology Assessment; NICE: National Institute for Health and Care Excellence; OME: otitis media with effusion; PRESS: Peer Review of Electronic Search Strategies; ROBIS: risk of bias in Systematic Reviews

Appendix B Literature search strategies

Literature search strategies for review question: What information is valued by children under 12 years with suspected or confirmed OME and their parents and carers?

Database: MEDLINE – OVID interface

Date last searched: 09/11/2022

#	Searches
1	otitis media with effusion/
2	(glue ear or ((middle ear or otitis media) adj2 effusion*) or ome or ((secretory or serous) adj2 otitis media)).ti,ab.
3	1 or 2
4	Access to Information/ or Activities of Daily Living/ or Attitude of Health Personnel/ or exp Audiovisual Aids/ or Communication/ or exp Communication Barriers/ or exp Communications Media/ or exp Community Health Services/ or exp Computers, Handheld/ or Consumer Advocacy/ or Consumer Health Information/ or exp Counseling/ or Decision Making/ or Decision Support Systems, Clinical/ or Electronic Mail/ or Empowerment/ or Government Publications as Topic/ or Health Communication/ or Health Education/ or exp Health Information Management/ or Health Knowledge, Attitudes, Practice/ or Health Literacy/ or Health Promotion/ or Help-Seeking Behavior/ or Hotlines/ or Information Centers/ or Information Dissemination/ or Information Seeking Behavior/ or Information Services/ or exp Internet/ or Internet-Based Intervention/ or Mass Media/ or Mobile Applications/ or exp Mobile Phone/ or exp Nurses/ or Pamphlets/ or Patient Advocacy/ or exp Patient Care Team/ or Patient Education as Topic/ or Patient Education Handout/ or Patient Medication Knowledge/ or Patient Participation/ or Patient Safety/ or Peer Group/ or exp Professional-Patient Relations/ or exp Psychotherapy/ or Radio/ or Self-Help Groups/ or Social Media/ or exp Social Networking/ or exp Social Support/ or Telemedicine/ or Telephone/ or Television/ or Text Messaging/ or Therapy, Computer-Assisted/ or Uncertainty/ or exp Video-Audio Media/ or Web Browser/
5	((daily or decision or function* or group* or psycho*) adj2 support*).ti,ab.
6	(app or apps or blog* or booklet* or brochure* or cellphone* or cell phone* or discussion* or download* or dvd* or elearn* or e-learn* or email* or e mail* or facebook or facetime or fora or forum* or google or handout* or hand out* or helpline* or help line* or hotline* or hot line* or ict or information* or internet* or ipad* or iphone* or leaflet* or letter* or magazine* or manual or manuals or media or messag* board or mobile* or myspace or newsletter* or pamphlet* or phone* or podcast* or poster? or publication* or skype* or smartphone* or social media or social network* or sms or telephone* or text messag* or tiktok or twitter or tweet* or video* or webpage* or web page* or web based or web search or website* or web site* or wiki* or written or youtube* or zoom or helpseek* or help seek* or healthcareseek* or healthcare seek* or healthseek* or health seek* or care seek* or careseek*).ti,ab.
7	((brother* or carer* or caregiv* or care giv* or famil* or father* or mother* or parent* or relative* or sibling* or sister* or consumer* or inpatient* or patient* or person or people or population or user* or audiologist* or clinician* or counselor* or counsellor* or doctor* or general practi* or gp? or health visitor* or coordinator* or nurs* or officer* or personal assistant* or personnel or physician* or practitioner* or primary care or professional* or psychiatrist* or psychologist* or worker* or community team*) adj2 (advice or advise? or advising or communicat* or educat* or guid* or inform* or involv* or knowledge* or learn* or support* or understand*)).ti,ab.
8	((information* or support* or advice or guidance) adj2 (access* or contact* or disseminat* or model* or need* or prOVID* or provision or program* or requir* or resource* or seek* or service* or shar*)).ti,ab.
9	((communicat* or inform* or support*) adj2 (accura* or barrier* or benefi* or clear* or facilitat* or help* or hinder* or hindran*or or practical* or support*)).ti,ab.
10	((information* or support* or advice or guidance) adj2 (aid* or content* or format* or handout* or hand out* or method* or quality or sheet* or symptom* or type*)).ti,ab.
11	((added or additional or extra or further or prompt* or time* or timing or when) adj3 (advice or informat* or support* or guidance)).ti,ab.
12	patient education handout.pt.
13	or/4-12
14	3 and 13
15	Anthropology, Cultural/ or Cluster Analysis/ or Focus Groups/ or Grounded Theory/ or Health Care Surveys/ or Interview.pt. or "Interviews As Topic"/ or Narration/ or Nursing Methodology Research/ or Observation/ or "Personal Narratives As Topic"/ or Personal Narrative/ or Qualitative Research/ or "Surveys And Questionnaires"/ or Sampling Studies/ or Tape Recording/ or Videodisc Recording/
16	(qualitative* or interview* or focus or questionnaire* or narrative* or narration* or survey* or experience* or themes).tw.
17	(ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic adj4 analys*) or theoretical sampl* or purposive sampl*).tw.
18	(hermeneutic* or heidegger* or husser* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*).tw.
19	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them*).tw.
20	(critical interpretive synthes* or (realist adj (review* or synthes*)) or (noblit and hare) or (meta adj (method or triangulation)) or (cerqual or conqual) or ((thematic or framework) adj synthes*)).tw.
21	or/15-20
22	Patient Preference/ or exp Patient Satisfaction/
23	(dissatisf* or expectation* or experienc* or opinion* or perceive* or perspective* or preferenc* or satisf* or view*).ti.

#	Searches
24	((child* or adolescen* or boy? or girl? or infan* or juvenile? or kid? or kindergar* or minors or p?ediatric* or prepubert* or pre pubert* or prepubescen* or pre pubescent or preschool* or pre school* or preteen* or pre teen* or schoolchild* or school age? or toddler* or young or adult* or people* or population* or consumer* or patient* or user* or parent* or grandparent? or famil* or relati* or carer* or caregiver* or care giver* or inpatient* or mother* or father* or grandmother? or grandfather? or sibling* or sister* or brother*) adj6 (attitude* or concern* or dissatisf* or expect* or experienc* or opinion* or perceive* or perception* or perspective* or prefer* or satisf* or view*)).ti,ab.
25	or/22-24
26	21 or 25
27	14 and 26
28	limit 27 to english language
29	limit 28 to yr="2000 -Current"
30	(animals not humans).sh. or exp animals, laboratory/ or exp animal experimentation/ or exp models, animal/ or exp rodentia/ or (rat or rats or mouse or mice).ti.
31	29 not 30

Database: Embase – OVID interface

Date last searched: 09/11/2022

#	Searches
1	exp secretory otitis media/
2	(glue ear or ((middle ear or otitis media) adj2 effusion*) or ome or ((secretory or serous) adj2 otitis media)).ti,ab.
3	1 or 2
4	access to information/ or attitude to health/ or exp audiovisual aid/ or bibliotherapy/ or exp blogging/ or care coordinator/ or exp community care/ or consumer advocacy/ or consumer health information/ or computer assisted therapy/ or exp counselling/ or exp decision support system/ or education program/ or e-mail/ or email support/ or empowerment/ or health education/ or health literacy/ or health personnel attitude/ or health promotion/ or help seeking behavior/ or hotline/ or information/ or information center/ or information dissemination/ or information seeking/ or information service/ or exp internet/ or exp interpersonal communication/ or exp mass communication/ or medical information/ or mobile application/ or exp mobile phone/ or patient advocacy/ or patient decision making/ or patient education/ or patient information/ or exp patient participation/ or exp patient safety/ or peer group/ or personal digital assistant/ or professional knowledge/ or psychological aspect/ or psychosocial care/ or publication/ or radio/ or exp self help/ or social media/ or social network/ or social support/ or support group/ or teleconsultation/ or telehealth/ or telemedicine/ or telephone/ or telephone support/ or television/ or text messaging/ or text messaging support/ or uncertainty/ or visual information/ or web-based intervention/ or web browser/ or webcast/ or webinar/
5	((daily or decision or function* or group* or psycho*) adj2 support*).tw.
6	(app or apps or blog* or booklet* or brochure* or cellphone* or cell phone* or discussion* or download* or dvd* or elearn* or e-learn* or email* or e mail* or facebook or facetime or fora or forum* or google or handout* or hand out* or helpline* or help line* or hotline* or hot line* or ict or information* or internet* or ipad* or iphone* or leaflet* or letter* or magazine* or manual or manuals or media or messag* board or mobile* or myspace or newsletter* or pamphlet* or phone* or podcast* or poster? or publication* or skype* or smartphone* or social media or social network* or sms or telephone* or text messag* or tiktok or twitter or tweet* or video* or webpage* or web page* or web based or web search or website* or web site* or wiki* or written or youtube* or zoom or helpseek* or help seek* or healthcareseek* or healthcare seek* or healthseek* or health seek* or care seek* or careseek*).ti,ab.
7	((brother* or carer* or caregiv* or care giv* or famil* or father* or mother* or parent* or relative* or sibling* or sister* or consumer* or inpatient* or patient* or person or people or population or user* or audiologist* or clinician* or counselor* or counsellor* or doctor* or general practi* or gp? or health visitor* or coordinator* or nurs* or officer* or personal assistant* or personnel or physician* or practitioner* or primary care or professional* or psychiatrist* or psychologist* or worker* or community team*) adj2 (advice or advise? or advising or communicat* or educat* or guid* or inform* or involv* or knowledge* or learn* or support* or understand*)).ti,ab.
8	((information* or support* or advice or guidance) adj2 (access* or contact* or disseminat* or model* or need* or prOVID* or provision or program* or requir* or resource* or seek* or service* or shar*)).ti,ab.
9	((communicat* or inform* or support*) adj2 (accura* or barrier* or benefi* or clear* or facilitat* or help* or hinder* or hindran* or practical* or support*)).ti,ab.
10	((information* or support* or advice or guidance) adj2 (aid* or content* or format* or handout* or hand out* or method* or quality or sheet* or symptom* or type*)).ti,ab.
11	((added or additional or extra or further or prompt* or time* or timing or when) adj3 (advice or informat* or support* or guidance)).ti,ab.
12	or/4-11
13	3 and 12
14	cluster analysis/ or content analysis/ or discourse analysis/ or ethnography/ or grounded theory/ or health care survey/ or exp interviews/ or narrative/ or nursing methodology research/ or observation/ or personal experience/ or phenomenology/ or qualitative research/ or questionnaire/ or exp recording/
15	(qualitative* or interview* or focus or questionnaire* or narrative* or narration* or survey* or experience* or themes).tw.
16	(ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic adj4 analys*) or theoretical sampl* or purposive sampl*).tw.
17	(hermeneutic* or heidegger* or husser* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*).tw.
18	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them*).tw.
19	(critical interpretive synthes* or (realist adj (review* or synthes*)) or (noblit and hare) or (meta adj (method or triangulation)) or (cerqual or conqual) or ((thematic or framework) adj synthes*)).tw.

#	Searches
20	or/14-19
21	parental attitude/ or patient satisfaction/ or patient preference/ or personal experience/
22	(dissatisf* or expect* or experienc* or opinion* or perceive* or perception* or perspective* or prefer* or satisf* or view*).ti.
23	((child* or adolescen* or boy? or girl? or infan* or juvenile? or kid? or kindergar* or minors or p?ediatric* or prepubert* or pre pubert* or prepubescen* or pre pubescent or preschool* or pre school* or preteen* or pre teen* or schoolchild* or school age? or toddler* or young or adult* or people* or population* or consumer* or patient* or user* or parent* or grandparent? or famil* or relati* or carer* or caregiver* or care giver* or inpatient* or inpatient* or mother* or father* or grandmother? or grandfather? or sibling* or sister* or brother*) adj6 (attitude* or concern* or dissatisf* or expect* or experienc* or opinion* or perceive* or perception* or perspective* or prefer* or satisf* or view*)).ti,ab.
24	or/21-23
25	20 or 24
26	13 and 25
27	limit 26 to english language
28	limit 27 to yr="2000 -Current"
29	(animal/ not human/) or nonhuman/ or exp animal experiment/ or exp experimental animal/ or animal model/ or exp rodent/ or (rat or rats or mouse or mice).ti.
30	28 not 29
31	limit 30 to (conference abstract or conference paper or conference review or conference proceeding)
32	30 not 31

Database: CINAHL – Ebsco interface

Date last searched: 09/11/2022

#	Query	Limiters/Expanders
S23	S14 AND S25	Limiters - Publication Year: 2000-2022; English Language
S25	S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24	
S24	TI ((child* or adolescen* or boy? or girl? or infan* or juvenile? or kid? or kindergar* or minors or p#ediatric* or prepubert* or "pre pubert*" or prepubescen* or "pre pubescen*" or preschool* or "pre school*" or preteen* or "pre teen*" or schoolchild* or "school age?" or toddler* or young or adult* or people* or population* or consumer* or patient* or user* or parent* or grandparent? or famil* or relati* or carer* or caregiver* or "care giver*" or inpatient* or mother* or grandmother? or father* or grandfather? or sibling* or sister* or brother*) N6 (attitude* or concern* or dissatisf* or expect* or experienc* or opinion* or perceive* or perception* or perspective* or prefer* or satisf* or view*)) OR AB ((child* or adolescen* or boy? or girl? or infan* or juvenile? or kid? or kindergar* or minors or p#ediatric* or prepubert* or "pre pubert*" or prepubescen* or "pre pubescen*" or preschool* or "pre school*" or preteen* or "pre teen*" or schoolchild* or "school age?" or toddler* or young or adult* or people* or population* or consumer* or patient* or user* or parent* or grandparent? or famil* or relati* or carer* or caregiver* or "care giver*" or inpatient* or mother* or grandmother? or father* or grandfather? or sibling* or sister* or brother*) N6 (attitude* or concern* or dissatisf* or expect* or experienc* or opinion* or perceive* or perception* or perspective* or prefer* or satisf* or view*))	
S23	TI (dissatisf* or expect* or experienc* or opinion* or perceive* or perception* or perspective* or prefer* or satisf* or view*)	
S22	(MH "Patient Satisfaction+")	
S21	TI ("critical interpretive synthes*" or (realist N1 (review* or synthes*)) or (noblit and hare) or (meta N1 (method or triangulation)) or (cerqual or conqual) or ((thematic or framework) N1 synthes*)) OR AB ("critical interpretive synthes*" or (realist N1 (review* or synthes*)) or (noblit and hare) or (meta N1 (method or triangulation)) or (cerqual or conqual) or ((thematic or framework) N1 synthes*))	
S20	TI (metasynthes* or "meta synthes*" or metasummar* or "meta summar*" or metastud* or "meta stud*" or metathem* or "meta them*") OR AB (metasynthes* or "meta synthes*" or metasummar* or "meta summar*" or metastud* or "meta stud*" or metathem* or "meta them*")	
S19	TI (hermeneutic* or heidegger* or husser* or colaizzi* or "van kaam*" or "van manen*" or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*) OR AB (hermeneutic* or heidegger* or husser* or colaizzi* or "van kaam*" or "van manen*" or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*)	
S18	TI (ethno* or emic or etic or phenomenolog* or "grounded theory" or "constant compar*" or (thematic N4 analys*) or "theoretical sampl*" or "purposive sampl*") OR AB (ethno* or emic or etic or phenomenolog* or "grounded theory" or "constant compar*" or (thematic N4 analys*) or "theoretical sampl*" or "purposive sampl*")	
S17	TI (qualitative* or interview* or focus or questionnaire* or narrative* or narration* or survey* or experience* or themes) OR AB (qualitative* or interview* or focus or questionnaire* or narrative* or narration* or survey* or experience* or themes)	
S16	PT interview	

#	Query	Limiters/Expanders
S15	(MH "Anthropology, Cultural") OR (MH "Cluster Analysis+") OR (MH "Focus Groups") OR (MH "Grounded Theory") OR (MH "Surveys") OR (MH "Interviews+") OR (MH "Narratives+") OR (MH "Nursing Practice, Research-Based") OR (MH "Observational Methods+") OR (MH "Qualitative Studies+") OR (MH "Questionnaires+") OR (MH "Sampling Methods+") OR (MH "Audiorecording") OR (MH "Videorecording")	
S14	S3 AND S13	
S13	S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12	
S12	TI ((added or additional or extra or further or prompt* or time* or timing or when) N3 (advice or informat* or support* or guidance)) OR AB ((added or additional or extra or further or prompt* or time* or timing or when) N3 (advice or informat* or support* or guidance))	
S11	TI ((information* or support* or advice or guidance) N2 (aid* or content* or format* or handout* or "hand out*" or method* or quality or sheet* or symptom* or type*))) OR AB (((information* or support* or advice or guidance) N2 (aid* or content* or format* or handout* or "hand out*" or method* or quality or sheet* or symptom* or type*))	
S10	TI ((communicat* or inform* or support*) N2 (accura* or barrier* or benefi* or clear* or facilitat* or help* or hinder* or hindran* or practical* or support*)) OR AB ((communicat* or inform* or support*) N2 (accura* or barrier* or benefi* or clear* or facilitat* or help* or hinder* or hindran* or practical* or support*))	
S9	TI ((information* or support* or advice or guidance) N2 (access* or contact* or disseminat* or model* or need* or prOVID* or provision or program* or requir* or resource* or seek* or service* or shar*)) OR AB ((information* or support* or advice or guidance) N2 (access* or contact* or disseminat* or model* or need* or prOVID* or provision or program* or requir* or resource* or seek* or service* or shar*))	
S8	TI ((brother* or carer* or caregiv* or "care giv* " or famil* or father* or grandfather? or husband* or mother* or grandparent? or wife* or wive* or parent* or grandparent? or partner* or relative* or sibling* or sister* or spous* or consumer* or inpatient* or man or men or patient* or person or people or population or user* or women or woman or audiologist* or clinician* or counselor* or counsellor* or doctor* or "general practi*" or gp? or "health visitor* " or coordinator* or nurs* or officer* or "personal assistant* " or personnel or physician* or practitioner* or "primary care " or professional* or psychiatrist* or psychologist* or worker* or "community team* ") N2 (advice or advise? or advising or communicat* or educat* or guid* or inform* or involv* or knowledge* or learn* or support* or understand*)) OR AB ((brother* or carer* or caregiv* or "care giv* " or famil* or father* or grandfather? or husband* or mother* or grandparent? or wife* or wive* or parent* or grandparent? or partner* or relative* or sibling* or sister* or spous* consumer* or inpatient* or man or men or patient* or person or people or population or user* or women or woman or audiologist* or clinician* or counselor* or counsellor* or doctor* or "general practi*" or gp? or "health visitor* " or coordinator* or nurs* or officer* or "personal assistant* " or personnel or physician* or practitioner* or "primary care " or professional* or psychiatrist* or psychologist* or worker* or "community team*") N2 (advice or advise? or advising or communicat* or educat* or guid* or inform* or involv* or knowledge* or learn* or support* or understand*))	
S7	TI (app or apps or blog* or booklet* or brochure* or cellphone* or "cell phone*" or discussion* or download* or dvd* or elearn* or "e learn*" or email* or "e mail*" or facebook or facetime or fora or forum* or google or handout* or "hand out*" or helpline* or "help line*" or hotline* or "hot line*" or ict or information* or internet* or ipad* or iphone* or leaflet* or letter* or magazine* or manual or manuals or media or "messag* board" or mobile* or myspace or newsletter* or pamphlet* or phone* or podcast* or poster? or publication* or skype* or smartphone* or "social media" or "social network*" or sms or telephone* or text messag* or twitter or tweet* or video* or webpage* or "web page*" or "web based" or "web search*" or website* or "web site*" or wiki* or written or youtube* or zoom or helpseek* or "help seek*" or healthcareseek* or "healthcare seek*" or healthseek* or "health seek*" or "care seek*" or careseek*) OR AB (app or apps or blog* or booklet* or brochure* or cellphone* or "cell phone*" or discussion* or download* or dvd* or elearn* or "e-learn*" or email* or "e mail*" or facebook or facetime or fora or forum* or google or handout* or "hand out*" or helpline* or "help line*" or hotline* or "hot line*" or ict or information* or internet* or ipad* or iphone* or leaflet* or letter* or magazine* or manual or manuals or media or "messag* board" or mobile* or myspace or newsletter* or pamphlet* or phone* or podcast* or poster? or publication* or skype* or smartphone* or "social media" or "social network*" or sms or telephone* or text messag* or twitter or tweet* or video* or webpage* or "web page*" or "web based" or "web search*" or website* or "web site*" or wiki* or written or youtube* or zoom or helpseek* or "help seek*" or healthcareseek* or "healthcare seek*" or healthseek* or "health seek*" or "care seek*" or careseek*)	
S6	TI ((daily or decision or function* or group* or psycho*) N2 support*) OR AB ((daily or decision or function* or group* or psycho*) N2 support*)	
S5	MH ("Audiovisuals+" or “"Communication Barriers+" or “Communications Media+” or “Community Health Services+” or “Computers, Handheld+” or “Counseling+” or “Health Information Management+” or “Internet+” or “Mobile Phone+” or “Nurses+” or “Patient Care Team+” or “Professional-Patient Relations+” or “Psychotherapy+” or “Social Networking+” or “Social Support+” or “Video-Audio Media+”)	

#	Query	Limiters/Expanders
S4	MH ("Access to Information" or "Activities of Daily Living" or "Audiologists" or "Audiologist Attitudes" or "Attitude of Health Personnel" or "Communication"or "Consumer Advocacy" or "Consumer Health Information" or "Decision Making" or "Decision Support Systems, Clinical" or "Electronic Mail" or Empowerment or "Government Publications as Topic" or "Health Communication" or "Health Education" or "Health Knowledge, Attitudes, Practice" or "Health Literacy" or "Health Promotion" or "Help-Seeking Behavior" or "Hotlines" or "Information Centers" or "Information Dissemination" or "Information Seeking Behavior" or "Information Services" or "Internet-Based Intervention" or "Mass Media" or "Mobile Applications" or "Pamphlets" or "Patient Advocacy" or "Patient Education as Topic" or "Patient Education Handout" or "Patient Medication Knowledge" or "Patient Participation" or "Patient Safety" or "Peer Group" or "Radio" or "Self-Help Groups" or "Social Media" or "Telemedicine" or "Telephone" or Television or "Text Messaging" or "Therapy, Computer-Assisted" or "Uncertainty" or "Web Browser")	
S3	S1 OR S2	
S2	TI ("glue ear " or (("middle ear " or "otitis media ") N2 effusion*) or ome or ((secretory or serous) N2 "otitis media ")) OR AB ("glue ear " or (("middle ear " or "otitis media ") N2 effusion*) or ome or ((secretory or serous) N2 "otitis media "))	
S1	(MH "Otitis Media with Effusion")	

Database: Cochrane Database of Systematic Reviews (CDSR); Cochrane Central Register of Controlled Trials (CENTRAL) – Wiley interface

Date last searched: 09/11/2022

ID	Search
#1	MeSH descriptor: [Otitis Media with Effusion] this term only
#2	(("glue ear" or (("middle ear" or "otitis media") near/2 effusion*) or ome or ((secretory or serous) near/2 "otitis media"))):ti,ab,kw
#3	#1 or #2
#4	MeSH descriptor: [Audiovisual Aids] explode all trees
#5	MeSH descriptor: [Communication Barriers] explode all trees
#6	MeSH descriptor: [Communications Media] explode all trees
#7	MeSH descriptor: [Community Health Services] explode all trees
#8	MeSH descriptor: [Computers, Handheld] explode all trees
#9	MeSH descriptor: [Counseling] explode all trees
#10	MeSH descriptor: [Health Information Management] explode all trees
#11	MeSH descriptor: [Internet] explode all trees
#12	MeSH descriptor: [Cell Phone] explode all trees
#13	MeSH descriptor: [Nursing] explode all trees
#14	MeSH descriptor: [Patient Care Team] explode all trees
#15	MeSH descriptor: [Professional-Patient Relations] explode all trees
#16	MeSH descriptor: [Psychotherapy] explode all trees
#17	MeSH descriptor: [Social Networking] explode all trees
#18	MeSH descriptor: [Social Support] explode all trees
#19	(Access to Information or Activities of Daily Living or Attitude of Health Personnel or Communication or Consumer Advocacy or Consumer Health Information or Decision Making or Decision Support Systems, Clinical or Electronic Mail or Empowerment or Government Publications as Topic or Health Communication or Health Education or Health Knowledge, Attitudes, Practice or Health Literacy or Health Promotion or Help-Seeking Behavior or Hotlines or Information Centers or Information Dissemination or Information Seeking Behavior or Information Services or Internet-Based Intervention or Mass Media or Mobile Applications or Pamphlets or Patient Advocacy or Patient Education as Topic or Patient Education Handout or Patient Medication Knowledge or Patient Participation or Patient Preference or Patient Safety or Patient Satisfaction or Peer Group or Radio or Self-Help Groups or Social Media or Telemedicine or Telephone or Television or Text Messaging or Therapy, Computer-Assisted or Uncertainty or Web Browser):kw
#20	((daily or decision or function* or group* or psycho*) near/2 support*):ti,ab
#21	(app or apps or blog* or booklet* or brochure* or cellphone* or "cell phone*" or discussion* or download* or dvd* or elearn* or "e learn*" or email* or "e mail*" or facebook or facetime or fora or forum* or google or handout* or "hand out*" or helpline* or "help line*" or hotline* or "hot line*" or ict or information* or internet* or ipad* or iphone* or leaflet* or letter* or magazine* or manual or manuals or media or "messag* board" or mobile* or myspace or newsletter* or pamphlet* or phone* or podcast* or poster? or publication* or skype* or smartphone* or "social media" or "social network*" or sms or telephone* or "text messag*" or tiktok or twitter or tweet* or video* or webpage* or "web page*" or "web based" or "web search*" or website* or "web site*" or wiki* or written or youtube* or zoom or helpseek* or "help seek*" or healthcareseek* or "healthcare seek*" or healthseek* or "health seek*" or "care seek*" or careseek*):ti,ab
#22	((brother* or carer* or caregiv* or "care giv*" or famil* or father* or mother* or parent* or grandparent? or grandmother? or grandfather? or relative* or sibling* or sister* or consumer* or inpatient* or patient* or person or people or population or user* or audiologist* or clinician* or counselor* or counsellor* or doctor* or "general practi*" or gp? or "health visitor*" or coordinator* or nurs* or officer* or "personal assistant*" or personnel or physician* or practitioner* or "primary care" or professional* or psychiatrist* or psychologist* or worker* or "community team*") near/2 (advice or advise? or advising or communicat* or educat* or guid* or inform* or involv* or knowledge* or learn* or support* or understand*)):ti,ab

ID	Search
#23	((information* or support* or advice or guidance) near/2 (access* or contact* or disseminat* or model* or need* or prefer* or prOVID* or provision or program* or requir* or resource* or seek* or service* or shar* or view*)):ti,ab
#24	((communicat* or inform* or support*) near/2 (accura* or clear* or help* or support* or benefi* or hinder* or hindran* or barrier* or facilitat* or practical* or prefer* or view*)):ti,ab
#25	((information* or support* or advice or guidance) near/2 (aid* or content* or format* or handout* or "hand out*" or method* or quality or sheet* or symptom* or type*)):ti,ab
#26	((added or additional or extra or further or prompt* or time* or timing or when) near/3 (advice or informat* or support* or guidance)):ti,ab
#27	"patient education handout":pt
#28	{or #4-#27}
#29	#3 and #28 with Cochrane Library publication date Between Jan 2000 and Nov 2022
#30	"conference":pt or (clinicaltrials or trialsearch):so
#31	#29 not #30

Database: Epistemonikos

Date last searched: 09/11/2022

#	Searches
1	(title:(("glue ear" OR (("middle ear" OR "otitis media") AND effusion*) OR ome OR ((secretory OR serous) AND "otitis media"))) OR abstract:(("glue ear" OR (("middle ear" OR "otitis media") AND effusion*) OR ome OR ((secretory OR serous) AND "otitis media")))
2	(title:((app OR apps OR blog* OR booklet* OR brochure* OR cellphone* OR discussion* OR download* OR dvd* OR elearn* OR "e learn" OR "e learning" OR email* OR "e mail" OR "e mails" OR facebook OR facetime OR fora OR forum* OR google OR handout* OR "hand out" OR "hand outs" OR helpline* OR "help line" OR "help lines" OR hotline* OR "hot line" OR "hot lines" OR ict OR information* OR internet* OR ipad* OR iphone* OR leaflet* OR letter* OR magazine* OR manual OR manuals OR media OR message* OR messaging OR mobile* OR myspace OR network* OR newsletter* OR pamphlet* OR phone* OR podcast* OR poster* OR publication* OR skype* OR smartphone* OR "social media" OR sms OR telephone* OR text* OR tiktok OR twitter OR tweet* OR video* OR web* OR wiki* OR written OR youtube* OR zoom OR helpseek* OR "help seek*" OR healthcareseek* OR "healthcare seek*" OR healthseek* OR "health seek*" OR "care seek*" OR careseek* OR advice OR advis* OR communicat* OR educat* OR guid* OR inform* OR involv* OR knowledge* OR learn* OR support* OR understand*)) OR abstract:((app OR apps OR blog* OR booklet* OR brochure* OR cellphone* OR discussion* OR download* OR dvd* OR elearn* OR "e learn" OR "e learning" OR email* OR "e mail" OR "e mails" OR facebook OR facetime OR fora OR forum* OR google OR handout* OR "hand out" OR "hand outs" OR helpline* OR "help line" OR "help lines" OR hotline* OR "hot line" OR "hot lines" OR ict OR information* OR internet* OR ipad* OR iphone* OR leaflet* OR letter* OR magazine* OR manual OR manuals OR media OR message* OR messaging OR mobile* OR myspace OR network* OR newsletter* OR pamphlet* OR phone* OR podcast* OR poster* OR publication* OR skype* OR smartphone* OR "social media" OR sms OR telephone* OR text* OR tiktok OR twitter OR tweet* OR video* OR web* OR wiki* OR written OR youtube* OR zoom OR helpseek* OR "help seek*" OR healthcareseek* OR "healthcare seek*" OR healthseek* OR "health seek*" OR "care seek*" OR careseek* OR advice OR advis* OR communicat* OR educat* OR guid* OR inform* OR involv* OR knowledge* OR learn* OR support* OR understand*)))
3	1 AND 2
4	[Filters: min_year=2000, max_year=2022]

Database: International Network of Agencies for Health Technology Assessment (INAHTA)

Date last searched: 09/11/2022

#	Searches
1	"Otitis Media with Effusion"[mhe]
2	((glue ear or ((middle ear or otitis media) and effusion*) or ome or ((secretory or serous) and otitis media))
3	1 OR 2
4	(advice or advis* or app or apps or blog* or booklet* or brochure* or cellphone* or communicat* or discussion* or download* or dvd* or educat* or elearn* or “e learn” or “e learning” or email* or “e mail” or “e mails” or facebook or facetime or fora or forum* or google or guid* or handout* or “hand out” or “hand outs” or helpline* or “help line” or “help lines” or hotline* or “hot line” or “hot lines” or ict or inform* or internet* or involv* or ipad* or iphone* or knowledge* or leaflet* or learn* or letter* or magazine* or manual or manuals or media or messag* or myspace or network* or newsletter* or pamphlet* or phone* or podcast* or poster* or publication* or skype* or smartphone* or “social media” or sms or support* or telephone* or text* or twitter or tweet* or understand* or video* or web* or wiki* or written or youtube* or zoom or helpseek* or “help seek” or healthcareseek* or “healthcare seek” or healthseek* or “health seek” or “care seek” or careseek*)
5	3 AND 4 FROM 2000 TO 2022 AND (English)[Language]

Database: APA PsycInfo – OVID interface

Date last searched: 09/11/2022

#	Searches
1	(glue ear or ((middle ear or otitis media) adj2 effusion*) or ome or ((secretory or serous) adj2 otitis media)).ti,ab.

#	Searches
2	Activities of Daily Living/ or exp Advocacy/ 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 Counseling/ or exp Decision Support Systems/ or exp Digital Interventions/ or exp Educational Programs/ or exp Empowerment/ or exp Health Attitudes/ or exp Health Care Utilization/ or exp Health Education/ or exp Health Personnel/ or exp Health Personnel Attitudes/ or exp Help Seeking Behavior/ or exp Health Literacy/ or exp Health Promotion/ or exp Hot Line Services/ or exp "Information and Communication Technology"/ or exp Information/ or Information Services/ or exp Mobile Devices/ or exp Peers/ or exp Reading Materials/ or exp Self-Help Techniques/ or exp Support Groups/ or Treatment Barriers/ or Treatment Compliance/ or exp Uncertainty/
3	((daily or decision or function* or group* or psycho*) adj2 support*).ti,ab.
4	(app or apps or blog* or booklet* or brochure* or cellphone* or cell phone* or discussion* or download* or dvd* or elearn* or e-learn* or email* or e mail* or facebook or facetime or fora or forum* or google or handout* or hand out* or helpline* or help line* or hotline* or hot line* or ict or information* or internet* or ipad* or iphone* or leaflet* or letter* or magazine* or manual or manuals or media or messag* board or mobile* or myspace or newsletter* or pamphlet* or phone* or podcast* or poster? or publication* or skype* or smartphone* or social media or social network* or sms or telephone* or text messag* or tiktok or twitter or tweet* or video* or webpage* or web page* or web based or web search or website* or web site* or wiki* or written or youtube* or zoom or helpseek* or help seek* or healthcareseek* or healthcare seek* or healthseek* or health seek* or care seek* or careseek*).ti,ab.
5	((brother* or carer* or caregiv* or care giv* or famil* or father* or mother* or parent* or grandparent? or grandmother? or grandfather? or relative* or sibling* or sister* or consumer* or inpatient* or patient* or person or people or population or user* or audiologist* or clinician* or counselor* or counsellor* or doctor* or general practi* or gp? or health visitor* or coordinator* or nurs* or officer* or personal assistant* or personnel or physician* or practitioner* or primary care or professional* or psychiatrist* or psychologist* or worker* or community team*) adj2 (advice or advise? or advising or communicat* or educat* or guid* or inform* or involv* or knowledge* or learn* or support* or understand*)).ti,ab.
6	((information* or support* or advice or guidance) adj2 (access* or contact* or disseminat* or model* or need* or prOVID* or provision or program* or requir* or resource* or seek* or service* or shar*)).ti,ab.
7	((communicat* or inform* or support*) adj2 (accura* or barrier* or benefi* or clear* or facilitat* or help* or hinder* or hindran*or or practical* or support*)).ti,ab.
8	((information* or support* or advice or guidance) adj2 (aid* or content* or format* or handout* or hand out* or method* or quality or sheet* or symptom* or type*)).ti,ab.
9	((added or additional or extra or further or prompt* or time* or timing or when) adj3 (advice or informat* or support* or guidance)).ti,ab.
10	or/2-9
11	1 and 10
12	"EXPERIENCES (EVENTS)"/ or CLUSTER ANALYSIS/ or FOCUS GROUP/ or CONTENT ANALYSIS/ or DISCOURSE ANALYSIS/ or ETHNOGRAPHY/ or GROUNDED THEORY/ or INTERVIEWERS/ or INTERVIEWING/ or INTERVIEWS/ or NARRATIVES/ or OBSERVATION METHODS/ or PHENOMENOLOGY/ or QUALITATIVE METHODS/ or QUESTIONNAIRES/ or QUESTIONING/ or exp SURVEYS/ or TAPE RECORDERS/
13	(qualitative* or interview* or focus or questionnaire* or narrative* or narration* or survey* or experience* or themes).tw.
14	(ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic adj4 analys*) or theoretical sampl* or purposive sampl*).tw.
15	(hermeneutic* or heidegger* or husser* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*).tw.
16	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them*).tw.
17	(critical interpretive synthes* or (realist adj (review* or synthes*)) or (noblit and hare) or (meta adj (method or triangulation)) or (cerqual or conqual) or ((thematic or framework) adj synthes*)).tw.
18	or/12-17
19	Client Satisfaction/ or exp Parental Attitudes/
20	(dissatisf* or expect* or experienc* or opinion* or perceiv* or perception* or perspective* or prefer* or satisf* or view*).ti.
21	((child* or adolescen* or boy? or girl? or infan* or juvenile? or kid? or kindergar* or minors or p?ediatric* or prepubert* or pre pubert* or prepubescen* or pre pubescen* or preschool* or pre school* or preteen* or pre teen* or schoolchild* or school age? or toddler* or young or adult* or people* or population* or consumer* or patient* or user* or parent* or grandparent* or famil* or relati* or carer* or caregiver* or care giver* or inpatient* or mother* or father* or grandmother* or grandfather* or sibling* or sister* or brother*) adj6 (attitude* or concern* or dissatisf* or expect* or experienc* or opinion* or perceiv* or perception* or perspective* or prefer* or satisf* or view*)).ti,ab.
22	or/18-21
23	11 and 22
24	animal.po.
25	(rat or rats or mouse or mice).ti.
26	or/24-25
27	23 not 26
28	limit 27 to english language
29	limit 28 to yr="2000 -Current"

Economic literature search strategy

A global, population-based search was undertaken to find economic evidence covering all parts of the guideline.

Database: MEDLINE – OVID interface

Date last searched: 09/11/2022

#	Searches
1	otitis media with effusion/
2	(glue ear or ((middle ear or otitis media) adj2 effusion*) or ome or ((secretory or serous) adj2 otitis media)).ti,ab.
3	1 or 2
4	Economics/
5	Value of life/
6	exp "Costs and Cost Analysis"/
7	exp Economics, Hospital/
8	exp Economics, Medical/
9	Economics, Nursing/
10	Economics, Pharmaceutical/
11	exp "Fees and Charges"/
12	exp Budgets/
13	budget*.ti,ab.
14	cost*.ti.
15	(economic* or pharmaco?economic*).ti.
16	(price* or pricing*).ti,ab.
17	(cost* adj2 (effective* or utilit* or benefit* or minimi* or unit* or estimat* or variable*)).ab.
18	(financ* or fee or fees).ti,ab.
19	(value adj2 (money or monetary)).ti,ab.
20	or/4-19
21	exp models, economic/
22	*Models, Theoretical/
23	*Models, Organizational/
24	markov chains/
25	monte carlo method/
26	exp Decision Theory/
27	(markov* or monte carlo).ti,ab.
28	econom* model*.ti,ab.
29	(decision* adj2 (tree* or analy* or model*)).ti,ab.
30	or/21-29
31	20 or 30
32	3 and 31
33	(animals/ not humans/) or exp animals, laboratory/ or exp animal experimentation/ or exp models, animal/ or exp rodentia/ or (rat or rats or mouse or mice).ti.
34	32 not 33
35	limit 34 to english language
36	limit 35 to yr="2000 -Current"

Database: Embase – OVID interface

Date last searched: 09/11/2022

#	Searches
1	exp secretory otitis media/
2	(glue ear or ((middle ear or otitis media) adj2 effusion*) or ome or ((secretory or serous) adj2 otitis media)).ti,ab.
3	1 or 2
4	health economics/
5	exp economic evaluation/
6	exp health care cost/
7	exp fee/
8	budget/
9	funding/
10	budget*.ti,ab.
11	cost*.ti.
12	(economic* or pharmaco?economic*).ti.
13	(price* or pricing*).ti,ab.
14	(cost* adj2 (effective* or utilit* or benefit* or minimi* or unit* or estimat* or variable*)).ab.
15	(financ* or fee or fees).ti,ab.
16	(value adj2 (money or monetary)).ti,ab.
17	or/4-16
18	statistical model/
19	exp economic aspect/

#	Searches
20	18 and 19
21	*theoretical model/
22	*nonbiological model/
23	stochastic model/
24	decision theory/
25	decision tree/
26	monte carlo method/
27	(markov* or monte carlo).ti,ab.
28	econom* model*.ti,ab.
29	(decision* adj2 (tree* or analy* or model*)).ti,ab.
30	or/20-29
31	17 or 30
32	3 and 31
33	(animal/ not human/) or nonhuman/ or exp animal experiment/ or exp experimental animal/ or animal model/ or exp rodent/ or (rat or rats or mouse or mice).ti.
34	32 not 33
35	limit 34 to english language
36	limit 35 to yr="2000 -Current"

Database: Cochrane Central Register of Controlled Trials (CENTRAL) – Wiley interface

Date last searched: 09/11/2022

ID	Search
#1	MeSH descriptor: [Otitis Media with Effusion] this term only
#2	(("glue ear" or (("middle ear" or "otitis media") near/2 effusion*) or ome or ((secretory or serious) near/2 "otitis media"))):ti,ab,kw
#3	#1 or #2
#4	MeSH descriptor: [Economics] this term only
#5	MeSH descriptor: [Value of Life] this term only
#6	MeSH descriptor: [Costs and Cost Analysis] explode all trees
#7	MeSH descriptor: [Economics, Hospital] explode all trees
#8	MeSH descriptor: [Economics, Medical] explode all trees
#9	MeSH descriptor: [Economics, Nursing] this term only
#10	MeSH descriptor: [Economics, Pharmaceutical] this term only
#11	MeSH descriptor: [Fees and Charges] explode all trees
#12	MeSH descriptor: [Budgets] explode all trees
#13	budget*:ti,ab
#14	cost*:ti
#15	(economic* or pharmaco?economic*):ti
#16	(price* or pricing*):ti,ab
#17	(cost* near/2 (effective* or utilit* or benefit* or minimi* or unit* or estimat* or variable*)):ab
#18	(financ* or fee or fees):ti,ab
#19	(value near/2 (money or monetary)):ti,ab
#20	{or #4-#19}
#21	MeSH descriptor: [Models, Economic] explode all trees
#22	MeSH descriptor: [Models, Theoretical] this term only
#23	MeSH descriptor: [Models, Organizational] this term only
#24	MeSH descriptor: [Markov Chains] this term only
#25	MeSH descriptor: [Monte Carlo Method] this term only
#26	MeSH descriptor: [Decision Theory] explode all trees
#27	(markov* or "monte carlo"):ti,ab
#28	(econom* next model*):ti,ab
#29	(decision* near/2 (tree* or analy* or model*)):ti,ab
#30	{or #21-#29}
#31	#20 or #30
#32	#3 and #31 with Cochrane Library publication date Between Jan 2000 and Apr 2022

Database: International Network of Agencies for Health Technology Assessment (INAHTA)

Date last searched: 09/11/2022

#	Searches
1	((("Otitis Media with Effusion"[mhe]) OR ((("glue ear" or (("middle ear" or "otitis media") and effusion*) or ome or ((secretory or serous) and "otitis media")))
2	1 and FROM 2000 TO 2022 AND (English)[Language]

Database: NHS Economic Evaluation Database (NHS EED) – CRD interface

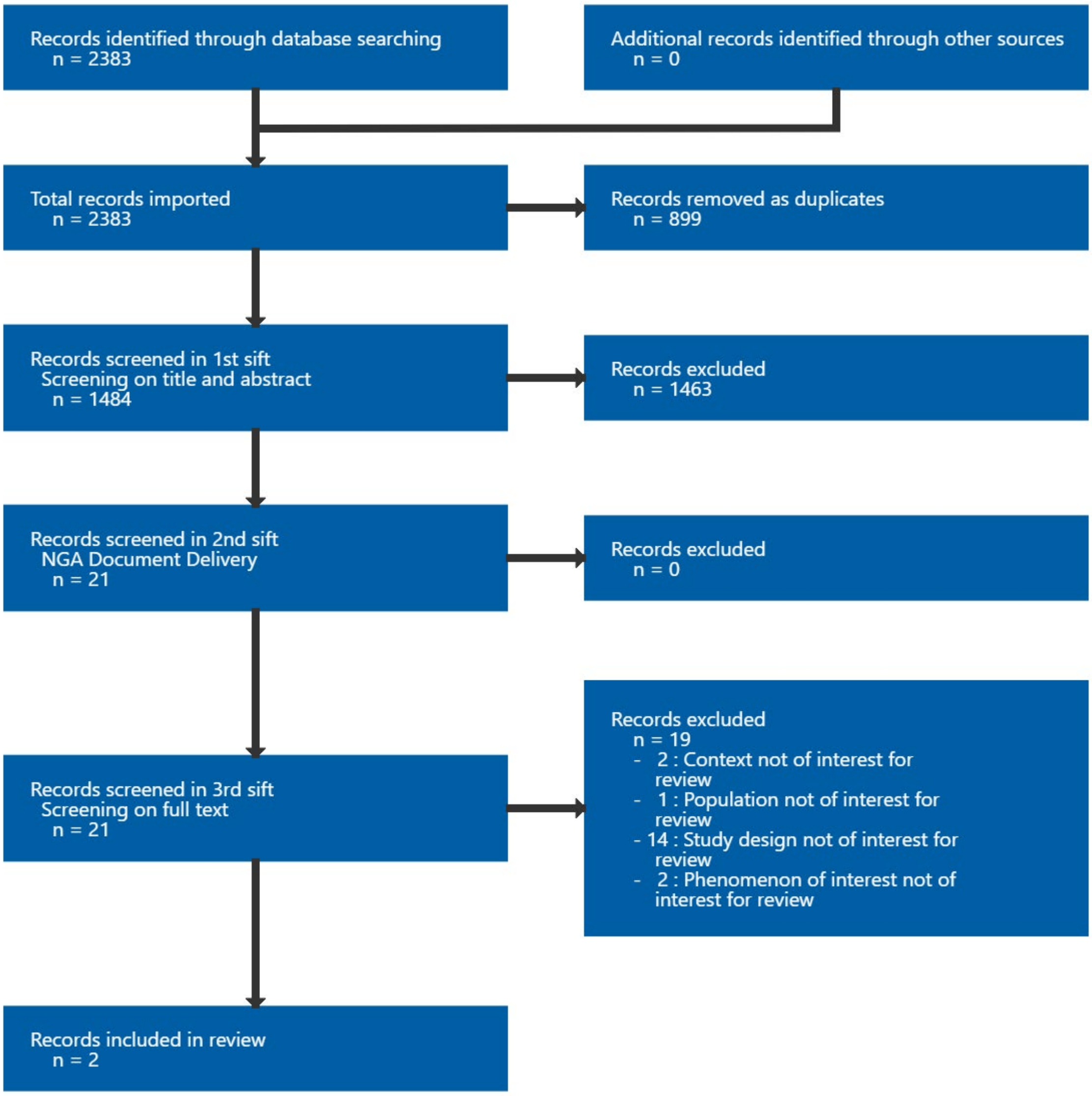
Date last searched: 09/11/2022

Line	Search for
1	MeSH DESCRIPTOR Otitis Media with Effusion EXPLODE ALL TREES
2	((glue ear or ((middle ear or otitis media) and effusion*) or ome or ((secretory or serous) and otitis media))) IN NHS EED
3	#1 OR #2

Appendix C Qualitative evidence study selection

Study selection for: What information is valued by children under 12 years with suspected or confirmed OME and their parents and carers?

Figure 2: Study selection flow chart



Appendix D Evidence tables

Evidence tables for review question: What information is valued by children under 12 years with suspected or confirmed OME and their parents and carers?

Table 4: Evidence tables

Gkiousias, 2016

Bibliographic Reference	Gkiousias, Vasileios; Butler, Christopher Collett; Shepherd, Victoria; Kilgour, James Michael; Waldron, Cherry-Ann; Thomas-Jones, Emma; Francis, Nick; Parental perceptions and understanding of information provision, management options and factors influencing the decision-making process in the treatment of children with glue ear.; International journal of pediatric otorhinolaryngology; 2016; vol. 89; 6-12

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	United Kingdom
Setting	Parents of children with OME who attended an Ear, Nose and Throat (ENT) outpatient clinic and had been recruited as part of the Oral STeroids for Resolution of otitis media with effusion In CHildren (OSTRICH) Study
Data collection and analysis	Semi-structured interviews were used to collect data. Analysis was conducted using an inductive thematic approach
Recruitment strategy	As part of the OSTRICH study, child participants were recruited through convenience sampling from ENT clinics across a number of UK hospitals. For this present study, parents of children were recruited through convenience sampling at a single site, a hospital in South Wales, UK. Parents of children enrolled as part of the OSTRICH study were approached about participating in an optional semi-structured interview
Study dates	June 2014 to January 2015
Sources of funding	Not industry funded

Inclusion criteria	OSTRICH study inclusion criteria • Between two and nine years of age • Had symptoms of hearing loss attributable to OME for at least three months (or audiometry proving hearing loss for at least three months) • Had a diagnosis of bilateral OME made in an ENT clinic on the day of recruitment or during the preceding week • Had audiometry confirming hearing loss on the day of recruitment or within the preceding 14 days • Was child's first time in the OSTRICH study • Parent/carer was able to understand & give informed consent
Exclusion criteria	OSTRICH study exclusion criteria: • Was participating (or had participated during the preceding 4 months) in another clinical trial of an investigational medicinal product • Had systemic infection or ear infection at time of recruitment • Had cleft palate, Down Syndrome, diabetes mellitus, Kartagener's or Primary Ciliary Dyskinesia • Had renal failure, hypertension or congestive heart failure • Had confirmed, major developmental difficulties, tube fed, chromosomal abnormalities • Had taken oral steroids in the preceding four weeks • Had had a live vaccine in the preceding four weeks if aged under 3 years old • Had a condition that increased their risk of adverse effects from oral steroids • Had been in close contact with someone known or suspected to have Varicella or active Zoster during the three weeks prior to recruitment and had no prior history of Varicella infection or immunisation • Had existing known sensory hearing loss • Child already had grommets (ventilation tubes) • Was on a waiting list for grommet surgery and anticipated having surgery within 5 weeks and would have been unwilling to delay it
Sample size	12 parents of 11 child participants
Participant characteristics	Gender of participating parents (n) Male = 1 Female = 11 Age of children (range) 3 to 7 years Gender of children (n) Male = 6 Female = 5

	First episode of OME (n) = 10 Previously affected sibling (n) = 2
Results	**Themes (information in bullet points are theme(s) applied after thematic synthesis)** Original theme: How do parents make decisions? Sources of information • Information sources ○ Health professionals - Researcher: “Did you feel that the information they provided you with from the beginning until now, was sufficient for you to make a choice?” Participant 12: “Yes, definitely”. Researcher: “How important was that to you and why?” Participant 12: “Very important … I think that you could have … you can be given a pile of leaflets about something and that's fine but I think for me … I trust what the consultants tell me. I would put my trust in a consultant, you know, they have done it before, they have experience, they've got all the necessary qualifications etc. so I think I prefer that “face to face”. page 8 ○ Internet - Researcher: “On the internet, did you look at any particular websites or was it just generally googling?” Participant 9: “NHS direct I looked on and that was good because anything I wasn't told, I was able to read on there and you know, NHS direct is good. I don't google things, problems, anything like that because it always ends up with god knows what. I'll only gone on the NHS one and I thought: “I'll be curious about it and have a nose” and that was nice.” page 9 - Researcher: “Ok, you said previously you visited the Internet. When you went online, was it anything specific you looked for? What was your strategy in looking up information?” Participant 4: “I didn't look a lot to be honest, not more than I normally do. I think I just went on the NHS website and had a look on what they said about it really. I don't trawl too far cause you read all sorts of rubbish (laughter)!” page 9 ○ Personal experiences - No quotes ○ Lay sources - No quotes • Information format ○ Verbal - Researcher: “Did you feel that the information they provided you with from the beginning until now, was sufficient for you to make a choice?” Participant 12: “Yes, definitely”. Researcher: “How important was that to you and why?” Participant 12: “Very important … I think that you could have … you can be given a pile of leaflets about something and that's fine but I think for me … I trust what the consultants tell me. I would put my trust in a consultant, you know, they have done it before, they have experience, they've got all the necessary qualifications etc. so I think I prefer that “face to face”. page 8 ○ Written - Researcher: “Did you feel that the information they provided you with from the beginning until now, was sufficient for you to make a choice?” Participant 12: “Yes, definitely”. Researcher: “How important was that to you and why?” Participant 12: “Very important

… I think that you could have … you can be given a pile of leaflets about something and that's fine but I think for me … I trust what the consultants tell me. I would put my trust in a consultant, you know, they have done it before, they have experience, they've got all the necessary qualifications etc. so I think I prefer that “face to face”. page 8

  - Accessible
    - No quotes
- Information content
  - Unclear information
    - No quotes

Original theme: How do parents make decisions? Satisfaction with information provision

- Information sources
  - Health professionals
    - No quote
- Information content
  - Adequacy of information received
    - Researcher: “So, were you satisfied with the whole process, in the sense that they gave you enough information to make informed decisions? Participant 10: “Ehm … not for me. But then that is not criticism of them, I just wanted to make sure that I wasn't missing anything. They did give me quite a lot of information, but then I'm also aware that when you are in an appointment you miss information as well … that someone has told you. So for my peace of mind and went on and researched it.” page 9

Original theme: How do parents make decisions? Decision-making process

- Information sources
  - Personal experiences
    - No quotes
  - Lay sources
    - No quotes
- Information format
  - Accessible
    - No quotes
- Information content
  - Adequacy of information received
    - No quotes
- Communication
  - Parental involvement and choice

	- Researcher: “And did you feel they involved you in the whole decision-making process?” Participant 12: “I think it was more of a case they were trying to talk me out of it (grommets), it was almost as if: “You're really sure you wanna have grommets? You're really sure? This is a really last resort” …”page 9

ENT: Ear, Nose and Throat (ENT); NHS: National Health Service; OME: otitis media with effusion: OSTRICH: Oral STeroids for Resolution of otitis media with effusion In CHildren

Critical appraisal – Qualitative CASP checklist

Section	Question	Answer
Overall risk of bias and relevance	Overall risk of bias	Minor concerns *(Some concerns about potential influence of researchers on study findings)*
Overall risk of bias and relevance	Relevance	Relevant

CASP: Critical Appraisal Skills Programme

Tierney, 2013

Bibliographic Reference	Tierney, S; O'Brien, K; Harman, N L; Madden, C; Sharma, R K; Callery, P; Risks and benefits of ventilation tubes and hearing aids from the perspective of parents of children with cleft palate.; International journal of pediatric otorhinolaryngology; 2013; vol. 77 (no. 10); 1742-8

Study Characteristics

Study type	General qualitative inquiry
Country/ies where study was carried out	United Kingdom
Setting	Parents of children who had non-syndromic cleft palate (with or without cleft lip) from two cleft centres in Northern England.
Data collection and analysis	Semi-structured interviews were conducted with parents at a place and time of their convenience, usually at their own home, using a topic guide. Framework analysis was used to analyse the data.
Recruitment strategy	Purposive sampling was used to collect data
Study dates	Not reported

Sources of funding	Not industry funded
Inclusion criteria	Parents were eligible to participate if they • had a child with cleft palate (with or without cleft lip) who was non-syndromic • had a child aged between 0 and 11 years • had a child who has experienced OME, although it did not need to be current or to have been treated. • were able to converse in the English Language
Exclusion criteria	Parents were excluded if regarded to be experiencing significant psychosocial difficulties by their treatment team (e.g., child protection or a recent bereavement).
Sample size	43 parents of 37 children (Six parents were interviewed as a couple, whilst one father and 30 mothers were interviewed on their own)
Participant characteristics	Age of parents (mean ± SD) = 34.9 ± 6.7 years Age of their children (mean ± SD) = 6.5 ± 3.4 years Gender of their children (n) Females = 16 Males = 21 Type of cleft experienced by their children Bilateral cleft lip and palate = 6 Unilateral cleft lip and palate = 13 Cleft palate =18 Type of treatment received by their children Hearing aids only = 5 Watchful waiting = 5 Grommets only = 13 Grommets and hearing aids = 11 Location for interviews Clinic = 5 Home = 32
Results	**Themes (information in bullet points are theme(s) applied after thematic synthesis)** Original theme: Treatment recommendations

	• Information sources ○ Healthcare professionals - No quotes ○ Internet - No quotes ○ Lay sources - Henry's mother: I was put off by the grommets cause like somebody had told me that they might need keep redoing so it would be like multiple operations, so I'd want to know that that wasn't going to happen. Page 1745 • Information format ○ Verbal - No quotes • Information content ○ Adequacy of information received - Ian's mother: ...he was chatting to us with the pros and cons was that if he had to have the grommets more than two or three times it could cause permanent damage with scar tissue and all this. So that's why we went, plus also we thought well Ian's gone through operations, he's gonna go through more, don't have to, want to put him under anaesthetic if we can do it through the non-invasive way, so we went for the hearing aids. page 1745 ○ Unclear information - No quotes • Communication ○ Parental involvement and choice - Elaine's mother: She had them when she was 3½ and then she just had the one then put in her left ear when she was 5. Interviewer: What made you decide to let her have them at 3½? Elaine's mother: Urm, a bit of pressure from the ENT people [laughs]...my opinion is they love putting them in and given the chance they'd put them in everyone [laughs]. page 1744 ○ Language - No quotes

ENT: Ear, Nose and Throat; OME: otitis media with effusion; SD: standard deviation

Critical appraisal – Qualitative CASP checklist

Section	**Question**	**Answer**
Overall risk of bias and relevance	Overall risk of bias	Minor concerns *(No discussion of data saturation)*
Overall risk of bias and relevance	Relevance	Relevant

CASP: Critical Appraisal Skills Programme

Appendix E Forest plots

Forest plots for review question: What information is valued by children under 12 years with suspected or confirmed OME and their parents and carers?

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

Appendix F GRADE-CERQual tables

GRADE tables for review question: What information is valued by children under 12 years with suspected or confirmed OME and their parents and carers?

Table 5: Evidence profile: Theme 1. Information sources

Study information			CERQual assessment of the evidence		
Number of studies	Design	Description of theme or finding	Criteria	Level of concern	Overall confidence
Sub-theme 1.1: Healthcare professionals					
2 (Gkiousias 2016, Tierney 2013) n= 49	Qualitative studies using semi-structured interviews	Parents reported getting most of their information on OME from healthcare professionals and trusting the experience and qualifications of a clinician over written materials. However, some parents reported not receiving adequate information from their healthcare professionals. *"Very important … I think that you could have … you can be given a pile of leaflets about something and that's fine but I think for me … I trust what the consultants tell me. I would put my trust in a consultant, you know, they have done it before, they have experience, they've got all the necessary qualifications etc. so I think I prefer that "face to face" (Gkiousias 2016, page 8)*	Methodological limitations	Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns. Studies together offered some rich data on a simple theme	
Subtheme 1.2: Internet					
2 (Gkiousias 2016, Tierney 2013) n= 49	Qualitative studies using semi-structured interviews	Some parents reported using the internet to clarify or add to the information received from their healthcare professionals and to access stories of people with similar experiences. Others avoided the internet due to concerns about the quality and reliability of the information and the likelihood that it may increase their worries and lead to poor decision making. Time constraints and a preference for personal contact further reduced internet use. Parents that accessed the internet reported being critical, preferring recognised websites such as the NHS. One study reported that none of the parents used social media while the other study reported the use of social media.	Methodological limitations	Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	Minor concerns. Some evidence is	

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall confidence**
		"NHS direct I looked on and that was good because anything I wasn't told, I was able to read on there and you know, NHS direct is good. I don't google things, problems, anything like that because it always ends up with God knows what. I'll only gone on the NHS one and I thought: "I'll be curious about it and have a nose" and that was nice." (Gkiousias 2016, page 9)		ambiguous or contradictory without a credible explanation for differences	
			Adequacy	Minor concerns. Studies together offered some rich data on a simple theme	
Subtheme 1.3: Personal experiences					
1 (Gkiousias 2016) n= 12	Qualitative study using semi-structured interviews	Parents reported getting information on OME from their personal experiences such as from older children who have had OME and educational scientific background. *No quotes*	Methodological limitations	Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist	Low
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Serious concerns. A single study did not offer rich data	
Subtheme 1.4: Lay sources					
2 (Gkiousias 2016, Tierney 2013) n= 49	Qualitative studies using semi-structured interviews	Parents reported getting information from communications within their social (friends and family) or occupational networks, as well as other parents in baby groups. Parents explained that this helped them compare experiences and learn from them. *"I was put off by the grommets cause like somebody had told me that they might need keep redoing so it would be like multiple operations, so I'd want to know that that wasn't going to happen" (Tierney 2013, page 1745)*	Methodological limitations	Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			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 confidence**
			Adequacy	Minor concerns. Studies together offer some rich data on a simple theme	

CASP: Critical Appraisal Skills Programme; CERQual: Confidence in the Evidence from Reviews of Qualitative research; NHS: National Health Service; OME: otitis media with effusion

Table 6: Evidence profile: Theme 2. Information format

Study information			**CERQual assessment of the evidence**		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall confidence**
Sub-theme 2.1: Verbal					
2 (Gkiousias 2016, Tierney 2013) n= 49	Qualitative studies using semi-structured interviews	Parents reported obtaining verbal information from clinicians through discussion or counselling. *“Very important … I think that you could have … you can be given a pile of leaflets about something and that's fine but I think for me … I trust what the consultants tell me. I would put my trust in a consultant, you know, they have done it before, they have experience, they've got all the necessary qualifications etc. so I think I prefer that “face to face”. (Gkiousisa 2016, page 8)*	Methodological limitations	Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns. Studies together offered some rich data on a simple theme	
Subtheme 2.2: Written					
1 (Gkiousias 2016) n= 12	Qualitative study using semi-structured interviews	Parents reported obtaining written information in the form of leaflets or booklets from their health professionals or in ENT clinics, and such information was valued and used as an aid when explaining OME to family members. On the contrary, one parent expressed a preference for personal contact with a health professional to reading written-up materials.	Methodological limitations	Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist	Moderate

Study information			**CERQual assessment of the evidence**		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall confidence**
		"Very important … I think that you could have … you can be given a pile of leaflets about something and that's fine but I think for me … I trust what the consultants tell me. I would put my trust in a consultant, you know, they have done it before, they have experience, they've got all the necessary qualifications etc. so I think I prefer that "face to face" (Gkiousias 2016, page 8)	Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Minor concerns. Studies together offered some rich data on a simple theme	
Subtheme 2.3: Accessible					
1 (Gkiousias 2016) n= 12	Qualitative study using semi-structured interviews	Parents reported a difficulty accessing information. One parent described the unavailability of written materials in the ENT clinic attended while another described not being able to obtain high quality information needed for decision making, both in clinical settings and from other sources. *No quotes*	Methodological limitations	Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist	Low
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Serious concerns. A single study did not offer rich data	

CASP: Critical Appraisal Skills Programme; CERQual: Confidence in the Evidence from Reviews of Qualitative research; ENT: Ear, Nose and Throat; OME: otitis media with effusion

Table 7: Evidence profile: Theme 3. Information content

Study information			**CERQual assessment of the evidence**		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall confidence**
Sub-theme 3.1: Adequacy of information received					
2 (Gkiousias 2016, Tierney 2013)	Qualitative studies using semi-	Parents reported satisfaction with the overall information received about OME and the treatment options, and the details provided by the healthcare	Methodological limitations	Minor concerns about methodological limitations of the	Moderate

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall confidence**
n= 49	structured interviews	professional which aided their decision making. However, some parents reported receiving inadequate information on treatment options for OME. *"...he was chatting to us with the pros and cons was that if he had to have the grommets more than two or three times it could cause permanent damage with scar tissue and all this. So that's why we went, plus also we thought well Ian's gone through operations, he's gonna go through more, don't have to, want to put him under anaesthetic if we can do it through the non-invasive way, so we went for the hearing aids." (Tierney 2013, page 1745)* *"Ehm … not for me. But then that is not criticism of them, I just wanted to make sure that I wasn't missing anything. They did give me quite a lot of information, but then I'm also aware that when you are in an appointment you miss information as well … that someone has told you. So for my peace of mind and went on and researched it." (Gkiousias 2016, page 9)*		evidence as per CASP qualitative checklist	
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns. Studies together offered some data but theme could have benefited from richer data	
Subtheme 3.2: Ambiguous information					
2 (Gkiousias 2016, Tierney 2013) n= 49	Qualitative studies using semi-structured interviews	Parents reported receiving conflicting information from different healthcare professionals or confusing information from the same healthcare professional *No quotes*	Methodological limitations	Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist	Low
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Serious concerns. Studies together did not offer rich data	

CASP: Critical Appraisal Skills Programme; CERQual: Confidence in the Evidence from Reviews of Qualitative research; OME: otitis media with effusion

Table 8: Evidence profile: Theme 4. Communication

Study information			**CERQual assessment of the evidence**		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Level of concern**	**Overall confidence**
Sub-theme 4.1: Parental involvement and choice					
2 (Gkiousias 2016, Tierney 2013) n= 49	Qualitative studies using semi-structured interviews	Parents described not having their views taken into consideration by healthcare professionals and sometimes not given a choice about treatment. They described being coerced into a treatment option for their child. *"I think it was more of a case they were trying to talk me out of it (grommets), it was almost as if: "You're really sure you wanna have grommets? You're really sure? This is a really last resort" (Gkiousias 2016, page 9)* *"Urm, a bit of pressure from the ENT people [laughs]...my opinion is they love putting them in and given the chance they'd put them in everyone [laughs]" (Tierney 2013, page 1744)*	Methodological limitations	Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist	High
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	None or very minor concerns	
Subtheme 4.2: Language					
1 (Tierney 2013) n= 37	Qualitative study using semi-structured interviews	Parents reported not being able to understand some information received due to the medical terms used that were incomprehensible. *No quotes*	Methodological limitations	Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist	Low
			Relevance	None or very minor concerns	
			Coherence	None or very minor concerns	
			Adequacy	Moderate concerns. A single study did not offer rich data, though the theme is straightforward	

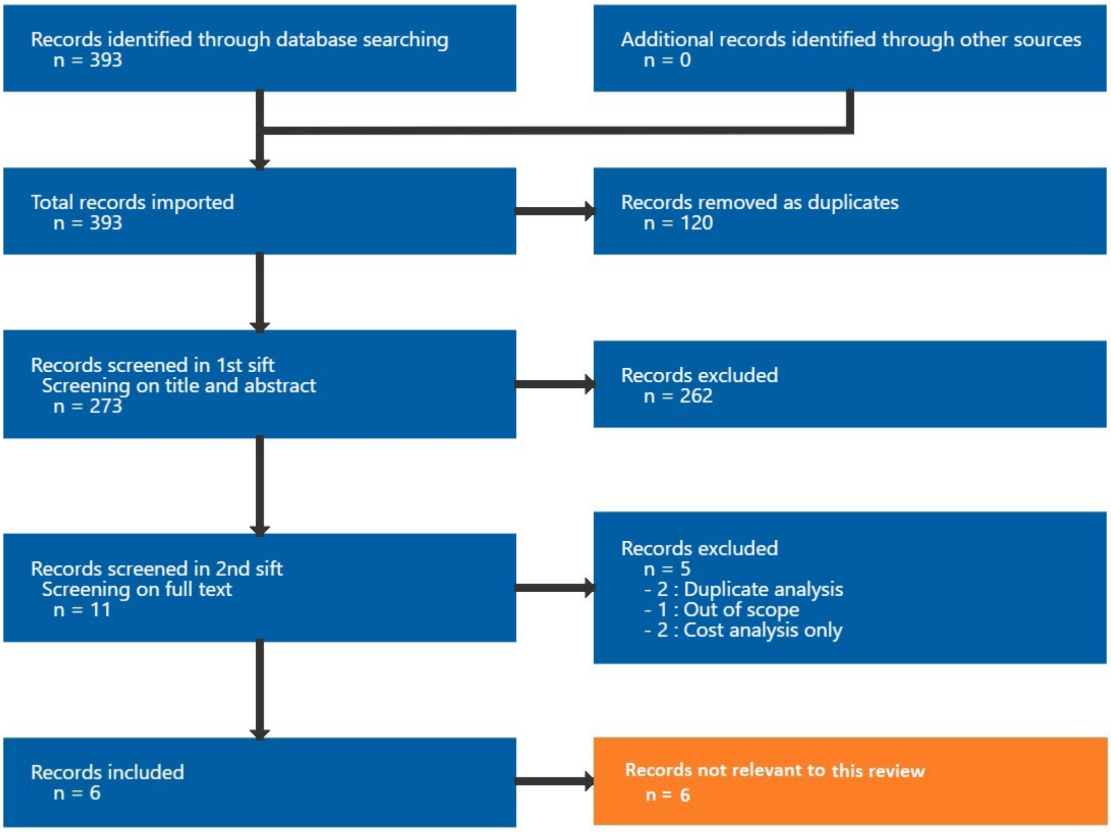
CASP: Critical Appraisal Skills Programme; CERQual: Confidence in the Evidence from Reviews of Qualitative research; ENT: Ear, Nose and Throat

Appendix G Economic evidence study selection

Study selection for: What information is valued by children under 12 years with suspected or confirmed OME and their parents and carers?

A global search was undertaken to cover all the review questions considered in this guideline, but no economic evidence was identified which was applicable to this review question (see Figure).

Figure 3: Study selection flow chart



Appendix H Economic evidence tables

Economic evidence tables for review question: What information is valued by children under 12 years with suspected or confirmed OME and their parents and carers?

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

Appendix I Economic model

Economic model for review question: What information is valued by children under 12 years with suspected or confirmed OME and their parents and carers?

No economic analysis was conducted for this review question.

Appendix J Excluded studies

Excluded studies for review question: What information is valued by children under 12 years with suspected or confirmed OME and their parents and carers?

Excluded qualitative studies

Table 9: Excluded studies and reasons for their exclusion

Study	Code [Reason]
Anonymous. (2005) Parent satisfaction OK with no treatment of otitis. Journal of Family Practice 54(9): 754	- Study design not of interest for review Quantitative study
Arason, Vilhjalmur A, Sigurdsson, Johann A, Kristinsson, Karl G et al. (2002) Tympanostomy tube placements, sociodemographic factors and parental expectations for management of acute otitis media in Iceland. The Pediatric infectious disease journal 21(12): 1110-5	- Study design not of interest for review Results were presented quantitatively
Arens, A (2011) Treatment of acute otitis media in children under 2 years of age. Journal of emergency medicine 40(6): 722-723	- Study design not of interest for review Quantitative study
Chando, S., Young, C., Craig, J.C. et al. (2016) Parental views on otitis media: systematic review of qualitative studies. European Journal of Pediatrics 175(10): 1295-1305	- Context not of interest for review Study described parental experiences and perspectives of caring for a child with otitis media but no data on information for OME presented
Finkelstein, JA, Stille, CJ, Rifas-Shiman, SL et al. (2005) Watchful waiting for acute otitis media: are parents and physicians ready?. Pediatrics 115(6): 1466-73	- Study design not of interest for review Quantitative study
Fortnum, H., Leighton, P., Smith, M.D. et al. (2014) Assessment of the feasibility and clinical value of further research to evaluate the management options for children with Down syndrome and otitis media with effusion: A feasibility study. Health Technology Assessment 18(60): 1-148	- Phenomenon of interest not of interest for review
Higson, J. and Haggard, M. (2005) Parent versus professional views of the developmental impact of a multi-faceted condition at school age: Otitis media with effusion ('glue ear'). British Journal of Educational Psychology 75(4): 623-643	- Study design not of interest for review Quantitative study
Kubba, H. (2000) An evidence-based patient information leaflet about otitis media with effusion. British Journal of Clinical Governance 5(2): 93-99	- Study design not of interest for review Qualitatively collected data was analysed quantitatively
La Mantia, I; Varricchio, A; Ciprandi, G (2021) Allergen immunotherapy in children with otitis media with effusion: a preliminary experience. European annals of allergy and clinical immunology 53(6): 288-290	- Study design not of interest for review letter to editor

Study	Code [Reason]
Laplante-Lévesque, Ariane and Thorén, Elisabet Sundewall (2015) Readability of Internet Information on Hearing: Systematic Literature Review. American Journal of Audiology 24(3): 284-288	- Context not of interest for review Study focuses on the readability of internet information on hearing for people with hearing impairment and their partners, which was not focused on OME alone. Findings were presented quantitatively
Lo, Phoebe S Y, Tong, Michael C F, Wong, Eric M C et al. (2006) Parental suspicion of hearing loss in children with otitis media with effusion. European journal of pediatrics 165(12): 851-7	- Study design not of interest for review Quantitative study
Marchbank, Alison Margaret (2011) Early Detection of Hearing Loss: The Case for Listening to Mothers. Deafness & Education International 13(4): 199-219	- Population not of interest for review Population was mothers of well-babies screened for hearing loss at birth
Margas, K, Exarchakos, G, Barkas, K et al. (2004) Conservative treatment of otitis media with effusion: our experience. 5th european congress of oto-rhino-laryngology head and neck surgery (EUFOS) . Rhodes, kos, greece, 11-16 september, 2004: 86abstractnofp143	- Study design not of interest for review Findings reported quantitatively
McAndrew, Lucy (2020) Parental Judgement of Hearing Loss in Infants With Cleft Palate. The Cleft palate-craniofacial journal : official publication of the American Cleft Palate-Craniofacial Association 57(7): 886-894	- Study design not of interest for review Quantitative study
Middleton, B. (2003) Reducing children's hearing loss. Interview by Anne Manchester. Nursing New Zealand (Wellington, N.Z. : 1995) 9(2): 24	- Study design not of interest for review Newspaper/Magazine article
Ryan, R, Harkness, P, Fowler, S et al. (2001) Management of paediatric otitis media with effusion in the UK: a survey conducted with the guidance of the Clinical Effectiveness Unit at the Royal College of Surgeons of England. The Journal of laryngology and otology 115(6): 475-8	- Study design not of interest for review Quantitative study
Smaka, C (2010) Interview with Shlomo Silman, Ph.D. AudiologyOnline: 6p-6p	- Study design not of interest for review Interview transcript describing interviewee's interest in OME
Tierney, Stephanie, O'Brien, Kevin, Harman, Nicola L et al. (2015) Otitis media with effusion: experiences of children with cleft palate and their parents. The Cleft palate-craniofacial journal : official publication of the American Cleft Palate-Craniofacial Association 52(1): 23-30	- Phenomenon of interest not of interest for review Study focuses on the emotions from managing OME, with no data on information for OME. Also, same population as Tierney 2013 which has been included in the review.
Vlastos, I M; Hajiioannou, J; Houlakis, M (2008) Otitis media with effusion: what parents want to know. The Journal of laryngology and otology 122(1): 21-4	- Study design not of interest for review Data was not qualitatively generated. Closed data generation asking for qualitative opinions on pre-existing data

Excluded economic studies

No economic evidence was identified for this review.

Appendix K Research recommendations – full details

Research recommendations for review question: What information is valued by children under 12 years with suspected or confirmed OME and their parents and carers?

No research recommendations were made for this review question.