

## Babies, children and young people's experience of healthcare

### [A] Planning healthcare and making shared decisions

*NICE guideline NG204*

*Evidence reviews underpinning recommendations 1.1.4 to 1.1.7 and 1.3.1 to 1.3.4 in the NICE guideline*

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*Final*

*These evidence reviews were developed by the National Guideline Alliance which is a part of the Royal College of Obstetricians and Gynaecologists*



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# Planning healthcare and making shared decisions

## Review question

How do children and young people, and the parents and carers of babies and young children, prefer to be involved and supported in planning their healthcare and making informed, shared decisions about their health?

## Introduction

Wherever possible, healthcare decisions should be made in consultation with those they affect. For example, decisions about treatment options and treatment plans will require a discussion of the available options and consideration of the risks and benefits of each option. To facilitate this, healthcare professionals need to be good listeners and be able to facilitate these conversations with children and young people, their parents and the parents of babies and very young children.

However, there may be circumstances where children and young people, or the parents or carers of babies and young children, wish to leave the final choice of treatment to their healthcare professionals, and although this in itself is a valid option, it is important that their preferences and values are taken into account.

This review aims to establish how children and young people, and the parents and carers of babies and young children, prefer to be involved in planning their healthcare and making informed, shared decisions about their health.

## Summary of the protocol

See Table 1 for a summary of the population, phenomenon of interest and primary outcome characteristics of this review.

**Table 1: Summary of the protocol**

<p><b>Population</b></p>	<ul style="list-style-type: none"> <li>• People &lt;18 years old who have experience of healthcare</li> <li>• Studies that use the views of parents or carers as proxies will be included only if they are responding on behalf of their child or charge, and                         <ul style="list-style-type: none"> <li>○ The baby or child of the parent or carer is under 5 years old, or</li> <li>○ There is a clear rationale provided as to why the study is using parents' or carers' views on and experiences of healthcare as proxies for their child.</li> </ul> </li> </ul>
<p><b>Phenomenon of interest</b></p>	<p>Experience of healthcare, in particular of planning one's own healthcare (for example, being asked to indicate which treatment one prefers) or of shared decision making (for example, being supported by parents to choose between two reasonable treatment alternatives).</p>
<p><b>Primary outcome</b></p>	<p>Themes will be identified from the literature. The committee identified the following potential themes (however, not all of these themes may be found in the literature, and additional themes may be identified):</p> <ul style="list-style-type: none"> <li>• Availability of different and appropriate types of information about the condition and related treatment</li> <li>• Availability of staff for answering questions or to provide (e.g. emotional) support</li> <li>• Conflict due to different power dynamics associated with parents and carers, and healthcare staff</li> <li>• Early and continuing involvement of children and young people, or their parents and carers as appropriate, in treatment decisions</li> <li>• Information provision about alternative forms of support (e.g. peer support, voluntary or charity groups, buddy system)</li> <li>• Nature of healthcare decision and possible sequelae/consequences of the choices</li> <li>• Parents, carers, or healthcare staff's knowledge and understanding of children's and young people's rights</li> <li>• Physical availability of staff with appropriate competence</li> <li>• Respecting the autonomy of children and young people</li> <li>• Sensitivity of staff support to circumstances and health literacy of child or young person</li> <li>• The use of patient decision aids</li> </ul>

For full details, see the review protocol in Appendix A.

## Methods and process

This evidence review was developed using the methods and process described in the [developing NICE guideline manual](#). Methods for this review question are described in the review protocol in appendix A and the methods supplement.

## Clinical evidence

### Included studies

This was a qualitative review with the aim of:

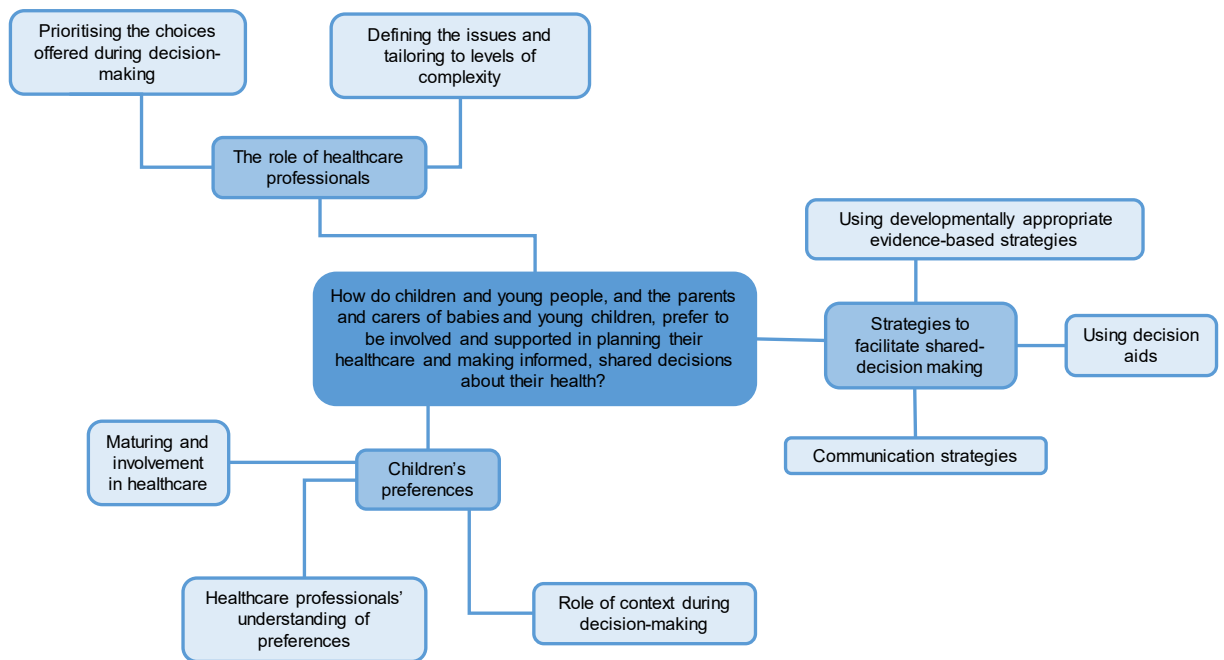
- Understanding how children and young people, or the parents or carers of babies and very young children prefer to be involved in planning their own healthcare.
- Understanding how children and young people, or the parents or carers of babies and very young children prefer to be involved in the process of shared decision making.

A systematic review of the literature was conducted using a combined search. Six qualitative studies were included in this evidence review: 1 study used participatory-based activities including play activities, peer interviews, focus groups and semi-structured interviews to gather data (Gibson 2010); 2 studies used observation or recording of conversations as well as semi-structured interviews (Astbury 2017, Barber 2019) and 3 studies used semi-structured interviews (Flett 2014, Mitchell 2012, Sherratt 2020). As per the protocol, all 6 studies were conducted in the UK.

The included studies are summarised in Table 2.

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

**Figure 1: Theme map**



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 studies included in the evidence review

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



**Table 2: Summary of included studies**

Study	Participants	Methods	Themes
<p>Astbury 2017</p> <p><b>Study design</b>                      Conversation analysis and semi-structured interviews</p> <p><b>Aim of the study</b>                      To describe what was currently happening when health visitors and parents were making decisions and planning interventions together with a view to exploring what specific processes supported shared decision making in this context of health visitor practice.</p> <p>Scotland, UK</p>	<p>N = 22</p> <ul style="list-style-type: none"> <li>• n=11 health visitors</li> <li>• n=11 parental proxies                             <ul style="list-style-type: none"> <li>○ n=2 parental proxies, Phase 1</li> <li>○ n=9 parental proxies, Phase 2</li> </ul> </li> <li>• Only the views of parental proxies are included in this review as children under 5 years old.</li> </ul> <p><b>Characteristics</b>                      Not reported but health visitors are a national service for parents of children aged 0-5 years old.</p>	<p><b>Recruitment</b>                      Health visitors recruited a convenience sample of parents who had a decision to make regarding their child in the last 6 months.</p> <p><b>Data collection</b></p> <ul style="list-style-type: none"> <li>• Phase 1: Conversations recorded between health visitors and parents</li> <li>• Phase 2: Semi-structured interviews</li> </ul> <p><b>Analysis</b>                      Framework analysis.</p>	<ul style="list-style-type: none"> <li>• Children's preferences: Healthcare professional's understanding of preferences</li> <li>• Healthcare professionals: Defining the issues and tailoring to levels of complexity</li> <li>• Healthcare professionals: Prioritising the choices offered during decision-making</li> <li>• Strategies: Using developmentally appropriate evidence-based strategies</li> <li>• Strategies: Communication strategies</li> </ul>

Study	Participants	Methods	Themes
<p>Barber 2019</p> <p><b>Study design</b>                      Observation and semi-structured interviews</p> <p><b>Aim of the study</b>                      To explore the extent and describe the process of shared decision making in current care pathway in hypodontia.</p> <p>Yorkshire, UK</p>	<p>N=26 young people and parents</p> <ul style="list-style-type: none"> <li>• n=13 young people</li> <li>• n=13 parents</li> <li>• Only the views of young people are included in this review.</li> </ul> <p><b>Characteristics</b>                      Age (range): 12-16 years</p> <p>Gender (M/F): 4/9</p>	<p><b>Recruitment</b>                      Purposive and convenience sampling from Orthodontic Departments of two NHS teaching hospitals.</p> <p><b>Data collection</b>                      Observation of consultations and semi-structured interviews.</p> <p><b>Analysis</b>                      Framework analysis.</p>	<ul style="list-style-type: none"> <li>• Children's preferences: Healthcare professional's understanding of preferences</li> <li>• Strategies: Using developmentally appropriate evidence-based strategies</li> <li>• Strategies: Communication strategies</li> <li>• Strategies: Using decision aids</li> </ul>
<p>Flett 2014</p> <p><b>Study design</b>                      Semi-structured interviews</p> <p><b>Aim of the study</b>                      To explore the role of the BOS DVD in the decision-making process of patients considering orthognathic treatment.</p> <p>Sheffield, UK</p>	<p>N=10 people</p> <ul style="list-style-type: none"> <li>• Only the views of participants under 18 years old are included in this review.</li> </ul> <p><b>Characteristics</b>                      Age (range): 16 – 48 years</p> <p>Gender (M/F): 4/6</p>	<p><b>Recruitment</b>                      Purposive and convenience sampling recruited from joint orthodontic/orthognathic clinics.</p> <p><b>Data collection</b>                      Individual semi-structured interviews.</p> <p><b>Analysis</b>                      Thematic framework analyses.</p>	<ul style="list-style-type: none"> <li>• Strategies: Using decision aids</li> </ul>

Study	Participants	Methods	Themes
<p>Gibson 2010</p> <p><b>Study design</b> Participatory-based activities</p> <p><b>Aim of the study</b> To explore children's and young people's views about cancer care and to present a conceptual model of communication and information sharing.</p> <p>London, UK</p>	<p>N=38 children and young people</p> <p><b>Characteristics</b> Age (range): 4–19 years</p> <p>Gender (M/F): 18/20</p>	<p><b>Recruitment</b> Purposive sampling</p> <p><b>Data collection</b> Play activities, peer and focus group interviews</p> <p><b>Analysis</b> Inductive thematic analysis</p>	<ul style="list-style-type: none"> <li>• Children's preferences: Healthcare professional's understanding of preferences</li> <li>• Strategies: Communication strategies</li> </ul>
<p>Mitchell 2012</p> <p><b>Study design</b> Semi-structured interviews</p> <p><b>Aim of the study</b> To explore parental perspectives on their and their child's role in choice-making when there were significant choices to be made regarding their son/daughter's life</p> <p>England, UK</p>	<p>N=14 parental proxies</p> <ul style="list-style-type: none"> <li>• Parents of children with learning disabilities.</li> </ul> <p><b>Characteristics</b> Not reported</p>	<p><b>Recruitment</b> Purposive sampling from two English children's hospices</p> <p><b>Data collection</b> Semi-structured interviews</p> <p><b>Analysis</b> Inductive thematic framework analysis</p>	<ul style="list-style-type: none"> <li>• Children's preferences: Healthcare professional's understanding of preferences</li> <li>• Children's preferences: Maturing and involvement in healthcare</li> <li>• Healthcare professionals: Defining the issues and tailoring to levels of complexity</li> <li>• Strategies: Using developmentally appropriate evidence-based strategies</li> <li>• Strategies: Using decision aids</li> </ul>

Study	Participants	Methods	Themes
<p>Sherratt 2020</p> <p><b>Study design:</b> Semi-structured interviews</p> <p><b>Aim of the study:</b> To explore healthcare professionals' communication when discussing potential involvement of children in clinical trials, and use this to inform a specialised communication training to increase recruitment rates.</p> <p>Liverpool, London and Southampton, UK</p>	<p>N=73 children, young people, parents and healthcare professionals</p> <ul style="list-style-type: none"> <li>• n=28 families</li> <li>• n=14 children and young people</li> <li>• n=34 parents</li> <li>• n=35 healthcare professionals</li> <li>• Only the views of children, young people and their parents have been included in this review. Parents' views have been included as interviews were conducted in family units and the children and young people were recalling experiences of presenting to A&amp;E with suspected appendicitis. This is associated with considerable pain which may affect communication at the time of admission and recall of the event.</li> </ul> <p><b>Characteristics</b></p> <p>Age of children (median; range): 11 years; 5-15 years</p> <p>Gender of children in included families (M/F): 21/7</p>	<p><b>Recruitment</b></p> <p>Purposive sampling of children and young people - 7-15 years - and parents participating in CONTRACT (Conservative Treatment of Acute Appendicitis in Children feasibility Trial)</p> <p><b>Data collection</b></p> <p>Semi-structured interviews</p> <p><b>Analysis</b></p> <p>Thematic analysis</p>	<ul style="list-style-type: none"> <li>• Children's preferences: Role of context during decision-making</li> </ul>

BOS: British Orthodontic Society; F: female; M: male; NHS: National Health Service;  
 N: Number

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

## Quality assessment of studies included in the evidence review

A summary of the strength of evidence (overall confidence), assessed using GRADE-CERQual is presented according to the themes. For each of the sub-themes the overall confidence was judged to be:

### **Main theme 1: Children's preferences**

- Sub-theme 1.1: Healthcare professional's understanding of preferences. The overall confidence in this sub-theme was judged to be low.
- Sub-theme 1.2: Maturing and involvement in healthcare. The overall confidence in this sub-theme was judged to be low.
- Sub-theme 1.3: Role of context during decision-making. The overall confidence in this sub-theme was judged to be low.

### **Main theme 2: The role of healthcare professionals**

- Sub-theme 2.1: Defining the issues and tailoring to levels of complexity. The overall confidence in this sub-theme was judged to be moderate.
- Sub-theme 2.2: Prioritising the choices offered during decision-making. The overall confidence in this sub-theme was judged to be low.

### **Main theme 3: Strategies to facilitate shared decision making**

- Sub-theme 3.1: Using developmentally appropriate evidence-based strategies. The overall confidence in this sub-theme was judged to be moderate.
- Sub-theme 3.2: Communication strategies. The overall confidence in this sub-theme was judged to be moderate.
- Sub-theme 3.3: Using decision aids. 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.

## Evidence from reference groups and focus groups

The children and young people's reference groups and focus groups provided additional evidence for this review. A summary of the findings is presented in Table 3.

**Table 3: Summary of the evidence from reference groups and focus groups**

<b>Age groups</b>	<ul style="list-style-type: none"> <li>• 7-11 years</li> <li>• 11-14 years</li> </ul>
<b>Areas covered</b>	<ul style="list-style-type: none"> <li>• Giving opinions</li> <li>• Being listened to</li> <li>• Asking questions of healthcare staff</li> <li>• Decision making and choice</li> </ul>
<b>Illustrative quotes</b>	<ul style="list-style-type: none"> <li>• 'I just don't like to [give my opinion] sometimes but sometimes I want to share more'</li> <li>• 'I like people listening to my ideas, I want to share how you are feeling'</li> <li>• 'Will it hurt?'; 'How long until it will get sore'</li> <li>• 'It's your body so you should choose what to do with it'</li> <li>• 'Mum and nan to give more support with decision making ultimate decision is hers' ['hers' refers to Sarah, who is 13 years old and the patient in the shared decision making scenario]</li> </ul>

See the full evidence summary in appendix M.

### **Evidence from national surveys**

The grey literature review of national surveys of children and young people's experience provided additional evidence for this review. A summary of the findings is presented in Table 4.

**Table 4: Summary of the evidence from national surveys**

<b>National surveys</b>	<ul style="list-style-type: none"> <li>• Care Quality Commission. Children and young people’s inpatient and day case survey 2018</li> <li>• National Children’s Bureau. Listening to children’s views on health provision 2012</li> <li>• Picker Institute. Paediatric Emergency Department Survey 2015 and Children and Young People’s Outpatient Survey 2015</li> <li>• Picker Institute/NHS England/Bliss. Neonatal Survey 2014</li> <li>• Word of Mouth Research and Point of Care Foundation. An options appraisal for obtaining feedback on the experiences of children and young people with cancer 2018</li> </ul>
<b>Areas covered</b>	<ul style="list-style-type: none"> <li>• Level of involvement in care for different groups, including:</li> <li>• parents of babies, children and young people in hospital as an inpatient (planned or as an emergency) or as a day case</li> <li>• children and young people with disabilities or severe conditions</li> <li>• children and young people who received outpatient care</li> </ul>
<b>Key findings</b>	<ul style="list-style-type: none"> <li>• Children and young people mostly felt that opportunities to get involved in care decisions were limited. Those with severe conditions had mixed views, with some feeling too ill to consider the notion to make decisions, and others keen to get involved</li> <li>• Parents mostly felt they were given enough information to make decisions about their baby’s care</li> </ul>

See the full evidence summary in appendix N.

## 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. A single economic search was undertaken for all topics included in the scope of this guideline. See supplementary material 6 for details.

### Excluded studies

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

### Summary of studies included in the economic evidence review

No 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.



## **The committee's discussion of the evidence**

### **Interpreting the evidence**

#### ***The outcomes that matter most***

This review focused on how children and young people, and the parents or carers of babies and young children prefer to be involved in and supported when planning their healthcare and making informed, shared decision making about their health. To address this issue, the review was designed to include qualitative data, and as a result, the committee could not specify in advance the data that would be located. Instead, they identified the following main themes to guide the review:

- Availability of different and appropriate types of information about the condition and related treatment
- Availability of staff for answering questions or to provide (e.g. emotional) support
- Conflict due to different power dynamics associated with parents and carers, and healthcare staff
- Early and continuing involvement of children and young people, or their parents and carers as appropriate, in treatment decisions
- Information provision about alternative forms of support (e.g. peer support, voluntary or charity groups, buddy system)
- Nature of healthcare decision and possible sequelae/consequences of the choices
- Parents, carers, or healthcare staff's knowledge and understanding of children's and young people's rights
- Physical availability of staff with appropriate competence
- Respecting the autonomy of children and young people
- Sensitivity of staff support to circumstances and health literacy of child or young person
- The use of patient decision aids

Not all these themes were found in the literature, and the list was not exhaustive so that additional themes were identified. Additional themes and sub-themes which emerged from the data were healthcare professional's understanding of the preferences of babies, children and young people, gradual maturing of children's involvement in decision-making as they get older, prioritising the choices offered during decision-making, and the role of context (for example how ill the child is) during decision-making.

#### ***The quality of the evidence***

The evidence was assessed using GRADE-CERQual methodology, and the overall confidence in the findings ranged from low to moderate. Sub-themes were commonly downgraded due to methodological limitations, which was assessed using the Critical Appraisal Skills Programme (CASP) checklist, such as a lack of acknowledgement of reflexivity, potential selection bias and insufficient rigour of analysis. There were very few concerns over the coherence of the findings, but some evidence was downgraded for adequacy, being supported by only a few studies offering thin data. Finally, the findings were judged to be generally applicable with only a minor concern where some data were generated from participants over 18 years of age. The study in question (Gibson 2010) was nevertheless included because the themes identified from the study were supported by evidence from participants under 18.

#### ***Benefits and harms***

The committee discussed that evidence from a number of clinical settings was included in the review – dental care, cancer care, end-of-life care, clinical trials, as well as more general evidence on shared decision making between parents and health visitors, but agreed that

shared decision making should happen in all healthcare settings and that their recommendations should reflect this.

The systematic review evidence showed that a trusting relationship between healthcare professionals and children or young people was necessary to enable them to engage in shared decision making discussions and to be aware of children and young people's preferences (although the committee noted that it must be recognised that these may change over time). The committee discussed that it was important that healthcare professionals were aware of the rights of children and young people to be involved in making decisions about their healthcare, and that they should respect that right and provide support to enable it to happen, therefore the committee made a recommendation to this effect. The committee discussed the practical factors that are necessary for shared decision making and agreed that children and young people should be given opportunities to share their opinions in early as well as ongoing discussions. Based on their experience, the committee discussed that shared decision making is often thought to refer to 'big clinical decisions', but that other smaller decisions which do not have an impact on health outcomes were just as important to children and young people and can also help with choice-making skills. The committee therefore included this in a recommendation, with the examples of choosing the colour of a plaster cast or whether to take medicine as tablets or liquid.

Evidence from the systematic review suggested that the decision-making roles of children evolve as they get older, and the committee agreed that while parents or carers would make decisions for babies and young children, older children and young people should be supported to make independent and autonomous decisions if they wanted to. However, there was evidence that some children may not always want to be involved in decision-making, or that their involvement may vary and there would be times when they felt less able to be involved, or were more keen to be involved. The committee agreed that this reflected their experience, but that it was also important that the healthcare professionals recognised this variability and do not develop a static view of how involved a child or young person wished to be. The committee agreed that even if a child or young person does not want to make the final decision themselves, it was important that their preferences were taken into account.

There was evidence from the systematic review relating to the preferred way for healthcare professionals to engage in discussions with children and young people, and parents or carers, and this included defining issues clearly, tailoring the complexity of discussions, and prioritising choices. The committee agreed these were all important factors and made recommendations to reflect this. From their own experience, the committee also agreed that it was important to allow enough time for the discussions, and to ensure that the appropriate people were involved (for example, this might be a play specialist or a social worker, rather than a doctor or a nurse). The committee agreed with the evidence on strategies to facilitate shared decision making, that showed that involving children and young people in shared decision making required good communication skills from healthcare professionals, with tailoring of communication methods, taking into account specific communication needs and making sure that information was provided in a suitable format. Recommendations on these topics had been made in the sections of the guideline on communication and information provision, so the committee included a cross-reference to these recommendations.

There was evidence from the systematic review that different methods of communication could help promote discussions and decision-making, as could the use of decision aids and the committee agreed and made recommendations to use these where it would be helpful.

There was little evidence from the systematic review on shared decision making with the parents or carers of babies and young children. However the committee agreed that this was just as important, and recommended that parents or carers should be given the opportunity to be involved, and that the same principles should be applied as had been recommended for children and young people themselves.

The committee also drew on evidence from the children and young people's focus and reference groups and the grey literature review of national surveys to make their recommendations.

The information from the reference groups showed there was a wide range of views with some children very keen to give their opinions and be involved in asking questions and making decisions about their healthcare, while others did not like sharing their views, asking questions and making decisions. The committee agreed that this backed up the evidence from the systematic review and was reflected in their recommendations that children and young people should be supported to be involved in shared decision making but also supported if they did not wish to be involved. Some children said their desire to be involved varied from day to day or depending how ill they were feeling. The committee agreed that this also supported the evidence from the systematic review and was already reflected in their recommendations.

The national surveys provided evidence that parents felt more involved in care or decisions about care than children and young people, and there was some evidence that young people with disabilities wished to be involved in decisions and that this may require special consideration of how this could be facilitated. The committee agreed that the recommendations on communication and information to which they had cross-referred, addressed the support required to enable these conversations for people with additional communication needs.

The national survey evidence from children with cancer also confirmed the systematic review evidence that children and young people's involvement in decision-making can vary, depending on factors such as how ill a child or young person is feeling. Again the committee noted that this was already reflected in their recommendations.

The committee did not identify any potential harms from the evidence but from their own experience were aware that shared decision making could make children and young people feel pressured to make decisions that they did not feel confident to make. However, the committee agreed that on balance, this risk was outweighed by the improvements that the recommendations would make to practice in ensuring that children and young people's wishes were taken into account, and that the recommendations they had made would in any case mitigate this risk.

### **Cost-effectiveness and resource use**

There was no existing economic evidence for this review. The committee discussed that ensuring shared decision making may take more time to have the necessary discussions and additional conversations, but that in many settings it was already standard practice and this is not expected to result in additional resources to the health service. The committee noted that recommendations about the use of communication aids, information leaflets or decision aids may have resource implications in terms of the costs associated with developing such aids / leaflets. There may also be additional resource required to train and bring up to date staff in the use of such aids / leaflets, communication strategies to facilitate shared decision making etc. However, the committee expressed the view that additional costs, if any, are likely to be negligible compared to the potential benefits associated with involving children and young people in decision making about their care, including improvements in their experience of care and potential impact this may have on their quality of life.

### **Recommendations supported by this evidence review**

This evidence review supports recommendations 1.1.4 to 1.1.7 and 1.3.1 to 1.3.4 in the NICE guideline.

## References

### **Astbury 2017**

Astbury R, Shepherd A, Cheyne H. Working in partnership: the application of shared decision-making to health visitor practice. *Journal of Clinical Nursing*, 26, 1-2, 215-224. 2017

### **Barber 2019**

Barber S, Pavitt S, Meads D, Khambay B, Bekker H. Can the current hypodontia care pathway promote shared decision-making? *Journal of Orthodontics*, 46, 2, 126-136. 2019

### **Flett 2014**

Flett AM, Hall M, McCarthy C, Marshman Z, Benson PE. Does the British Orthodontic Society orthognathic DVD aid a prospective patient's decision making? A qualitative study. *Journal of Orthodontics*, 41, 2, 88-97. 2014

### **Gibson 2010**

Gibson F, Aldiss S, Horstman M, Kumpunen S, Richardson A. Children and young people's experiences of cancer care: a qualitative research study using participatory methods. *International Journal of Nursing Studies*. 47, 11, 1397-407. 2010

### **Mitchell 2012**

Mitchell, Wendy, Parents' accounts: Factors considered when deciding how far to involve their son/daughter with learning disabilities in choice-making, *Children and Youth Services Review*, 34, 1560-1569, 2012

### **Sherratt 2020**

Sherratt, F C, Beasant L, Crawley E M, Hall N J, Young B. Enhancing communication, informed consent and recruitment in a paediatric urgent care surgical trial: a qualitative study. *BioMed Central Paediatrics*, 20, 140, 2020.

# Appendices

## Appendix A – Review protocol

**Review protocol for review question: How do children and young people, and the parents and carers of babies and young children, prefer to be involved and supported in planning their healthcare and making informed, shared decisions about their health?**

**Table 5: Review protocol**

Field	Content
PROSPERO registration number	CRD42019152442
Review title	Involvement and support in healthcare and making shared decisions
Review question	How do children and young people, and the parents and carers of babies and young children, prefer to be involved and supported in planning their healthcare and making informed, shared decisions about their health?
Objective	To establish how children and young people, and the parents and carers of babies and young people, prefer to be involved in planning their own healthcare and making informed, shared decisions about it.
Searches	<p>The following databases will be searched:</p> <ul style="list-style-type: none"> <li>• CCTR</li> <li>• CDSR</li> <li>• Embase</li> <li>• MEDLINE</li> <li>• MEDLINE IN-Process</li> <li>• PsycINFO</li> </ul> <p>One broad, guideline-wide, search will be conducted for qualitative questions, capturing the population and the settings. A UK filter will be applied to identify relevant UK studies and a systematic review filter will be applied to the remainder of the results to identify relevant reviews that include evidence from non-UK high-income countries. If no systematic reviews of this type are identified, then a more focused search may be conducted to identify studies conducted in the following high-income countries: Australia, Austria, Belgium,</p>

Field	Content
	<p>Canada Denmark, Finland, France, Germany, Greece, Iceland, Ireland, Italy, Liechtenstein, Luxembourg, Malta, Monaco, Netherlands, New Zealand, Norway, Portugal, Spain, Sweden, Switzerland, and USA.</p> <p>Searches will be restricted by:  Date: 2009  Language of publication: English language only  Publication status: Conference abstracts will be excluded because these do not typically provide sufficient information to fully assess risk of bias  Standard exclusions filter (animal studies/low level publication types) will be applied</p> <ul style="list-style-type: none"> <li>• For each search (including economic searches), the principal database search strategy is quality assured by a second information specialist using an adaption of the PRESS 2015 Guideline Evidence-Based Checklist</li> </ul>
Condition or domain being studied	<ul style="list-style-type: none"> <li>• Babies, children’s and young people’s experience of healthcare</li> </ul>
Population	<ul style="list-style-type: none"> <li>• People &lt;18 years-old who have experience of healthcare</li> </ul> <p>Studies that use the views of parents or carers as proxies will be included only if they are responding on behalf of their child or charge, and</p> <ul style="list-style-type: none"> <li>○ The baby or child of the parent or carer is under-5 years-old, or</li> <li>○ There is a clear rationale provided as to why the study is using parents’ or carers’ views on and experiences of healthcare as proxies for their child.</li> </ul> <p>Note: Studies where part of the population is &lt;18 years-old and part of the population is ≥18 years-old will only be included if it is clear that the themes are supported by evidence from the former group only.</p>
Intervention/Exposure/Test	<ul style="list-style-type: none"> <li>• Experience of healthcare, in particular of planning one’s own healthcare (e.g. being asked to indicate which treatment one prefers) or of shared decision making (e.g. being supported by parents to choose between two reasonable treatment alternatives)</li> </ul>
Comparator/Reference standard/Confounding factors	Not applicable
Types of study to be included	<ul style="list-style-type: none"> <li>• Systematic reviews of qualitative studies</li> <li>• Studies using qualitative methods: focus groups, semi-structured and structured interviews, observations</li> <li>• Surveys conducted using open-ended questions and a qualitative analysis of responses</li> </ul>

Field	Content
	<p>Note: Mixed-method studies will be included but only qualitative data will be extracted, and risk of bias assessed. Systematic reviews that include evidence from countries not listed in the search strategy will be excluded if the sources of the themes and evidence from high-income countries cannot be clearly established. Evidence from individual qualitative studies conducted in the high-income countries listed in the search strategy will be included only if no relevant systematic review evidence is identified.</p>
Other exclusion criteria	<p><b>STUDY DESIGN</b></p> <ul style="list-style-type: none"> <li>• Studies using quantitative methods only (including surveys that report only quantitative data)</li> <li>• Surveys using mainly closed questions or which quantify open-ended answers for analysis</li> </ul> <p><b>TOPIC OF STUDY</b></p> <p>Studies on the following topics will also be excluded:</p> <ul style="list-style-type: none"> <li>• Accessing non-NHS commissioned health promotion interventions</li> <li>• Views and experiences of healthcare professionals and service managers</li> <li>• Views and experiences of people reporting only on social care planning and shared decision making</li> </ul> <p>Studies that focus explicitly on the following topics rather than focussing on the views on and experiences of babies, children and young people in healthcare will be excluded as they are covered by the following NICE guidelines:</p> <ul style="list-style-type: none"> <li>• Child abuse and maltreatment:             <ul style="list-style-type: none"> <li>○ Child abuse and neglect (NG76)</li> <li>○ Child maltreatment: when to suspect maltreatment in under 18s (CG89)</li> </ul> </li> <li>• Community engagement             <ul style="list-style-type: none"> <li>○ Community engagement (NG44)</li> </ul> </li> <li>• Drug misuse in children and young people:             <ul style="list-style-type: none"> <li>○ Alcohol: school-based interventions (PH7)</li> <li>○ Alcohol-use disorders: diagnosis, assessment and management of harmful drinking and alcohol dependence (CG115)</li> <li>○ Alcohol-use disorders: prevention (PH24)</li> <li>○ Drug misuse prevention: targeted interventions (NG64)</li> </ul> </li> <li>• End of life care for infants, children and young people with life-limiting conditions: planning and management (NG61)</li> </ul>

Field	Content
	<ul style="list-style-type: none"> <li>• Immunisations: reducing differences in uptake in under 19s (PH21)</li> <li>• Oral health promotion: general dental practice (NG30)</li> <li>• Physical activity and weight management: <ul style="list-style-type: none"> <li>○ Maternal and child nutrition (PH11)</li> <li>○ Obesity prevention (CG43)</li> <li>○ Physical activity for children and young people (PH17)</li> <li>○ Weight management: lifestyle services for overweight or obese children and young people (PH47)</li> </ul> </li> <li>• Pregnancy, including routine antenatal, intrapartum or postnatal care: <ul style="list-style-type: none"> <li>○ Antenatal and postnatal mental health: clinical management and service guidance (CG192)</li> <li>○ Antenatal care for uncomplicated pregnancies (CG62)</li> <li>○ Intrapartum care for healthy women and babies (CG190)</li> <li>○ Intrapartum care for women with existing medical conditions or obstetric complications and their babies (NG121)</li> <li>○ Multiple pregnancy: antenatal care for twin and triplet pregnancies (CG129)</li> <li>○ Postnatal care up to 8 weeks after birth (CG37)</li> <li>○ Pregnancy and complex social factors: a model for service provision for pregnant women with complex social factors (CG110)</li> </ul> </li> <li>• Self-harm: <ul style="list-style-type: none"> <li>○ Self-harm in over 8s: long-term management (CG133)</li> <li>○ Self-harm in over 8s: short-term management and prevention of recurrence (CG16)</li> </ul> </li> <li>• Sexual health and contraception <ul style="list-style-type: none"> <li>○ Contraceptive services for under 25s (PH51)</li> <li>○ Sexually transmitted infections and under-18 conceptions: prevention (PH3)</li> <li>○ Harmful sexual behaviour among children and young people (NG55)</li> </ul> </li> <li>• Smoking prevention: <ul style="list-style-type: none"> <li>○ Smoking: preventing uptake in children and young people (PH14)</li> <li>○ Smoking prevention in schools (PH23)</li> <li>○ Stop smoking interventions and services (NG92)</li> </ul> </li> <li>• The transition from children's to adults' services for young people using health or social care services (NG43)</li> </ul>



Field	Content
Context	<p>UK studies from 2009 onwards will be prioritised for decision making by the committee as those conducted in other countries may not be representative of current expectations about either services or current attitudes and behaviours of healthcare professionals. The committee presumes that due to their development, particular circumstances and/or condition, there are some topics that babies, children and young people may not be in a position to pronounce on and that in these circumstances, it may be necessary to treat the 'indirect' views of their parents or carers as proxies for their own views on and experiences of healthcare in order to make recommendations. The guideline committee will be consulted on whether a study should be included if it is unclear why parents' or carer's views are being reported instead of their child or charge, and reasons for exclusion if appropriate will be documented. The topic about which the babies, children and young people are talking should be generalizable to the wider healthcare context (e.g. a study on the views on and experience of communication with healthcare professionals whilst receiving chemotherapy would be included, whilst a study on experience of chemotherapy would be too narrow and not generalizable to wider healthcare context and therefore excluded). Recommendations will apply to those receiving care in all settings where NHS- or local authority- commissioned healthcare is provided (including home, school, community, hospital, specialist and transport settings). Specific recommendations for groups listed in the Equality Considerations section of the scope may be also be made as appropriate.</p>
Primary outcomes (critical outcomes)	<ul style="list-style-type: none"> <li>• Availability of different and appropriate types of information about condition and related treatment</li> <li>• Availability of staff for answering questions or to provide (e.g. emotional) support</li> <li>• Conflict due to different power dynamics associated with parents and carers, and healthcare staff</li> <li>• Early and continuing involvement of children and young people, or their parents and carers as appropriate, in treatment decisions</li> <li>• Information provision about alternative forms of support (e.g. peer support, voluntary or charity groups, buddy system)</li> <li>• Nature of healthcare decision and possible sequelae/consequences of the choices</li> <li>• Parents, carers, or healthcare staff's knowledge and understanding of children's and young people's rights</li> <li>• Physical availability of staff with appropriate competence</li> <li>• Respecting autonomy of children and young people</li> <li>• Sensitivity of staff support to circumstances and health literacy of child or young person</li> <li>• Use of patient decision aids</li> </ul>

Field	Content
	<p>The following themes will not be covered in this review despite relating to healthcare planning and shared decision making:</p> <ul style="list-style-type: none"> <li>• Availability of information in different formats (reviewed in RQ 2.1)</li> <li>• Confidentiality, privacy and consent for children and young people in healthcare (reviewed in RQ 1.3)</li> <li>• Factors promoting continuity and co-ordination of care (reviewed in RQ 8.2)</li> </ul>
Secondary outcomes (important outcomes)	Not applicable
Data extraction (selection and coding)	<ul style="list-style-type: none"> <li>• All references identified by the searches and from other sources will be uploaded into STAR and de-duplicated. Titles and abstracts of the retrieved citations will be screened to identify studies that potentially meet the inclusion criteria outlined in the review protocol.</li> <li>• Duplicate screening will not be undertaken for this question.</li> <li>• 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, including study reference, research question, theoretical approach, data collection and analysis methods used, participant characteristics, second-order themes, and relevant first-order themes (i.e. supporting quotes). One reviewer will extract relevant data into a standardised form, and this will be quality assessed by a senior reviewer.</li> </ul>
Risk of bias (quality) assessment	<p>Risk of bias of individual qualitative studies will be assessed using the CASP (Critical Skills Appraisal Programme) Qualitative checklist. Risk of bias of systematic reviews of qualitative studies will be assessed using the CASP (Critical Skills Appraisal Programme) Systematic Review checklist. See Appendix H in <a href="#">Developing NICE guidelines: the manual</a> for further details. The quality assessment will be performed by one reviewer and this will be quality assessed by a senior reviewer.</p>
Strategy for data synthesis	<ul style="list-style-type: none"> <li>• Extracted second-order study themes and related first-order quotes will be synthesised by the reviewer into third-order themes and related sub-themes.</li> <li>• The GRADE-CERQual (Confidence in the Evidence from Reviews of Qualitative research; Lewin 2015) approach will be used to summarise the confidence in the third-order theme or sub-theme from the qualitative evidence. The overall confidence in evidence about each theme or sub-theme will be rated on four dimensions: methodological limitations, coherence, adequacy, and relevance.</li> <li>• 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 CASP checklist for qualitative studies or systematic reviews as appropriate. Coherence of findings will be assessed by examining the clarity of the data. Adequacy of</li> </ul>

Field	Content		
	data will be assessed by looking at the degree of richness and quantity of findings. Relevance 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.		
Analysis of sub-groups	<p>If there is sufficient data, views and experiences will be analysed separately by the following age ranges:</p> <ul style="list-style-type: none"> <li>• &lt;1-year-old (i.e. 364 days old or less)</li> <li>• ≥1 to &lt;12 years-old (i.e. 365 days old to 11 years and 364 days old)</li> <li>• ≥12 to &lt;18 years-old (i.e. 12 years and 0 days old to 17 years and 364 days old)</li> </ul> <p>The committee are aware that children can experience substantial cognitive and developmental change during the ages of 1 and 12, and that there may be (though not necessarily) substantive differences between children in this group depending on the topic about which they are being asked. The committee will, therefore, be consulted regarding whether data regarding further subgroups within this age range (e.g. 1-5, 6-11) should be used.</p> <p>Subgroup analysis according to any of the groups listed in the Equality Considerations section of the scope will be conducted if there is sufficient data.</p>		
Type and method of review	<input type="checkbox"/>	Intervention	
	<input type="checkbox"/>	Diagnostic	
	<input type="checkbox"/>	Prognostic	
	<input checked="" type="checkbox"/>	Qualitative	
	<input type="checkbox"/>	Epidemiologic	
	<input type="checkbox"/>	Service Delivery	
	<input type="checkbox"/>	Other (please specify)	
Language	English		
Country	England		
Anticipated or actual start date	13 January 2020		
Anticipated completion date	07 April 2021		
	Review stage	Started	Completed

Field	Content		
Stage of review at the time of this submission	Preliminary searches	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Piloting of the study selection process	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Formal screening of search results against eligibility criteria	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Data extraction	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Risk of bias (quality) assessment	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
	Data analysis	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Named contact	<p><b>5a. Named contact</b> National Guideline Alliance</p> <p><b>5b. Named contact e-mail</b> Infant&amp;younghealth@nice.org.uk</p> <p><b>5c Organisational affiliation of the review</b> National Institute for Health and Care Excellence (NICE) and National Guideline Alliance</p>		
Review team members	NGA Technical Team		
Funding sources/sponsor	This systematic review is being completed by the National Guideline Alliance, which receives funding from NICE.		
Conflicts of interest	All guideline committee members and anyone who has direct input into NICE guidelines (including the evidence review team and expert witnesses) must declare any potential conflicts of interest in line with NICE's code of practice for declaring and dealing with conflicts of interest. Any relevant interests, or changes to interests, will also be declared publicly at the start of each guideline committee meeting. Before each meeting, any potential conflicts of interest will be considered by the guideline committee Chair and a senior member of the development team. Any decisions to exclude a person from all or part of a meeting will be documented. Any changes to a member's declaration of interests will be recorded in the minutes of the meeting. Declarations of interests will be published with the final guideline.		
Collaborators	Development of this systematic review will be overseen by an advisory committee who will use the review to inform the development of evidence-based recommendations in line with section 3 of <a href="#">Developing NICE guidelines: the manual</a> . Members of the guideline committee are available on the NICE website: <a href="https://www.nice.org.uk/guidance/indevelopment/gid-ng10119/documents">https://www.nice.org.uk/guidance/indevelopment/gid-ng10119/documents</a>		

Field	Content	
Other registration details	-	
URL for published protocol	<a href="https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42019152442">https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42019152442</a>	
Dissemination plans	<p>NICE may use a range of different methods to raise awareness of the guideline. These include standard approaches such as:</p> <ul style="list-style-type: none"> <li>• notifying registered stakeholders of publication</li> <li>• publicising the guideline through NICE's newsletter and alerts</li> <li>• 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.</li> </ul>	
Keywords	Access; accessibility; babies; children; experience; healthcare; infants; qualitative; services; views; young people.	
Details of existing review of same topic by same authors	Not applicable	
Current review status	<input checked="" type="checkbox"/>	Ongoing
	<input type="checkbox"/>	Completed but not published
	<input type="checkbox"/>	Completed and published
	<input type="checkbox"/>	Completed, published and being updated
	<input type="checkbox"/>	Discontinued
Additional information	-	
Details of final publication	<a href="http://www.nice.org.uk">www.nice.org.uk</a>	

CASP: critical appraisal skills programme; CDSR: Cochrane Database of Systematic Reviews; CCTR/CENTRAL: Cochrane Central Register of Controlled Trials; GRADE-CERQual: Grading of Recommendations Assessment, Development and Evaluation – Confidence in the evidence from reviews of qualitative research; NGA: National Guideline Alliance; NHS: National health service; NICE: National Institute for Health and Care Excellence

## Appendix B – Literature search strategies

**Literature search strategies for review question: How do children and young people, and the parents and carers of babies and young children, prefer to be involved and supported in planning their healthcare and making informed, shared decisions about their health?**

**Databases: Embase/Medline/PsycINFO**

Date searched: 29/07/2020

#	Searches
1	(ADOLESCENT/ or MINORS/) use ppez
2	exp ADOLESCENT/ use emez
3	(adolescen\$ or teen\$ or youth\$ or young or juvenile? or minors or highschool\$).ti,ab,jw,nw.
4	exp CHILD/
5	(child\$ or schoolchild\$ or "school age" or "school aged" or preschool\$ or toddler\$ or kid? or kindergar\$ or boy? or girl?).ti,ab,jw,nw.
6	exp INFANT/
7	(infan\$ or neonat\$ or newborn\$ or baby or babies).ti,ab,jw,nw.
8	exp PEDIATRICS/ or exp PUBERTY/
9	(p?ediatric\$ or pubert\$ or prepubert\$ or pubescen\$ or prepubescen\$).ti,ab,jx,ec.
10	or/1-9
11	(Ambulance/ or Ambulance Transportation/ or Child Health Care/ or Community Care/ or Day Care/ or Dentist/ or Dental Facility/ or Pediatric Dentist/ or Dietitian/ or Emergency Care/ or Emergency Health Service/ or Emergency Ward/ or General Practice/ or Health Care/ or Health Care Delivery/ or Health Care Facility/ or Health Service/ or exp Home Care/ or Home Mental Health Care/ or Hospice/ or Hospice Care/ or exp Hospital/ or Hospital Care/ or Intensive Care Unit/ or Mental Health Care/ or Mental Health Service/ or Nursing Care/ or Newborn Care/ or Newborn Intensive Care/ or Neonatal Intensive Care Unit/ or Occupational Therapy/ or Ophthalmology/ or Orthodontics/ or Pediatric Intensive Care Unit/ or Pharmacy/ or exp Primary Health Care/ or Physiotherapy/ or Respite Care/ or School Health Nursing/ or exp School Health Service/ or Secondary Care Center/ or Secondary Health Care/ or "Speech and Language Rehabilitation"/ or Telemedicine/ or Tertiary Care Center/ or Tertiary Health Care/) use emez
12	(Ambulances/ or Adolescent Health Services/ or exp Child Health Services/ or Community Health Services/ or Community Pharmacy Services/ or Community Health Centers/ or Community Mental Health Centers/ or "Delivery of Health Care"/ or Dental Care for Children/ or exp Dental Health Services/ or Dentists/ or Dental Facilities/ or Emergency Medical Services/ or Emergency Service, Hospital/ or General Practice/ or Health Facilities/ or Health Services/ or Home Care Services/ or Home Care Services, Hospital-Based/ or Home Nursing/ or Hospice Care/ or Hospices/ or exp Hospitals/ or Intensive Care Units/ or Intensive Care Units, Pediatric/ or Intensive Care Units, Neonatal/ or exp Mental Health Services/ or Nutritionists/ or Occupational Therapy/ or Orthodontists/ or Pediatric Nursing/ or Pharmacies/ or Primary Health Care/ or Respite Care/ or exp School Health Services/ or School Nursing/ or Secondary Care/ or Telemedicine/ or Tertiary Healthcare/ or "Transportation of Patients"/) use ppez
13	(Adolescent Psychiatry/ or Community Health/ or Community Services/ or Dentists/ or Dental Health/ or Educational Psychology/ or Health Care Delivery/ or Health Care Services/ or Home Care/ or Home Visiting Programes/ or Hospice/ or exp Hospitals/ or Intensive Care/ or Language Therapy/ or exp Mental Health Services/ or Neonatal Intensive Care/ or Occupational Therapy/ or Outreach Programs/ or Pharmacy/ or Physical Therapy/ or Primary Health Care/ or Psychiatric Clinics/ or Psychiatric Units/ or Respite Care/ or Speech Therapy/ or Telemedicine/ or Telepsychiatry/ or Telepsychology/ or Walk In Clinics/) use psyh

#	Searches
14	(hospital patient/ or hospitalized adolescent/ or hospitalized child/ or hospitalized infant/ or hospitalization/ or hospital patient/ or outpatient/) use emez
15	(adolescent, hospitalized/ or child, hospitalized/ or Hospitalization/ or inpatients/ or outpatients/) use ppez
16	(hospitalized patients/ or exp hospitalization/ or outpatients/) use psyh
17	(hospital* or inpatient* or outpatient*).tw.
18	(health* adj3 (care or center* or centre* or clinic* or facility or facilities or service* or setting* or specialist*).tw.
19	((dental or communit* or emergency or hospital* or home or intensive or high-dependen* or mental* or primary or secondary or tertiary) adj3 (care or health*).tw.
20	(emergency adj2 room*).tw.
21	(ambulance* or CAMHS or dentist* or dietics or dieti?ian or hospice* or NICU or nutritionist* or orthodont* or ophthalmolog* or (outreach adj2 team*) or pharmacy or pharmacies or physio* or SCBU or SENCO or telemedicine*).tw.
22	((virtual* or online) adj2 (physician* or clinician* or doctor*).tw.
23	(communit* adj3 (p?ediatric* or nurs*).tw.
24	(home adj3 visit*).tw.
25	((walk-in or "urgent care") adj2 (centre* or center* or clinic* or service*).tw.
26	"speech and language therap*".tw.
27	general practice*.tw.
28	(health* and (nursery or nurseries or school*).tw.
29	(respite adj2 care).tw.
30	(foster care or "looked after children" or "children in care").tw.
31	or/11-30
32	(Experience/ or personal experience/ or attitude to health/ or patient attitude/ or patient preference/ or patient satisfaction/) use emez
33	(attitude to death/ or patient advocacy/ or consumer advocacy/ or professional-patient relationship/) use emez
34	(adverse childhood experience/ or exp attitude to health/ or exp Patient satisfaction/) use ppez
35	(exp Consumer Participation/ or "Patient Acceptance of Health Care"/ or *exp consumer satisfaction/ or patient preference/ or Attitude to Death/ or health knowledge, attitudes, practice/ or Patient Advocacy/ or consumer advocacy/ or narration/ or focus groups/ or Patient-Centered Care/ or exp Professional-Patient Relations/) use ppez
36	(exp Client Attitudes/ or exp Client Satisfaction/ or exp Attitudes/ or exp Health Attitudes/ or exp Preferences/ or exp Client Satisfaction/ or exp Death Attitudes/ or exp Advocacy/ or exp Preferences/ or client centered therapy/) use psyh
37	(attitude* or choice* or dissatisf* or expectation* or experienc* or inform* or opinion* or perceive* or perception* or perspective* or preferen* or priorit* or satisf* or thought* or view*).tw.
38	((adolescen* or baby or babies or child* or infant* or patient* or teen* or young person*) adj4 (decisi* or decid* or involv* or participat*).tw.
39	("informed choice" or "shared decision making").tw.
40	empowerment.tw.
41	(patient-focused or patient-cent?red).tw.
42	(advocate or advocacy).tw.
43	((aversion or barrier* or facilitat* or hinder* or obstacle* or obstruct*) adj2 (care or health* or intervention* or pathway* or program* or service* or therap* or treat*).ti,ab.
44	or/32-43
45	10 and 31 and 44

#	Searches
46	Qualitative Research/
47	exp interview/ use emez
48	interview/ use ppez
49	interviews/ use psyh
50	interview*.tw.
51	thematic analysis/ use emez
52	(theme\$ or thematic).mp.
53	qualitative.af.
54	questionnaire\$.mp.
55	ethnological research.mp.
56	ethnograph\$.mp.
57	ethnonursing.af.
58	phenomenol\$.af.
59	(life stor\$ or women* stor\$).mp.
60	(grounded adj (theor\$ or study or studies or research or analys?s)).af.
61	((data adj1 saturat\$) or participant observ\$).tw.
62	(field adj (study or studies or research)).tw.
63	biographical method.tw.
64	theoretical sampl\$.af.
65	((purpos\$ adj4 sampl\$) or (focus adj group\$)).af.
66	open ended questionnaire/ use emez
67	(account or accounts or unstructured or openended or open ended or text\$ or narrative\$).mp.
68	(life world or life-world or conversation analys?s or personal experience\$ or theoretical saturation).mp.
69	((lived or life) adj experience\$).mp.
70	narrative analys?s.af.
71	or/46-70
72	45 and 71
73	limit 72 to (yr="2009 - current" and english language)
74	exp United Kingdom/
75	(national health service* or nhs*).ti,ab,in,ad,cq.
76	(english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab.
77	(gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*).ti,ab,jx,in,ad,cq.
78	(bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or



#	Searches
	"nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worchester not (massachusetts* or boston* or harvard*)) or ("worchester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))).ti,ab,in,ad,cq.
79	(bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's").ti,ab,in,ad,cq.
80	(aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's").ti,ab,in,ad,cq.
81	(armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's").ti,ab,in,ad,cq.
82	or/74-81
83	((exp africa/ or exp americas/ or exp antarctic regions/ or exp arctic regions/ or exp asia/ or exp oceania/) not (exp united kingdom/ or europe/)) use ppez
84	((exp "arctic and antarctic"/ or exp oceanic regions/ or exp western hemisphere/ or exp africa/ or exp asia/ or exp "australia and new zealand"/) not (exp united kingdom/ or europe/)) use emez
85	83 or 84
86	82 not 85
87	73 and 86
88	Letter/ use ppez
89	letter.pt. or letter/ use emez
90	note.pt.
91	editorial.pt.
92	Editorial/ use ppez
93	News/ use ppez
94	news media/ use psych
95	exp Historical Article/ use ppez
96	Anecdotes as Topic/ use ppez
97	Comment/ use ppez
98	Case Report/ use ppez
99	case report/ or case study/ use emez
100	Case report/ use psych
101	(letter or comment*).ti.
102	or/88-101
103	randomized controlled trial/ use ppez
104	randomized controlled trial/ use emez
105	random*.ti,ab.
106	cohort studies/ use ppez
107	cohort analysis/ use emez
108	cohort analysis/ use psych
109	case-control studies/ use ppez
110	case-control study/ use emez
111	or/103-110
112	102 not 111

#	Searches
113	animals/ not humans/ use ppez
114	animal/ not human/ use emez
115	nonhuman/ use emez
116	"primates (nonhuman)"/
117	exp Animals, Laboratory/ use ppez
118	exp Animal Experimentation/ use ppez
119	exp Animal Experiment/ use emez
120	exp Experimental Animal/ use emez
121	animal research/ use psych
122	exp Models, Animal/ use ppez
123	animal model/ use emez
124	animal models/ use psych
125	exp Rodentia/ use ppez
126	exp Rodent/ use emez
127	rodents/ use psych
128	(rat or rats or mouse or mice).ti.
129	or/112-128
130	87 not 129
131	meta-analysis/
132	meta-analysis as topic/
133	systematic review/
134	meta-analysis/
135	(meta analy* or metanaly* or metaanaly*).ti,ab.
136	((systematic or evidence) adj2 (review* or overview*)).ti,ab.
137	((systematic* or evidence*) adj2 (review* or overview*)).ti,ab.
138	(reference list* or bibliograph* or hand search* or manual search* or relevant journals).ab.
139	(search strategy or search criteria or systematic search or study selection or data extraction).ab.
140	(search* adj4 literature).ab.
141	(medline or pubmed or cochrane or embase or psychlit or psychlit or psychinfo or psycinfo or cinahl or science citation index or bids or cancerlit).ab.
142	cochrane.jw.
143	((pool* or combined) adj2 (data or trials or studies or results)).ab.
144	((comprehensive* or integrative or systematic*) adj3 (bibliographic* or review* or literature)).ti,ab,id.
145	(meta-analy* or metaanaly* or "research synthesis").ti,ab,id.
146	((information or data) adj3 synthesis) or (data adj2 extract*).ti,ab,id.
147	(review adj5 (rationale or evidence)).ti,ab,id. and "Literature Review".md.
148	(cinahl or (cochrane adj3 trial*) or embase or medline or psychlit or pubmed or scopus or "sociological abstracts" or "web of science").ab.
149	("systematic review" or "meta analysis").md.
150	(or/131-132,135,137-142) use ppez
151	(or/133-136,138-143) use emez
152	(or/144-149) use psych
153	150 or 151 or 152
154	73 and 153
155	154 not 130

#	Searches
156	155 not 129

### Database: Cochrane Library

Date searched: 29/07/2020

#	Search
1	MeSH descriptor: [Adolescent] this term only
2	MeSH descriptor: [Minors] this term only
3	(adolescen* or teen* or youth* or young or juvenile* or minors or highschool*):ti,ab,kw
4	MeSH descriptor: [Child] explode all trees
5	(child* or schoolchild* or "school age" or "school aged" or preschool* or toddler* or kid* or kindergar* or boy* or girl*):ti,ab,kw
6	MeSH descriptor: [Infant] explode all trees
7	(infan* or neonat* or newborn* or baby or babies):ti,ab,kw
8	MeSH descriptor: [Pediatrics] explode all trees
9	MeSH descriptor: [Puberty] explode all trees
10	(p*ediatric* or pubert* or prepubert* or pubescen* or prepubescen*):ti,ab,kw
11	#1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10
12	MeSH descriptor: [Ambulances] this term only
13	MeSH descriptor: [Adolescent Health Services] this term only
14	MeSH descriptor: [Child Health Services] explode all trees
15	MeSH descriptor: [Community Health Services] this term only
16	MeSH descriptor: [Community Pharmacy Services] this term only
17	MeSH descriptor: [Community Health Centers] this term only
18	MeSH descriptor: [Community Mental Health Centers] this term only
19	MeSH descriptor: [Delivery of Health Care] this term only
20	MeSH descriptor: [Dental Care for Children] this term only
21	MeSH descriptor: [Dental Health Services] explode all trees
22	MeSH descriptor: [Dentists] this term only
23	MeSH descriptor: [Dental Facilities] this term only
24	MeSH descriptor: [Emergency Medical Services] this term only
25	MeSH descriptor: [Emergency Service, Hospital] this term only
26	MeSH descriptor: [General Practice] this term only
27	MeSH descriptor: [Health Facilities] this term only
28	MeSH descriptor: [Health Services] this term only
29	MeSH descriptor: [Home Care Services] this term only
30	MeSH descriptor: [Home Care Services, Hospital-Based] this term only
31	MeSH descriptor: [Home Nursing] this term only
32	MeSH descriptor: [Hospice Care] this term only
33	MeSH descriptor: [Hospices] this term only
34	MeSH descriptor: [Hospitals] explode all trees
35	MeSH descriptor: [Intensive Care Units] this term only
36	MeSH descriptor: [Intensive Care Units, Pediatric] this term only
37	MeSH descriptor: [Intensive Care Units, Neonatal] this term only
38	MeSH descriptor: [Mental Health Services] explode all trees
39	MeSH descriptor: [Nutritionists] this term only
40	MeSH descriptor: [Occupational Therapy] this term only

#	Search
41	MeSH descriptor: [Orthodontists] this term only
42	MeSH descriptor: [Pediatric Nursing] this term only
43	MeSH descriptor: [Pharmacies] this term only
44	MeSH descriptor: [Primary Health Care] this term only
45	MeSH descriptor: [Respite Care] this term only
46	MeSH descriptor: [School Health Services] explode all trees
47	MeSH descriptor: [School Nursing] this term only
48	MeSH descriptor: [Secondary Care] this term only
49	MeSH descriptor: [Telemedicine] this term only
50	MeSH descriptor: [Tertiary Healthcare] this term only
51	MeSH descriptor: [Transportation of Patients] this term only
52	MeSH descriptor: [Adolescent, Hospitalized] this term only
53	MeSH descriptor: [Child, Hospitalized] this term only
54	MeSH descriptor: [Hospitalization] this term only
55	MeSH descriptor: [Inpatients] this term only
56	MeSH descriptor: [Outpatients] this term only
57	(hospital* or inpatient* or outpatient*):ti,ab,kw
58	(health* near/3 (care or center* or centre* or clinic* or facility or facilities or service* or setting* or specialist*)):ti,ab,kw
59	((dental or communit* or emergency or hospital* or home or intensive or high-dependen* or mental* or primary or secondary or tertiary) near/3 (care or health*)):ti,ab,kw
60	(emergency near/2 room*):ti,ab,kw
61	(ambulance* or CAMHS or dentist* or dietics or dieti*ian or hospice* or NICU or nutritionist* or orthodont* or ophthalmolog* or (outreach near/2 team*) or pharmacy or pharmacies or physio* or SCBU or SENCO or telemedicine*):ti,ab,kw
62	((virtual* or online) near/2 (physician* or clinician* or doctor*)):ti,ab,kw
63	(communit* near/3 (p*ediatric* or nurs*)):ti,ab,kw
64	(home near/3 visit*):ti,ab,kw
65	((walk-in or "urgent care") near/2 (centre* or center* or clinic* or service*)):ti,ab,kw
66	("speech and language therap*"):ti,ab,kw
67	(general practice*):ti,ab,kw
68	(health* and (nursery or nurseries or school*)):ti,ab,kw
69	(respite near/2 care):ti,ab,kw
70	(foster care or "looked after children" or "children in care"):ti,ab,kw
71	#12 OR #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20 OR #21 OR #22 OR #23 OR #24 OR #25 OR #26 OR #27 OR #28 OR #29 OR #30 OR #31 OR #32 OR #33 OR #34 OR #35 OR #36 OR #37 OR #38 OR #39 OR #40 OR #41 OR #42 OR #43 OR #44 OR #45 OR #46 OR #47 OR #48 OR #49 OR #50 OR #51 OR #52 OR #53 OR #54 OR #55 OR #56 OR #57 OR #58 OR #59 OR #60 OR #61 OR #62 OR #63 OR #64 OR #65 OR #66 OR #67 OR #68 OR #69 OR #70
72	MeSH descriptor: [Adverse Childhood Experiences] this term only
73	MeSH descriptor: [Attitude to Health] explode all trees
74	MeSH descriptor: [Patient Satisfaction] explode all trees
75	MeSH descriptor: [Community Participation] explode all trees
76	MeSH descriptor: [Patient Acceptance of Health Care] this term only
77	MeSH descriptor: [Patient Preference] this term only
78	MeSH descriptor: [Attitude to Death] this term only
79	MeSH descriptor: [Health Knowledge, Attitudes, Practice] this term only

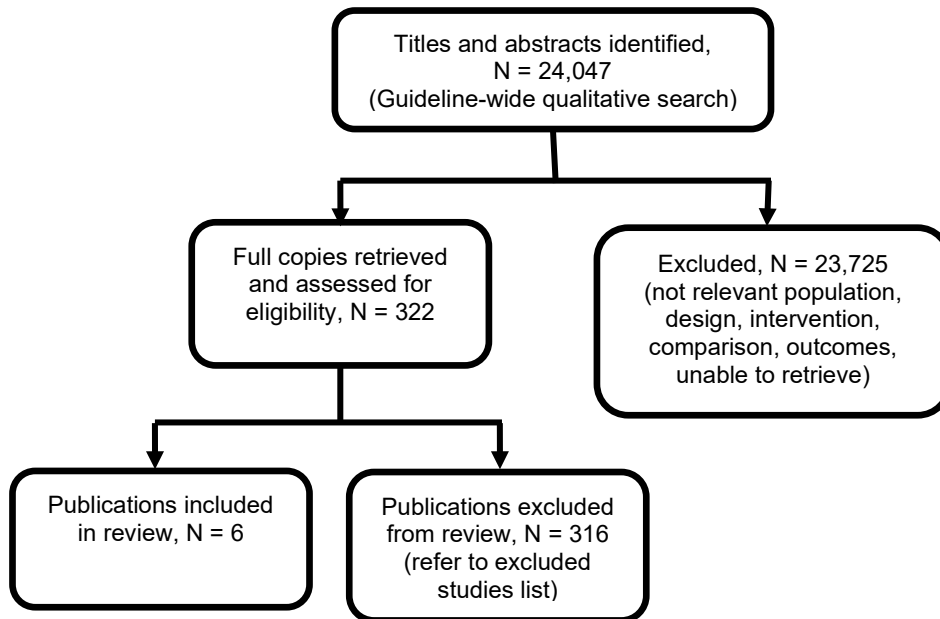
#	Search
80	MeSH descriptor: [Patient Advocacy] this term only
81	MeSH descriptor: [Consumer Advocacy] this term only
82	MeSH descriptor: [Narration] this term only
83	MeSH descriptor: [Focus Groups] this term only
84	MeSH descriptor: [Professional-Patient Relations] explode all trees
85	(attitude* or choice* or dissatisf* or expectation* or experienc* or inform* or opinion* or perceive* or perception* or perspective* or preferen* or priorit* or satisf* or thought* or view*):ti,ab,kw
86	((adolescen* or baby or babies or child* or infant* or patient* or teen* or young person*) near/4 (decisi* or decid* or involv* or participat*)):ti,ab,kw
87	("informed choice" or "shared decision making"):ti,ab,kw
88	(empowerment):ti,ab,kw
89	(patient-focused or patient-cent*red):ti,ab,kw
90	(advocate or advocacy):ti,ab,kw
91	((aversion or barrier* or facilitat* or hinder* or obstacle* or obstruct*) near/2 (care or health* or intervention* or pathway* or program* or service* or therap* or treat*)):ti,ab,kw
92	#72 OR #73 OR #74 OR #75 OR #76 OR #77 OR #78 OR #79 OR #80 OR #81 OR #82 OR #83 OR #84 OR #85 OR #86 OR #87 OR #88 OR #89 OR #90 OR #91
93	MeSH descriptor: [Qualitative Research] this term only
94	MeSH descriptor: [Interview] this term only
95	(interview*):ti,ab,kw
96	(theme* or thematic):ti,ab,kw
97	(qualitative):ti,ab,kw
98	(questionnaire*):ti,ab,kw
99	(ethnological research):ti,ab,kw
100	(ethnograph*):ti,ab,kw
101	(ethnonursing):ti,ab,kw
102	(phenomenol*):ti,ab,kw
103	(life stor* or women* stor*):ti,ab,kw
104	(grounded near (theor* or study or studies or research or analys*s)):ti,ab,kw
105	((data near/1 saturat*) or participant observ*):ti,ab,kw
106	(field near (study or studies or research)):ti,ab,kw
107	(biographical method):ti,ab,kw
108	(theoretical sampl*):ti,ab,kw
109	((purpos* near/4 samp**) or (focus near group*)):ti,ab,kw
110	(account or accounts or unstructured or openended or open ended or text* or narrative*):ti,ab,kw
111	(life world or life-world or conversation analys*s or personal experience* or theoretical saturation):ti,ab,kw
112	((lived or life) near experience*):ti,ab,kw
113	(narrative analys*s):ti,ab,kw
114	#93 OR #94 OR #95 OR #96 OR #97 OR #98 OR #99 OR #100 OR #101 OR #102 OR #103 OR #104 OR #105 OR #106 OR #107 OR #108 OR #109 OR #110 OR #111 OR #112 OR #113
115	#11 AND #71 AND #92 AND #114 with Cochrane Library publication date Between Jan 2009 and Jul 2019
116	MeSH descriptor: [United Kingdom] explode all trees
117	(national health service* or nhs*):ti,ab,kw

#	Search
118	(english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) near/5 english)):ti,ab,kw
119	(gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*):ti,ab,kw
120	(gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*):so
121	(bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))):ti,ab,kw
122	(bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's"):ti,ab,kw
123	(aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's"):ti,ab,kw
124	armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's":ti,ab,kw
125	#116 OR #117 OR #118 OR #119 OR #120 OR #121 OR #122 OR #123 OR #124
126	MeSH descriptor: [Africa] explode all trees
127	MeSH descriptor: [Americas] explode all trees
128	MeSH descriptor: [Antarctic Regions] explode all trees
129	MeSH descriptor: [Arctic Regions] explode all trees
130	MeSH descriptor: [Asia] explode all trees
131	MeSH descriptor: [Oceania] explode all trees
132	#126 OR #127 OR #128 OR #129 OR #130 OR #131
133	MeSH descriptor: [United Kingdom] explode all trees
134	MeSH descriptor: [Europe] this term only
135	#133 OR #134
136	#132 not #135
137	#125 not #136
138	#115 AND #137 with Cochrane Library publication date Between Jan 2009 and Jul 2019

## Appendix C – Clinical evidence study selection

**Study selection for review question: How do children and young people, and the parents and carers of babies and young children, prefer to be involved and supported in planning their healthcare and making informed, shared decisions about their health?**

**Figure 2: Study selection flow chart**



## Appendix D – Clinical evidence tables

**Evidence tables for review question: How do children and young people, and the parents and carers of babies and young children, prefer to be involved and supported in planning their healthcare and making informed, shared decisions about their health?**

**Table 6: Evidence tables**

Study details	Participants	Methods	Themes and findings	Limitations
<p><b>Full citation</b>                      Astbury R, Shepherd A, Cheyne H. Working in partnership: the application of shared decision-making to health visitor practice. <i>Journal of Clinical Nursing</i>, 26, 1-2, 215-224. 2017</p> <p><b>Ref Id</b>                      693901</p> <p><b>Country/ies where the study was carried out</b>                      Scotland, UK</p> <p><b>Study type</b>                      Conversation analysis and semi-structured interview</p> <p><b>Aim of the study</b>                      To describe what was currently happening when health visitors and parents were</p>	<p><b>Sample size</b>                      N=22                      n=11 health visitors                      n=11 parental proxies (n=2 parental proxies, Phase 1                      n=9 parental proxies, Phase 2)                      Only the views of parental proxies are included in this review as children under 5 years old.</p> <p>Observation (audio-recorded conversations)                      N=4                      n=2 parents of babies or children under 5                      n=2 health visitors</p> <p>Semi-structured interviews                      N=18                      n=9 parents of babies or children under 5                      n=9 health visitors</p> <p><b>Characteristics</b></p>	<p><b>Setting</b>                      Health visitors visiting parents of children under 5 in the community</p> <p><b>Recruitment</b>                      Health visitors were recruited by the researcher visiting the area. Health visitors who took part in phase 1 (audio recording of conversations) helped to recruit a convenience sample of parents who had decided about intervention on behalf of their baby or child, in partnership with their health visitor, within the last six months; and were willing to talk about their experience.</p> <p><b>Data collection</b>                      Phase 1 involved audio recording conversations between health visitor and parent dyads and then collecting each participant's perspective of the planning</p>	<p><b>Author's themes:</b>                      Identifying the Issue                      What supported discussions around the issue?                      Choice Talk                      Option Talk                      Relationships</p> <p><b>Findings</b>                      Clear definition of the 'issue', related to the baby's, child's, or young person's wellbeing, helped to support decision-making processes and a focus on resolving the issue. Tailoring levels of complexity and information to avoid overloading children at different stages. Participants also mentioned the need for shared understanding or agreement, between the health visitor and the parent before a decision was made. Urging professionals to use of evidence-based tools and resources (e.g. providing adequate time and engaging more experienced staff) to assess cognitive development supported health visitor findings and were found to be helpful; not only as</p>	<p><b>Limitations (assessed using the <u>CASP checklist for qualitative studies</u>).</b>                      Q1: Was there a clear statement of the aims of the research? Yes</p> <p>Q2: Was a qualitative methodology appropriate? Yes                      Qualitative; observation and interviews</p> <p>Q3: Was the research design appropriate to address the aims of the research? Yes. A qualitative design using interviews were used to explore experiences among parents and carers of young people.</p> <p>Q4: Was the recruitment strategy appropriate to the aims of the research? No. Convenience sampling was used to recruit caseload managers, although the inclusion criteria may have limited the sample, but this</p>



Study details	Participants	Methods	Themes and findings	Limitations
<p>making decisions and planning interventions together with a view to exploring what specific processes supported shared decision-making in this context of health visitor practice.</p> <p><b>Study dates</b> Not reported</p> <p><b>Source of funding</b> Study completed as part of a Doctor of Nursing Programme. Funding for expenses incurred by the General Nursing Council for Scotland (Education) 1983 Fund.</p>	<p>Age of babies and children: not reported</p> <p>Gender of babies and children: not reported</p> <p>Parents from mixed demographics in relation to region (rural and urban), affluence and deprivation.</p> <p><b>Inclusion criteria</b> Health visitors and parent dyads of babies and children who had to make a decision about their baby/child in the last 6 months.</p> <p><b>Exclusion criteria</b> None reported.</p>	<p>experience using a validated Elwyn’s OPTIONS questionnaire to establish the extent to which shared decision making has taken place within encounters/participants’ interpretations of their experiences.</p> <p>Phase 2 consisted of individual semi-structured interviews with health visitors and parents, asking them about their past experiences of planning interventions concerning a baby’s or child’s wellbeing using tailored topic guides.</p> <p><b>Analysis</b> The twenty recordings were transcribed verbatim, and analysis was supported by NVivo 10 using the framework analysis method - Elwyn’s Shared Decision-Making Framework.</p>	<p>an evidence base for their own decision making but to support discussions with parents. This also raised the issue on the need for relevant training in the use of evidence-based tools and resources varied amongst health visitors at the time of the study – although what was available appeared to make a valuable contribution to discussions and negotiations when sharing decision making with parents. Actually prioritising the types, order of suggesting and explaining the choices offered to parents when multiple issues were being considered was a suggestion for SDM. This facilitated deeper and meaningful conversations. Clearly articulating what the options are using effective communication strategies, across teams and streamlining information, in ways that was easy to explain to the parents, and less time consuming for the health visitor. For example, positive remarks were made in relation to creating ‘Teams around the Child’, based on ‘Networks of Support’ which consisted of a group of professionals, and the parents, meeting to support decision making around a child. They were found to be productive ways of informing parents directly what was on offer and to supporting them with their decision making during planning processes. This method of signposting instilled confidence in</p>	<p>was necessary to ensure a sample that was fit for purpose.</p> <p>Q5: Were the data collected in a way that addressed the research issue? Unclear. Authors do not provide a detailed description of ethical approval. A reference to "participants' permission" was briefly mentioned in the methods.</p> <p>Q6: Has the relationship between the researcher and participants been adequately considered? No. Descriptions of potential bias/influence between researcher and participants were not described, neither was reflexivity considered.</p> <p>Q7: Have ethical issues been taken into consideration? Yes. Ethical approval was given by the University of Stirling School of Health Sciences Ethics Committee and the NHS Research Ethics Service. However, the process of obtaining consent from participants was not described.</p> <p>Q8: Was the data analysis sufficiently rigorous? Yes. Themes were developed in an iterative manner using natural</p>

Study details	Participants	Methods	Themes and findings	Limitations
			<p>parents. Building trusting relationships with professionals allowed parents to express their personal issues, feelings, and emotions. It also provided opportunities to see links between family relationships and worse outcomes among children. The authors suggested training in using the Solihull approach.</p>	<p>observations, a validated questionnaire to in cooperate evolving ideas during the semi-structured interviews and allow for input from a research team to ensure rigour.</p> <p>Q9: Is there a clear statement of findings? Yes. The authors discuss of findings on shared decision making; supported by evidence from the literature.</p> <p>Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability) Yes. Details on recommendations for improving planning and shared decision making were provided that are applicable to the UK and future policymaking. 2. Yes. Findings are generalisable to other situations but may require tailoring within different clinical settings within the UK and were not supported by quotes.</p> <p>Overall judgement of quality: Serious concerns</p>
<p><b>Full citation</b>                      Barber S, Pavitt S, Meads D, Khambay B, Bekker H. Can the current hypodontia care pathway promote shared decision-</p>	<p><b>Sample size</b>                      N=26                      n= 13 young people                      n=13 parents (11 mothers, 2 fathers)</p>	<p><b>Setting</b>                      Orthodontic Departments of 2 NHS teaching hospitals in Yorkshire</p> <p><b>Recruitment</b></p>	<p><b>Author's themes:</b>                      Information exchange                      Preferences and values                      Understanding                      Preferences</p> <p><b>Findings</b></p>	<p><b>Limitations (assessed using the <u>CASP checklist for qualitative studies</u>).</b>                      Q1: Was there a clear statement of the aims of the research? Yes</p>

Study details	Participants	Methods	Themes and findings	Limitations
<p>making? Journal of Orthodontics, 46, 2, 126-136. 2019</p> <p><b>Ref Id</b> 1053083</p> <p>Country/ies where the study was carried out Yorkshire, UK</p> <p><b>Study type</b> Observation and semi-structured interview</p> <p><b>Aim of the study</b> To explore the extent and describe the process of shared decision making in current care pathway in hypodontia</p> <p><b>Study dates</b> August 2016 - August 2017</p> <p><b>Source of funding</b> The first author was funded through a National Institute for Health Research Fellowship. The research was supported by the National Institute for Health Research Clinical Research Network.</p>	<p>Only the views of young people are included in this review.</p> <p>Observation of consultation N=10 n=5 young people n=5 parents (4 mothers, 1 father)</p> <p>Patient–parent interview N=16 n=8 young people n=8 parents (7 mothers, 1 father)</p> <p>Characteristics Observation of consultation Age of young people (range): 12-16 years 12-13 years-old, n=3 14-16 years-old, n=2</p> <p>Gender of young people (M/F): 2/3</p> <p>Patient–parent interview Age of young people (range): 12-16 years 12-13 years-old, n=3 14-16 years-old, n=5</p> <p>Gender of young people (M/F): 2/6</p> <p><b>Inclusion criteria</b> Young people</p>	<p>Purposive sampling was used to select a convenience sample based on the severity of hypodontia, number of missing teeth, stage of treatment, age and gender. The relationship of accompanying parent was used to identify person and parent. Orthodontic Departments of two NHS teaching hospitals in Yorkshire that served a diverse population in terms of ethnicity, socioeconomic status, and general and oral health.</p> <p><b>Data collection</b> The first part of the study involved naturalist observation of clinical consultations between the dental team, adolescents with hypodontia and their parents. The second stage of the research involved semi-structured interviews. Audio-recorded consultations and interviews were transcribed.</p> <p><b>Analysis</b> Framework analysis method was used to analyse data</p>	<p>Professionals did not use evidence-based strategies to elicit or test patient engagement, perhaps due to lack of patient-centred methods. For example, using age-appropriate language or avoiding medical jargon. Encouraging richer and deeper dialogue during consultations with patients and family to understand their preferences and values. Professionals need to be aware of the general values of patients and parent perception of decision-making. Parents largely perceived the decision-making process to be led by the attending team, with their role being to support their child to ensure the treatment selected was appropriate. Hence, the need for clear information from professionals was articulated. Sometimes, participants sought additional information from other sources, most commonly the Internet, and expressed a desire for evidence-based information about treatment efficacy. Participants had pre-conceived ideas about treatment or beliefs about certain treatment options, affected discussion regarding it and referring to motivation to have treatment or expectation of treatment outcome. The use of decision aids or value clarification methods was not considered. This may have influenced perceptions of satisfaction.</p>	<p>Q2: Was a qualitative methodology appropriate? Yes. Two-staged interviews were used to explore the topic area.</p> <p>Q3: Was the research design appropriate to address the aims of the research? Yes. A qualitative design using interviews were used to explore experiences among young people and their parents. Adolescents were interviewed before their parents joined in order to prevent the ‘Hawthorne effect’.</p> <p>Q4: Was the recruitment strategy appropriate to the aims of the research? Yes. Observations were used to identify key recruitment factors for recruitment with two UK units.</p> <p>Q5: Were the data collected in a way that addressed the research issue? Yes. Interviews were conducted with a topic guide developed with input from a decision-making expert and patient representatives, but the topic guide was used with flexibility to participants to discuss experiences of relevance to their lives. Also, natural</p>

Study details	Participants	Methods	Themes and findings	Limitations
	<p>Aged 12-16 years                      Hypodontia of any severity                      At any stage of treatment</p> <p><b>Exclusion criteria</b>                      Adolescents with craniofacial conditions or significant medical histories if their condition was judged to impact on treatment options or provision of care potentially.                      Participants were not excluded based on language, but for feasibility reasons, only the English component was transcribed and analysed.</p>			<p>observations of the clinical environment were performed.</p> <p>Q6: Has the relationship between the researcher and participants been adequately considered? No. Descriptions of potential bias/influence between researcher and participants were not described, neither was reflexivity considered.</p> <p>Q7: Have ethical issues been taken into consideration? Yes. Ethical approval was granted by North West Lancaster Ethics Research Committee - although authors do not provide a detailed description of ethical approval.</p> <p>Q8: Was the data analysis sufficiently rigorous? Yes. Themes were developed iteratively to incorporate contrary ideas, data saturation and input from a research team to ensure rigour.</p> <p>Q9: Is there a clear statement of findings? Yes. The authors discuss the implications of the results on shared decision making among children and young people with parents as well as practitioners using broader UK evidence to support their conclusions.</p>

Study details	Participants	Methods	Themes and findings	Limitations
				<p>Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability) 1. Yes. Details on recommendations for improving shared decision making fits with current literature and the UK population, and how they can be used to inform best practice and future policymaking. 2. Yes. Findings are generalisable to other children and young people but maybe less so to non-dental settings.</p> <p>Overall judgement of quality                      Moderate concerns</p>
<p><b>Full citation</b>                      Flett AM, Hall M, McCarthy C, Marshman Z, Benson PE. Does the British Orthodontic Society orthognathic DVD aid a prospective patient's decision making? A qualitative study. Journal of Orthodontics, 41, 2, 88-97. 2014</p> <p><b>Ref Id</b>                      1055781</p>	<p><b>Sample size</b>                      N=10 people</p> <p><b>Characteristics</b>                      Age (range): 16-48 years (only quotes from those under 18 were analysed)</p> <p>Gender: (M/F) 4/6</p> <p><b>Inclusion criteria</b>                      Patients, of any ethnic origin, who were considering, but had not undergone, orthognathic treatment to address skeletal discrepancy</p>	<p><b>Setting</b>                      Orthodontic department of dental hospital in Sheffield</p> <p><b>Recruitment</b>                      Participants were recruited from joint orthodontic/ orthognathic clinics in the participating hospital. Purposive sampling was conducted to include patients, of any ethnic origin, who were considering but had not undergone, orthognathic treatment to address skeletal discrepancy. Recruitment continued until saturation at 10 participants.</p>	<p><b>Author's themes:</b>                      Patient stories                      Value                      Problems</p> <p><b>Findings</b>                      Using shared experiences to facilitate understanding and to establish the nature or reality of the decisions under consideration by applying the positive and negative aspects of the stories in the DVD to improve understanding. It was helpful in the decision-making process to gain additional knowledge and information. It provided CYPs with experiences to contextualise the impact of their choices. Other sources of supporting information</p>	<p><b>Limitations (assessed using the CASP checklist for qualitative studies).</b></p> <p>Q1: Was there a clear statement of the aims of the research? Yes</p> <p>Q2: Was a qualitative methodology appropriate? Yes. A qualitative design using interviews were used to explore their experiences.</p> <p>Q3: Was the research design appropriate to address the aims of the research? Probably yes. A qualitative design using interviews were used to</p>

Study details	Participants	Methods	Themes and findings	Limitations
<p><b>Country/ies where the study was carried out</b> Sheffield, UK</p> <p><b>Study type</b> Semi-structured interview</p> <p><b>Aim of the study</b> To explore, using qualitative methods, the role of the BOS DVD in the decision-making process of patients considering orthognathic treatment.</p> <p>Study dates October 2011 and March 2012.</p> <p><b>Source of funding</b> Not reported.</p>	<p>If teenage patient, then developmentally ready for surgery</p> <p><b>Exclusion criteria</b> Patients had a craniofacial syndrome (including cleft lip and/or palate), complex medical histories, were considering reoperation following a previous osteotomy or trauma Patients aged under 16 years Patients unable to speak or understand English.</p>	<p><b>Data collection</b> Interviews were conducted in the participant's home to ensure they were as relaxed as possible and more likely to respond naturally.</p> <p><b>Analysis</b> Data saturation was achieved after 10 interviews, transcribed and analysed based on framework analysis</p>	<p>included a BOS leaflet and the Internet, the latter being less trustworthy.</p>	<p>explore the role of adequate information (BOS DVD) in the decision-making process of patients considering orthognathic treatment their experiences.</p> <p>Q4: Was the recruitment strategy appropriate to the aims of the research? Yes. Participants were purposively selected from the clinical environment by a consultant (this could arguably have inadvertently influenced the decision to participate).</p> <p>Q5: Were the data collected in a way that addressed the research issue? Yes. Participants were interviewed in their homes to allow for a more relaxed and natural environment. Semi-structured interviews were used, developed using current literature and flexible to allow for different participants.</p> <p>Q6: Has the relationship between the researcher and participants been adequately considered? No. No description of potential bias/influence between researcher and participants.</p> <p>Q7: Have ethical issues been taken into consideration? Yes.</p>

Study details	Participants	Methods	Themes and findings	Limitations
				<p>Ethical approval was obtained from Yorkshire and the Humber Research Ethics Committee Research governance approval was obtained from Doncaster and Bassetlaw Hospitals NHS Foundation Trust (the sponsor for the study) and Sheffield Teaching Hospitals NHS Foundation Trust. Authors provide a detailed description of the ethical approval with adequate time prior to consent.</p> <p>Q8: Was the data analysis sufficiently rigorous? Yes. Themes were developed iteratively to incorporate contrary ideas and input from a research team to ensure rigour. Data analysis was based on an inductive thematic analysis approach.</p> <p>Q9: Is there a clear statement of findings? Yes. The authors discuss findings on shared decision making among children and young people with parents as well as practitioners using broader UK evidence to support their conclusions.</p> <p>Q10: Is the research valuable for the UK? (1. Contribution to</p>

Study details	Participants	Methods	Themes and findings	Limitations
				literature and 2. Transferability) 1. Yes. Recommendations for improving shared decision making fits with current literature and the UK population, and how they can be used to inform best practice and future policymaking. 2. Yes. Findings are generalisable to children and young people but evaluated an existing intervention – a DVD – as opposed theory generating.  Overall judgement of quality: Minor concerns
<p><b>Full citation</b>                      Gibson F, Aldiss S, Horstman M, Kumpunen S, Richardson A. Children and young people's experiences of cancer care: a qualitative research study using participatory methods. International Journal of Nursing Studies. 47, 11, 1397-407. 2010</p> <p><b>Ref Id</b>                      1056148</p> <p><b>Country/ies where the study was carried out</b></p>	<p><b>Sample size</b>                      N=38 children and young people</p> <p><b>Characteristics</b>                      Age (range): 4–19 years                      Gender (M/F): 18/20                      Ethnicity                      White British: n=29 (76.3%)                      White Other: n=2 (5.3%)                      Mixed: White and Black Caribbean: n=2 (5.3%)                      Asian Other: n=2 (5.3%)                      White Irish: n=1 (2.6%)                      Black African: n=1 (2.6%)                      Asian Pakistani: n=1 (2.6%)</p> <p><b>Inclusion criteria</b></p>	<p><b>Settings</b>                      Specialised cancer centre in London</p> <p><b>Recruitment</b>                      Purposive sampling strategy was used to recruit a target sample of 48 eligible children, ensuring a mix in terms of ethnicity, gender, age, social background and diagnosis. Eligible participants at 3 PCTs in the UK were recruited with assistance from clinical staff.</p> <p>Fifty children and young people initially agreed to take part, but only 38 were able to. Being unable to participate was due to</p>	<p><b>Author's themes:</b>                      Asking and telling—getting the balance right                      Worrying about now and the future</p> <p><b>Findings</b>                      Young children wanted to be supported in the decision-making process; relying on parents but receiving adequate - clear, specific, unambiguous- information using appropriate language (free of jargon, but not baby talk) about the issue by the experts. They also wanted the chance to lead conversations with health professionals (who could remain in the background), the opportunity to ask questions and at other times wanted staff to be perceptive, reading subjective cues (e.g. eye contact, curtains drawn) to</p>	<p><b>Limitations (assessed using the <u>CASP checklist for qualitative studies</u>).</b></p> <p>Q1: Was there a clear statement of the aims of the research? Yes</p> <p>Q2: Was a qualitative methodology appropriate? Yes</p> <p>Q3: Was the research design appropriate to address the aims of the research? Yes. Qualitative design using interviews</p> <p>Q4: Was the recruitment strategy appropriate to the aims of the research? Yes. Convenience sampling was</p>



Study details	Participants	Methods	Themes and findings	Limitations
<p>London, UK</p> <p><b>Study type</b> Participatory-based activities</p> <p><b>Aim of the study</b> The study sought to explore children’s and young people’s views about cancer care and to present a conceptual model of communication and information sharing.</p> <p><b>Study dates</b> Not reported</p> <p><b>Source of funding</b> This work was supported by Macmillan Cancer Support.</p>	<p>Children and young people aged 4–19 years at 6 stages of the cancer “journey” (e.g. at diagnosis, during and up to 18 months after treatment, receiving palliative care)</p> <p><b>Exclusion criteria</b> Critically-ill under-5s Clinical staff judge participant to be too unwell to participate</p>	<p>severe illness during data collection, or having other commitments, both medical and social.</p> <p><b>Data collection</b> Participatory-based activities including play activities, peer interviews and focus group were used to conduct interviews.</p> <p><b>Analysis</b> Data analysis was based on an inductive thematic analysis approach.</p>	<p>tailor the complex conversations. for example, the authors described the differences between preferences made by younger vs. older children. General communicative competence, preferences are affected by age, where younger children may change preferences within a short time without realising the inconsistency, and older children’s preferences are likely to remain more stable and differentiated because they are able to concentrate on issues aside from immediate needs and environmental forces of the moment. Young children’s preferences are more abstract and less influenced by adults’ or peers’ expectations, unlike older children’s preferences that become more articulated than broad and influenced by others. Asking for help when worried or anxious or acknowledging the need for help, due to fear of being judged by health professionals or the lack of competent care.</p>	<p>used to recruit caseload managers, although the inclusion criteria may have limited the sample, this was necessary to ensure a sample that was fit for purpose.</p> <p>Q5: Were the data collected in a way that addressed the research issue? Yes. An innovative strategy but applicable to the patient group and age ranges.</p> <p>Q6: Has the relationship between the researcher and participants been adequately considered? No. Descriptions of potential bias/influence between researcher and participants were not described, neither was reflexivity considered.</p> <p>Q7: Have ethical issues been taken into consideration? Yes. NHS Trusts where data were collected and approved by a relevant Local Research Ethics Committee. Consent was received before the interview and described within the methods. Participants were given a toy or a voucher as a token for participating. They were not informed of this until after they had participated to avoid coercion.</p>

Study details	Participants	Methods	Themes and findings	Limitations
				<p>Q8: Was the data analysis sufficiently rigorous? Can't tell. Themes were not presented to participants for triangulation, but this was perhaps due to the age range of participants.</p> <p>Q9: Is there a clear statement of findings? Yes. The authors discuss results on shared decision making among children, young people and parents as well as practitioners using broader UK evidence to support their conclusions.</p> <p>Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability) 1. Yes. Details on recommendations for improving shared decision making fits with current literature and the UK population, and how they can be used to inform best practice and future policymaking. 2. Unsure. An adequate and representative sample was used, but a unique clinical population may affect the applicability of findings.</p> <p>Overall judgement of quality: Moderate concerns</p>
<p><b>Full citation</b>                      Mitchell, Wendy,                      Parents' accounts:</p>	<p><b>Sample size</b>                      N = 14 parents (from 11 lone/dyad families [11</p>	<p><b>Setting</b>                      Two children's hospices in England</p>	<p><b>Author's themes:</b>                      The priority given to the young person's level of understanding</p>	<p><b>Limitations (assessed using the <u>CASP checklist for qualitative studies</u>).</b></p>

Study details	Participants	Methods	Themes and findings	Limitations
<p>Factors considered when deciding how far to involve their son/daughter with learning disabilities in choice-making, Children and Youth Services Review, 34, 1560-1569, 2012</p> <p><b>Ref Id</b> 1059661</p> <p><b>Country/ies where the study was carried out</b> England, UK</p> <p><b>Study type</b> Semi-structured interview</p> <p><b>Aim of the study</b> To explore parental perspectives on their and their child's role in choice-making when there were significant choices to be made regarding their son/daughter's life</p> <p><b>Study dates</b> 2007-2010</p> <p><b>Source of funding</b> This project was funded by the UK Department of Health</p>	<p>mothers and 3 fathers]) of children with learning disabilities</p> <p><b>Characteristics</b> Age of child (range): not reported</p> <p>Gender of child (M/F): not reported</p> <p><b>Inclusion criteria</b> Parents of children and young people aged 13-21 years, with learning disabilities and life-limiting conditions. Participated in all three-interview rounds to provide data on different choices and opportunities for reflection.</p> <p><b>Exclusion criteria</b> None reported.</p>	<p><b>Recruitment</b> A convenience sample of young people (with a wide range of degenerative conditions) and their parents were recruited from two English children's hospices. Thirty-three families were recruited to the study; the deteriorating health of young people affected the conduct of interviews, and only 11 families provided data.</p> <p><b>Data collection</b> Repeat semi-structured interviews (lasting between 60-180 minutes) with parents of children with learning disabilities. Eight interviews were with the mother whilst 3 were with both the mother and father.</p> <p><b>Analysis</b> Interviews were fully transcribed and then thematically analysed drawing on the Framework Approach (supported by MAXqda software).</p>	<p>Parents views on the nature of the choice                      Level of complexity                      Experience opportunities                      Parents' attitudes and beliefs                      Life-stage and transition to adulthood                      Confidence in practitioners' knowledge and understanding</p> <p><b>Findings</b>                      Using developmentally and age-appropriate communication (language tools) strategies to facilitate understanding and choice-making processes that allow for negotiation. Additional factors that affect the process included: their views on the nature of the choice; their desire to protect their child; personal beliefs and attitudes, especially around life-stage and transition to adulthood; confidence in practitioners' knowledge and understanding. Parents talked about evaluating the complexity of the choice being made as well as the significance of the decision on future well being. Engaging CYPs in everyday decision making was considered beneficial to facilitate involvement, but should be altered when the impact of such decisions was difficult to comprehend. Providing opportunities to experience the different options of the choices available using educational or leisure activity avenues supported this process. Some parents reported the need for professionals to be aware of</p>	<p>Q1: Was there a clear statement of the aims of the research? Yes.</p> <p>Q2: Was a qualitative methodology appropriate? Yes.</p> <p>Q3: Was the research design appropriate to address the aims of the research? Yes. Qualitative design; semi-structured interviews allowed for the discussion of sensitive topics with parents with limiting conditions.</p> <p>Q4: Was the recruitment strategy appropriate to the aims of the research? Yes. Due to the sensitive nature of the topic area, participants were recruited from hospices, and flexible approaches were used.</p> <p>Q5: Were the data collected in a way that addressed the research issue? Yes, Repeated interviews were used to ensure data triangulation and richness.</p> <p>Q6: Has the relationship between the researcher and participants been adequately considered? Yes. Although themes were not presented to participants for triangulation,</p>

Study details	Participants	Methods	Themes and findings	Limitations
<p>Policy Research Programme.</p>			<p>their parental responsibility, to filter information to their children and the need to support CYPs in the acquisition of these choice-making skills by simplifying choices and, where possible, providing direct experience of choice options. A sense of impending adulthood influenced some parents' decisions about their son/daughter's level of participation in choice-making, regardless of their son/daughter's learning disabilities. Parents of young people relinquished some parental responsibility and assumed an advisory role, especially paid support workers, had become more involved and trusted. Some parents acted as advocates to ensure that assumptions of health professionals were abated. This role was also reduced as parents felt care staff and other practitioners became more skilled and knowing of their child's communication preferences.</p>	<p>data collection was conducted in stages to allow the data to evolve naturally, and the study team met regularly to critically review the themes.</p> <p>Q7: Have ethical issues been taken into consideration? Yes. Ethical approval was received from an English National Health Service medical research ethics committee. Recognising that the study could raise potentially sensitive issues, the project identified an individual in each hospice to provide information and counselling if requested by parents.</p> <p>Q8: Was the data analysis sufficiently rigorous? Yes. Data were double-coded by a colleague; two researchers discussed their coding and amended the coding frame accordingly, as well as the project research team meeting regularly to discuss their analysis and data summary, sharing ideas and experiences.</p> <p>Q9: Is there a clear statement of findings? Yes. The authors discuss results on shared decision making among children, young people and parents as well as practitioners</p>

Study details	Participants	Methods	Themes and findings	Limitations
				using broader UK evidence to support their conclusions.  <i>Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability) Yes. 1. The study findings were well placed within the current literature on improving access within UK clinical settings and implications for practice. Ideas and directions for future research were presented. 2. Probably. Adequate population size for qualitative study and well-represented samples of the parent population.</i>  Overall judgement of quality: Minor concerns
<p><b>Full citation</b>                      Sherratt, F. C., Beasant, L., Crawley, E. M., Hall, N. J., Young, B., Enhancing communication, informed consent and recruitment in a paediatric urgent care surgical trial: A qualitative study, BMC Pediatrics, 20, 140, 2020</p> <p><b>Ref Id</b>                      1267376</p>	<p>Sample size  <b>N</b>=73 children, young people, parents and healthcare professionals                      n=28 families                      n=14 children and young people                      n=34 parents                      n=35 healthcare professionals                      Only the views of children, young people and their parents have been included in this review. Parents' views have been included as interviews were conducted in family units</p>	<p><b>Setting</b>                      3 paediatric surgical teaching hospitals (Liverpool, London and Southampton)  <b>Recruitment</b>                      A purposive sampling of children and young people – 7 to 15 years - and their parents (28 families) ensuring representation of child's age, socio-economic status, study site and participation in CONTRACT study.</p> <p><b>Data collection</b></p>	<p><b>Author's themes:</b></p> <p>Challenges involving children and young people in decision making: Children's capacity to engage in research conversation</p> <p>Findings                      Children and young people were unable to fully participate in discussions about their care because of the acute nature of their illness. They were often in a large amount of pain and unable to concentrate on the information presented to them by healthcare professionals. While the timing was not always right, some children were able to decide what treatment they wanted relatively</p>	<p><b>Limitations (assessed using the CASP checklist for qualitative studies.</b></p> <p><i>Q1: Was there a clear statement of the aims of the research? Yes</i></p> <p><i>Q2: Was a qualitative methodology appropriate? Yes</i></p> <p><i>Q3: Was the research design appropriate to address the aims of the research? Unsure. Can't tell - Qualitative study is appropriate for the aim of this specific question, but it is nested within the CONTRACT</i></p>

Study details	Participants	Methods	Themes and findings	Limitations
<p><b>Country/ies where the study was carried out</b>                      Liverpool, London and Southampton, UK</p> <p><b>Study type</b>                      Semi-structured interview</p> <p><b>Aim of the study</b>                      To explore healthcare professionals' communication when discussing potential involvement of children in clinical trials, and use this to inform a specialised communication training to increase recruitment rates.</p> <p><b>Study dates</b>                      March 2017-February 2018</p> <p><b>Source of funding</b>                      The study received funding from the UK National Institute for Health Research Health Technology Assessment programme.</p>	<p>and the children and young people were recalling experiences of presenting to A&amp;E with suspected appendicitis. This is associated with considerable pain which may affect communication at the time of admission and recall of the event.</p> <p>Characteristics                      Age (median; range): 11 years; 5-15)</p> <p>Gender (M/F): 21/7</p> <p>Ethnicity: not reported</p> <p><b>Inclusion criteria</b>                      Participants had to:                      Be aged 7-15 years.                      Have been approached about taking part in parent CONTRACT study (Conservative Treatment of Acute Appendicitis in Children feasibility trial)                      Or be a parent of one of the above.</p> <p><b>Exclusion criteria</b>                      None reported.</p> <p><b>Interventions</b>                      Not applicable</p>	<p>Semi-structured interviews (lasting between 22-89 minutes (median 59 minutes) either by telephone or face-to-face, were held between 1-4 weeks after hospital discharge. Children were interviewed along with the parents, in a family interview. The topic guide developed with patient and public involvement, but interviews were flexible, audio-recorded and transcribed.</p> <p><b>Analysis</b>                      Interviews were fully transcribed and then thematically analysed iteratively drawing on the framework analysis approach. Themes received input from the research team and healthcare professionals to ensure themes were valid.</p>	<p>quickly. However, it is not clear if they understood the implications - risks and benefits of the treatment options. Regardless of parental approval (and sometimes, regardless of the outcome), it seemed children wanted their opinions and preferences acknowledged; when they were able to decide.</p>	<p>feasibility study and therefore not the primary aim.</p> <p>Q4: Was the recruitment strategy appropriate to the aims of the research? Yes. Families recruited from those approached to take part in CONTRACT. Families refusing to take part were reported, with reasons given. Purposive sampling was used to ensure a range of characteristics within the sample.</p> <p>Q5: Were the data collected in a way that addressed the research issue? Yes. Semi-structured interviews using 2 researchers experienced in qualitative field. The time limit of 4 weeks limits recall bias. Topic guides were used, which were informed by children with a history of appendicitis and their parents. Separate ones developed for all participant groups, and interactive art-based techniques were employed with child interviewees. Data were audio-recorded and transcribed. However, the data setting of face-to-face interviews was not reported. Additionally, data saturation was discussed but difficult to tell if it was reached.</p>

Study details	Participants	Methods	Themes and findings	Limitations
				<p>Q6: Has the relationship between the researcher and participants been adequately considered? Yes. Can't tell - Descriptions of potential bias/influence between researcher and participants was not described. Important to consider the impact of having parents in the room.</p> <p>Q7: Have ethical issues been taken into consideration? Yes. Ethical approval received from South Central - Hampshire A Research Ethics Committee. Informed consent and assent received before interviews and anonymisation procedures described.</p> <p>Q8: Was the data analysis sufficiently rigorous? Yes. Adequate description of the analysis process, as well as how codes and themes were developed. 10% of transcripts were initially double-coded by 2 team members, and a proportion was read by a 3rd (although no mention of how many this was or if it continued throughout the study). Results were discussed with the wider team, although no mention of how using the results to inform subsequent consultations might affect the data. Good</p>

Study details	Participants	Methods	Themes and findings	Limitations
				<p>amount of data presented to support findings.</p> <p>Q9: Is there a clear statement of findings? Can't tell - Good descriptions of findings, with discussion including current evidence. Validation methods included multiple researchers and triangulation between groups. However, the fact that we are only extracting 1 of these groups limits the credibility of this technique. No discussion of how children's responses could have been affected by having family interviews.</p> <p>Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability) 1. Yes - The study makes existing contributions to recruitment strategies. 2. No - While the sample is diverse, the study aim is very specific, and there is limited child involvement in the study.</p> <p>Overall judgement of quality: Moderate concerns</p> <p><b>Other information</b>                      This study also included healthcare professionals as participants. However, as these are outside of the</p>



Study details	Participants	Methods	Themes and findings	Limitations
				protocol, these data have not been extracted.

*BOS: British Orthodontic Society; DVD: Digital Versatile Disc; N: Number; NIHR CRN: National Institute for Health Research Clinical Research Network*

## Appendix E – Forest plots

**Forest plots for review question: How do children and young people, and the parents and carers of babies and young children, prefer to be involved and supported in planning their healthcare and making informed, shared decisions about their health?**

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

## Appendix F – GRADE-CERQual tables

**GRADE-CERQual tables for review question: How do children and young people, and the parents and carers of babies and young children, prefer to be involved and supported in planning their healthcare and making informed, shared decisions about their health?**

**Table 7: Evidence summary (GRADE-CERQual) for theme 1: Children’s preferences**

Study information		Description of review finding	CERQual Quality assessment				
Number of studies	Design		Methodological limitations	Coherence of findings	Adequacy of data	Relevance of evidence	Overall confidence
<b>Sub-theme 1.1: Healthcare professional's understanding of preferences</b>							
4 (Astbury 2017, Barber 2019, Gibson 2010, Mitchell 2012)	Semi-structured interviews, observations, conversation analysis, participatory-based activities	Evidence from 4 studies showed that healthcare professionals that build dynamic relationships with babies, children, young people and their parents help to promote environments that facilitate the expression of issues, feelings, and preferences. For example, some authors describe differences between preferences made by younger compared to older children. Young children’s choices were more abstract and less influenced by expectations from adults or peers. In contrast, older children’s preferences seemed to become more articulated than broad and influenced by others. When trust was established between healthcare professionals, children and young people or their parents, it provided the opportunity for healthcare professionals to observe elements of family dynamics that may be driving poor health outcomes, as well as the platform to address these issues.  <i>‘they speak to Mum first, they should talk to me first’ (Gibson 2010, page 1402)</i>	Moderate concerns <sup>1</sup>	No/very minor concerns	Minor concerns <sup>2</sup>	Minor concerns <sup>3</sup>	LOW

Study information		Description of review finding	CERQual Quality assessment				
Number of studies	Design		Methodological limitations	Coherence of findings	Adequacy of data	Relevance of evidence	Overall confidence
<b>Sub-theme 1.2: Maturing and involvement in healthcare</b>							
1 (Mitchell 2012)	Semi-structured interviews	Evidence from 1 study showed that a sense of impending adulthood, the abilities of their child and having paid support influenced parental views and their choices with regards to their children's preferences.  <i>No quotes to support this finding.</i>	No/very minor concerns	No/very minor concerns	Serious concerns <sup>4</sup>	Minor concerns <sup>3</sup>	LOW
<b>Sub-theme 1.3: Role of context during decision-making</b>							
1 (Sherratt 2020)	Semi-structured interviews	Evidence from 1 study showed that children and young people were unable to fully participate in discussions about their care because of the acute nature of their illness. They were often in a large amount of pain and unable to concentrate on the information presented to them by healthcare professionals. While the timing was not always right, some children were able to decide what treatment they wanted relatively quickly. However, it is not clear if they understood the implications - risks and benefits of the treatment options. Regardless of parental approval (and sometimes, of the outcome), it seemed children wanted their opinions/preferences acknowledged; when they were able to decide.  <i>'Child: It was hard for me to concentrate...                      Mother: The lady was asking him questions, wasn't she? And you were just going, "Oh I just want it, I just want to stop it"'. (Sherratt 2020, page 9)</i>	Moderate concerns <sup>1</sup>	No/very minor concerns	Moderate concerns <sup>5</sup>	Minor concerns <sup>6</sup>	LOW

<sup>1</sup> Evidence was downgraded due to moderate concerns as per CASP qualitative checklist

<sup>2</sup> Evidence was downgraded for adequacy because studies together offered moderately rich data

3 Evidence was downgraded due to minor concerns about the relevance of findings, data generated were from study participants between 19 years of age and older (data was only extracted which related to those under 18 years; however, the number of participants in this age group was unclear).

4 Evidence was downgraded for adequacy because study did not offer rich data

5 Evidence was downgraded for adequacy because study offered some rich data

6 Evidence was downgraded due to minor concerns about the relevance of findings; data were generated from a study sub-sample with limited representation among children and young participants (however, data were extracted related to children making decisions during the conduct of the study).

**Table 8: Evidence summary (GRADE-CERQual) for theme 2: The role of healthcare professionals**

Study information		Description of review finding	CERQual Quality assessment				
Number of studies	Design		Methodological limitations	Coherence of findings	Adequacy of data	Relevance of evidence	Overall confidence
<b>Sub-theme 2.1: Defining the issues and tailoring to levels of complexity</b>							
2 (Astbury 2017, Mitchell 2012)	Conversation analysis and semi-structured interviews	<p>Evidence from 2 studies showed that defining the 'issue' relating to babies and children's wellbeing helped to support decision-making processes and focus on resolving the issue. Tailoring the complexity of conversations to the development needs of children and the situations at hand (taking baby steps) helped to improve shared understanding or agreement before a decision was made.</p> <p><i>'We've found our role is like having to put a big ring-fence around him, give him the information and say [to practitioners, here in education] 'don't confuse him any further, let him choose'. (Mitchell 2012, page 17)</i></p>	Serious concerns <sup>1</sup>	No/very minor concerns	Minor concerns <sup>2</sup>	Minor concerns <sup>3</sup>	MODERATE
<b>Sub-theme 2.2: Prioritising the choices offered during decision-making</b>							
1 (Astbury 2017)	Conversation analysis and semi-structured interviews	<p>Evidence from 1 study showed that healthcare professionals should prioritise the types, order of suggestions and choices offered to parents making decisions for their children when multiple issues are being considered. This was a way of promoting shared decision making.</p> <p><i>No quotes to support this finding.</i></p>	Serious concerns <sup>1</sup>	No/very minor concerns	Moderate concerns <sup>4</sup>	No/very minor concerns	LOW

1 Evidence was downgraded due to serious concerns as per CASP qualitative checklist

2 Evidence was downgraded for adequacy because studies together offered moderately rich data

3 Evidence was downgraded due to minor concerns about the applicability of findings, data generated were from study participants between 19 years of age and older (data was only extracted which related to those under 18 years; however, the number of participants in this age group was unclear).

4 Evidence was downgraded for adequacy because study offered some rich data

**Table 9: Evidence summary (GRADE-CERQual) for theme 3: Strategies to facilitate shared decision making**

Study information		Description of review finding	CERQual Quality assessment				
Number of studies	Design		Methodological limitations	Coherence of findings	Adequacy of data	Applicability of evidence	Overall confidence
<b>Sub-theme 3.1: Using developmentally appropriate evidence-based strategies</b>							
3 (Astbury 2017, Barber 2019, Mitchell 2012)	Conversation analysis, observations and semi-structured interviews	Evidence from 3 studies showed that professionals should use evidence-based tools (e.g. language tools) and adequate resources (e.g. providing adequate time and engaging more experienced staff when assessing patients with cognitive impairments) to help facilitate discussions with parents. However, variation in the health visitor's ability to apply these tools or lack of resources influenced contributions to discussions and negotiations during decision making with parents. One strategy proffered was the provision of relevant training to equip healthcare professionals with the skills and know-how for addressing the view of parents on the nature of choice; their desire to protect their child; personal beliefs and attitudes, especially during the transition to adulthood.  <i>'When they first told me I didn't really understand but I think my mum understood so that's all that really mattered'. (Barber 2019, page 132)</i>	Serious concerns <sup>1</sup>	No/very minor concerns	Minor concerns <sup>2</sup>	No/very minor concerns	MODERATE
<b>Sub-theme 3.2: Communication strategies</b>							

Study information		Description of review finding	CERQual Quality assessment				
Number of studies	Design		Methodological limitations	Coherence of findings	Adequacy of data	Applicability of evidence	Overall confidence
3 (Astbury 2017, Barber 2019, Gibson 2010)	Conversation analysis, observations and semi-structured interviews, participatory-based activities	<p>Evidence from 3 studies showed that clearly articulating options using effective communication strategies such as using age-appropriate language, and streamlining information, in ways that are easy to explain to the parents, and less time consuming for the health visitor helped to support shared decision making. Signposting parents where necessary, was found to be a productive way of helping parents with decision making during planning; which instilled confidence in parents.</p> <p><i>'It's a shame that the health visitors don't have some kind of leaflet to give out that would've been good'. (Astbury 2017, page 220, parental proxy)</i></p>	Serious concerns <sup>1</sup>	No/very minor concerns	Minor concerns <sup>2</sup>	No/very minor concerns	MODERATE
<b>Sub-theme 3.3: Using decision aids</b>							
3 (Barber 2019, Flett 2014, Mitchell 2012)	Observation, semi-structured interviews	<p>Evidence from 3 studies showed that the use of decision aids or value clarification methods was considered necessary for promoting discussions of decision-making. For example, using shared experiences via videos to facilitate understanding and to establish the nature or reality of the decisions under consideration was helpful in the decision-making process to gain additional knowledge and information. It provided children and young people with experiences to contextualise the impact of their choices.</p> <p><i>'It was quite useful cos...obviously they weren't actors...they explained their concerns and</i></p>	Serious concerns <sup>1</sup>	No/very minor concerns	No/very minor concerns	Minor concerns <sup>3</sup>	LOW

Study information		Description of review finding	CERQual Quality assessment				
Number of studies	Design		Methodological limitations	Coherence of findings	Adequacy of data	Applicability of evidence	Overall confidence
		<i>things they found difficult about it'. (Flett 2014, page 6)</i>					

1 Evidence was downgraded due to serious concerns as per CASP qualitative checklist

2 Evidence was downgraded for adequacy because studies together offered moderately rich data

3 Evidence was downgraded due to minor concerns about the applicability of findings, data generated were from study participants 18 years and older (data was only extracted which related to those under 18 years; however, the number of participants in this age group was unclear).



## **Appendix G – Economic evidence study selection**

**Economic evidence study selection for review question: How do children and young people, and the parents and carers of babies and young children, prefer to be involved and supported in planning their healthcare and making informed, shared decisions about their health?**

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

## **Appendix H – Economic evidence tables**

**Economic evidence tables for review question: How do children and young people, and the parents and carers of babies and young children, prefer to be involved and supported in planning their healthcare and making informed, shared decisions about their health?**

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

## **Appendix I – Economic evidence profiles**

**Economic evidence profiles for review question: How do children and young people, and the parents and carers of babies and young children, prefer to be involved and supported in planning their healthcare and making informed, shared decisions about their health?**

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

## **Appendix J – Economic analysis**

**Economic evidence analysis for review question: How do children and young people, and the parents and carers of babies and young children, prefer to be involved and supported in planning their healthcare and making informed, shared decisions about their health?**

No economic analysis was conducted for this review question.

## Appendix K – Excluded studies

**Excluded studies for review question: How do children and young people, and the parents and carers of babies and young children, prefer to be involved and supported in planning their healthcare and making informed, shared decisions about their health?**

**Clinical studies:**

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

Study	Reason for Exclusion
Aagaard, L., Christensen, A., Hansen, E. H., Information about adverse drug reactions reported in children: A qualitative review of empirical studies, <i>British Journal of Clinical Pharmacology</i> , 70, 481-491, 2010	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Aantaa,R., Sedation in PICU, <i>Acta Anaesthesiologica Scandinavica</i> , Supplement, 53, 3-5, 2009	Conference abstract
Aarthun, A., Akerjordet, K., Parent participation in decision-making in health-care services for children: an integrative review, <i>Journal of nursing management</i> , 22, 177-191, 2014	Population of included studies not in protocol. Included studies checked for inclusion.
Aazh, H., Moore, B. C., Lammaing, K., Cropley, M., Tinnitus and hyperacusis therapy in a UK National Health Service audiology department: Patients' evaluations of the effectiveness of treatments, <i>International journal of audiology</i> , 55, 514-522, 2016	Phenomenon of interest not in protocol - No qualitative data.
Abbas, F., Luhar, A., Terry, D., Swallowing medicines: A study of paediatric patients, <i>Archives of disease in childhood</i> , 99 (8), e3, 2014	Conference abstract
Abbott, David, Carpenter, John, "The things that are inside of you are horrible": Children and young men with Duchenne muscular dystrophy talk about the impact of living with a long-term condition, <i>Child Care in Practice</i> , 21, 67-77, 2015	Phenomenon of interest not in protocol: No generalizable themes
Abbott, M., Bernard, P., Forge, J., Communicating a diagnosis of Autism Spectrum Disorder - a qualitative study of parents' experiences, <i>Clinical Child Psychology and Psychiatry</i> , 18, 370-382, 2013	Population not in protocol - parental views with age of children 8-15.
Abdelrahim, Z., Dooley, A., Khan, A., Development of a paediatric specialist multidisciplinary down syndrome clinic, <i>Archives of disease in childhood</i> , 103 (Supplement 1), A162-A163, 2018	Conference abstract
Abela, K. M., Wardell, D., Rozmus, C., LoBiondo-Wood, G., Impact of Pediatric Critical Illness and Injury on Families: An Updated Systematic Review, <i>Journal of pediatric nursing</i> , 51, 21-31, 2020	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Abelman, D. D., Mitigating risks of students use of study drugs through understanding motivations for use and applying harm reduction theory: a literature review, <i>Harm reduction journal</i> , 14, 68, 2017	Narrative review
Aberdeen, J. N., Burnett, R. K. F., Stewart, H. F., Greenberg, E., The use of patient reported outcome measures by primary medical providers in the pediatric sports population, <i>Orthopaedic Journal of Sports Medicine</i> . Conference: 6th Annual Meeting of the Pediatric Research in Sports Medicine Society, PRiSM, 7, 2019	Conference abstract
Abhyankar, P., Summers, B. A., Velikova, G., Bekker, H. L., Framing Options as Choice or Opportunity: Does the Frame Influence Decisions?, <i>Medical decision making : an international</i>	Population not in protocol - Adult women > 18 years

Study	Reason for Exclusion
journal of the Society for Medical Decision Making, 34, 567-582, 2014	
Abrines Jaume, N., Hoffman, J., Wolpert, M., Law, D., Wright, E., Shared decision making in child and adolescent mental health services, <i>Neuropsychiatrie de l'Enfance et de l'Adolescence</i> , 1), S294, 2012	Conference abstract
Abu-Rajab, K., Scoular, A., Church, S., Connell, J., Winter, A., Hart, G., Identifying opportunities for sexually transmitted infection prevention: Analysis of critical points in the care pathways of patients with gonorrhoea, <i>International Journal of STD and AIDS</i> , 20, 170-175, 2009	Population not in protocol - Age 15-66 with no way of discerning age of individual qualitative data.
Achten, J., Parsons, N. R., Edlin, R. P., Griffin, D. R., Costa, M. L., A randomised controlled trial of total hip arthroplasty versus resurfacing arthroplasty in the treatment of young patients with arthritis of the hip joint, <i>BMC musculoskeletal disorders</i> , 11, 8, 2010	Published protocol
Ackner, S., Skeate, A., Patterson, P., Neal, A., Emotional abuse and psychosis: A recent review of the literature, <i>Journal of Aggression, Maltreatment and Trauma</i> , 22, 1032-1049, 2013	Phenomenon of interest not in protocol – No themes relating to shared planning or decision making
Actrn,, A randomised controlled trial of a group intervention for family and friends of youth with borderline personality disorder, <a href="http://www.who.int/trialsearch/trial2.aspx?Trialid=actrn12616000304437">Http://www.who.int/trialsearch/trial2.aspx?Trialid=actrn12616000304437</a> , 2016	Ongoing trial - still recruiting
Actrn,, A randomized controlled trial comparing knowledge transfer regarding preoperative information to children and parents: interactive web-based format (Anesthesia Web) vs. conventional brochure information, <a href="http://www.who.int/trialsearch/trial2.aspx?Trialid=actrn12616000528459">Http://www.who.int/trialsearch/trial2.aspx?Trialid=actrn12616000528459</a> , 2016	Ongoing trial - still recruiting
Actrn,, A study of the impact of treating seizures that can be seen and those that can be seen only on a brain monitor in newborn babies, who are having seizures or at high risk of seizures, <a href="http://www.who.int/trialsearch/trial2.aspx?Trialid=actrn12611000327987">Http://www.who.int/trialsearch/trial2.aspx?Trialid=actrn12611000327987</a> , 2011	Ongoing trial - still recruiting
Actrn,, Action: pACT. Be Active. Online. A trial to promote physical activity in young people with cystic fibrosis, <a href="http://www.who.int/trialsearch/trial2.aspx?Trialid=actrn12617001009303">Http://www.who.int/trialsearch/trial2.aspx?Trialid=actrn12617001009303</a> , 2017	Ongoing trial - still recruiting
Actrn,, HARTI HAUORA TAMARIKI A Randomised Controlled Trial of an Opportunistic, Holistic and Family Centred Approach to Improving Outcomes for Hospitalised Children and their Families, <a href="http://www.who.int/trialsearch/trial2.aspx?Trialid=actrn12618001079235">Http://www.who.int/trialsearch/trial2.aspx?Trialid=actrn12618001079235</a> , 2018	Ongoing trial - still recruiting
Actrn,, Mitii ABI: "Move it to improve it": a randomised trial of novel web-based intervention for children with acquired brain injury, <a href="http://www.who.int/trialsearch/trial2.aspx?Trialid=actrn12613000403730">Http://www.who.int/trialsearch/trial2.aspx?Trialid=actrn12613000403730</a> , 2013	Ongoing trial - still recruiting
Actrn,, Patient navigators in children with chronic kidney disease, <a href="http://www.who.int/trialsearch/trial2.aspx?Trialid=actrn12618001152213">Http://www.who.int/trialsearch/trial2.aspx?Trialid=actrn12618001152213</a> , 2018	Ongoing trial - still recruiting
Adams, C., Lockton, E., Freed, J., Gaile, J., Earl, G., McBean, K., Nash, M., Green, J., Vail, A., Law, J., The Social Communication Intervention Project: a randomized controlled trial of the effectiveness of speech and language therapy for school-age children who have pragmatic and social communication problems with or without autism spectrum disorder, <i>International journal of</i>	Outcomes not in protocol - No qualitative data

Study	Reason for Exclusion
language & communication disorders / Royal College of Speech & Language Therapists, 47, 233-244, 2012	
Adams, C., Lockton, E., Gaile, J., Earl, G., Freed, J., Implementation of a manualized communication intervention for school-aged children with pragmatic and social communication needs in a randomized controlled trial: the Social Communication Intervention Project, International journal of language & communication disorders / Royal College of Speech & Language Therapists, 47, 245-256, 2012	Outcomes not in protocol - No qualitative data
Adams, N., Churchill, R., Eve, E., Chronic widespread pain in adolescents: A primary care based study, European Journal of Pain Supplements, 5 (1), 146, 2011	Conference abstract
Adewumi, A. D., Hollingworth, S. A., Maravilla, J. C., Connor, J. P., Alati, R., Prescribed Dose of Opioids and Overdose: A Systematic Review and Meta-Analysis of Unintentional Prescription Opioid Overdose, CNS Drugs, 32, 101-116, 2018	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Aebi, M., Kuhn, C., Banaschewski, T., Grimmer, Y., Poustka, L., Steinhausen, H. C., Goodman, R., The contribution of parent and youth information to identify mental health disorders or problems in adolescents, Child and adolescent psychiatry and mental health, 11 (1) (no pagination), 2017	Outcomes not in protocol - No qualitative data.
Aebi, Marcel, Kuhn, Christine, Metzke, Christa Winkler, Stringaris, Argyris, Goodman, Robert, Steinhausen, Hans-Christoph, The use of the development and well-being assessment (DAWBA) in clinical practice: A randomized trial, European child & adolescent psychiatry, 21, 559-567, 2012	Outcomes not in protocol - No qualitative data
Ager, A., Zimmerman, C., Unlu, K., Rinehart, R., Nyberg, B., Zeanah, C., Hunleth, J., Bastiaens, I., Weldy, A., Bachman, G., Blum, A. B., Strottman, K., What strategies are appropriate for monitoring children outside of family care and evaluating the impact of the programs intended to serve them?, Child Abuse & Neglect, 36, 732-42, 2012	Population of included studies not in protocol. Included studies checked for inclusion.
Agnew, T., Shared experience, Nursing Standard, 26, 22-4, 2012	Narrative article, not study
Agrawal, S., Morris, K., Whitehouse, W. P., Parent's views about drug trials in children with refractory convulsive status epilepticus, Developmental Medicine and Child Neurology, 1), 16, 2009	Conference abstract
Agwu, C. J., Scanlon, J., McCrea, K., Raffeeq, P., Kershaw, M., Broomhead, S., Eminson, J., Peer review: A tool to improve paediatric diabetes services, Hormone Research in Paediatrics, 1), 213, 2013	Conference abstract
Ahmed, M., Boyd, C., Vavilikolanu, R., Rafique, B., Visual symptoms and childhood migraine: Qualitative analysis of duration, location, spread, mobility, colour and pattern, Cephalalgia, 38, 2017-2025, 2018	Outcomes not in protocol - No qualitative data
Ahmed, S. A., Arasu, A., Another ethical dilemma in neonatology, Archives of Disease in Childhood, 96, A72, 2011	Conference abstract
Ahmed, S. A., Arasu, A., Ethical dilemma in neonatology, Archives of Disease in Childhood, 97, A300, 2012	Conference abstract
Ahmed, S., Ihe, C., Findings from a pre-clinic questionnaire given prior consultation at an NHS paediatric diabetes outpatient service in England-the patient's perspective: A survey of patient/carer experience of a paediatric diabetes outpatient service, Pediatric Diabetes, 17 (Supplement 24), 127-128, 2016	Conference abstract
Ainsworth, S., Ainsworth, J., Preston, J., Stones, S., Challinor, R., Rowe, M., Introducing RAIISE-raising awareness of invisible	Conference abstract

Study	Reason for Exclusion
illnesses in schools and education, <i>Pediatric Rheumatology</i> , 15 (Supplement 2), 67-68, 2017	
Ainsworth, S., Raising awareness of invisible illnesses in schools and education, <i>Annals of the rheumatic diseases</i> , 77 (Supplement 2), 10, 2018	Conference abstract
Akhtar, M. A., Honeyman, C., Aziz, F., Greenough, C., Kalyan, R., Hekal, W., The sky's the limit: Raising the quality and scope of communication for children with scoliosis and their families using digital and social media, <i>British journal of neurosurgery</i> , 30 (2), 177, 2016	Conference abstract
Al Maghaireh, Dua'a Fayiz, Abdullah, Khatijah Lim, Chan, Chong Mei, Piaw, Chua Yan, Al Kawafha, Mariam Mofleh, Systematic review of qualitative studies exploring parental experiences in the Neonatal Intensive Care Unit, <i>Journal of Clinical Nursing</i> , 25, 2745-2756, 2016	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Aladangady, N., Shaw, C., Gallagher, K., Stokoe, E., Marlow, N., Short-Term outcome of treatment limitation discussions for newborn infants, a multicentre prospective observational cohort study, <i>Archives of Disease in Childhood: Fetal and Neonatal Edition</i> , 102, F104-F109, 2017	No qualitative data
Alan, D., Woolner, A. F., Skinner, R., King, D., Evaluation of infection control advice for patients at risk of chemotherapy-induced neutropaenia in two paediatric oncology centres in south africa and the United Kingdom, <i>Pediatric Blood and Cancer</i> , 57 (5), 846-847, 2011	Conference abstract
Alderson, H., Brown, R., Copello, A., Kaner, E., Tober, G., Lingam, R., McGovern, R., The key therapeutic factors needed to deliver behavioural change interventions to decrease risky substance use (drug and alcohol) for looked after children and care leavers: a qualitative exploration with young people, carers and front line workers, <i>BMC medical research methodology</i> , 19, 38, 2019	Population not in protocol - age 15-19 with no way of determining source of quote.
Alderson, H., Brown, R., Smart, D., Lingam, R., Dovey-Pearce, G., 'You've come to children that are in care and given us the opportunity to get our voices heard': The journey of looked after children and researchers in developing a Patient and Public Involvement group, <i>Health expectations : an international journal of public participation in health care and health policy.</i> , 21, 2019	Phenomenon of interest not in protocol – No themes relating to shared planning or decision making
Alexakis, C., Davies, G., Stephens, J., Clark, S., Rogers, S., Poullis, A., Perspectives and attitudes of young patients with inflammatory bowel disease: Symptoms, burden of disease and communication with their healthcare professionals, <i>Frontline Gastroenterology</i> , 5, 197-202, 2014	Outcomes not in protocol - No qualitative data
Alexakis, C., Nash, A., Lloyd, M., Brooks, F., Lindsay, J. O., Poullis, A., Inflammatory bowel disease in young patients: challenges faced by black and minority ethnic communities in the UK, <i>Health &amp; Social Care in the Community</i> , 23, 665-672, 2015	Phenomenon of interest not in protocol - No qualitative data for shared planning or decision making in under 18s
Alexander, R., Walter, L. K., Progressive techniques to effectively prepare children for radiotherapy: A supportive framework combining informative films with a miniature working model LINAC, <i>Pediatric Blood and Cancer</i> , 62 (Supplement 4), S209, 2015	Conference abstract
Alexander, S., Bath, L., McDonald, M., Adolescent diabetic outpatient clinics-more than just an HbA1c, <i>Archives of disease in childhood</i> , 101 (Supplement 1), A275-A277, 2016	Conference abstract



Study	Reason for Exclusion
Al-Gamal, Ekhlas, Long, Tony, The MM-CGI Cerebral Palsy: Modification and pretesting of an instrument to measure anticipatory grief in parents whose child has cerebral palsy, <i>Journal of clinical nursing</i> , 23, 1810-1819, 2014	Outcomes not in protocol - No qualitative data
Al-Harthy, Z. S., Cowling, J. P., Mann, G. K., Salama, M., Medical intervention for children with medical complexity (MICMAC), <i>Archives of disease in childhood</i> , 3), A127-A128, 2015	Conference abstract
Ali, Nasreen, McLachlan, Niel, Kanwar, Shama, Randhawa, Gurch, Pakistani young people's views on barriers to accessing mental health services, <i>International Journal of Culture and Mental Health</i> , 10, 33-43, 2017	Phenomenon of interest not in protocol - No themes relating to shared planning or decision making
Alifrangis, C., Koizia, L., Rozario, A., Rodney, S., Harrington, M., Somerville, C., Peplow, T., Waxman, J., The experiences of cancer patients, <i>Qjm</i> , 104, 1075-81, 2011	Population not in protocol – adults aged 21 years and over
Aljafari, A. K., Scambler, S., Gallagher, J. E., Hosey, M. T., Parental views on delivering preventive advice to children referred for treatment of dental caries under general anaesthesia: A qualitative investigation, <i>Community dental health</i> , 31, 75-79, 2014	Unclear population - Views of parents with no way of discerning age of children.
Allcock, D., Smith, K., Exploring parent views of community matrons, <i>Nursing Times</i> , 110, 21-23, 2014	Unclear population - Questionnaires sent to parents with no way of discerning child age.
Allen, D., Gillen, E., Rixson, L., The Effectiveness of Integrated Care Pathways for Adults and Children in Health Care Settings: A Systematic Review, <i>JB Library of Systematic Reviews</i> , 7, 80-129, 2009	No qualitative data
Allen, D., Scarinci, N., Hickson, L., The Nature of Patient- and Family-Centred Care for Young Adults Living with Chronic Disease and their Family Members: A Systematic Review, <i>International Journal of Integrated Care [Electronic Resource]</i> Int J Integr Care, 18, 14, 2018	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Allen, Kimberly A., Parental decision-making for medically complex infants and children: An integrated literature review, <i>International Journal of Nursing Studies</i> , 51, 1289-1304, 2014	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Almunef, M., Mason, J., Curtis, C., Jalal, Z., Management of chronic illness in young people aged 10-24 years: A systematic review to explore the role of primary care pharmacists, <i>Archives of Disease in Childhood</i> , 104, 2019	Conference abstract
Almunef, M., Mason, J., Curtis, C., Jalal, Z., The role of primary care pharmacist in the management of chronic illnesses in young people aged 10-24 years: A systematic review, <i>International Journal of Pharmacy Practice</i> , 27, 48-49, 2019	Poster abstract
Alvi, S., Priestley, J., Whitehead, A., Walker, J., Mushtaq, T., The impact on families of receiving a diagnosis of congenital hypothyroidism, <i>Hormone Research in Paediatrics</i> , 1), 549, 2015	Conference abstract
Al-Zawaadi, M., Kayyali, R., Kelly, P., Evaluation of a pharmacist-led health intervention in a primary school, <i>International journal of pharmacy practice</i> , 27 (Supplement 1), 8-9, 2019	Conference abstract
Ambrogi, V., Tezenas Du Montcel, S., Collin, E., Coutaux, A., Bourgeois, P., Bourdillon, F., Care-related pain in hospitalized patients: Severity and patient perception of management, <i>European journal of pain (united kingdom)</i> , 19, 313-321, 2015	Outcomes not in protocol - No qualitative data.

Study	Reason for Exclusion
Ames, C. S., Richardson, J., Payne, S., Smith, P., Leigh, E., Mindfulness-based cognitive therapy for depression in adolescents, <i>Child and Adolescent Mental Health</i> , 19, 74-78, 2014	Population not in protocol - received psychological treatment for depression/anxiety and symptoms of depression
Ames, K., Rennick, J., & Baillargeon, S., A qualitative interpretive study exploring parents' perception of the parental role in the paediatric intensive care unit., <i>Intensive &amp; Critical Care Nursing</i> , 27, 143-150, 2011	Population not in protocol - views of parents of children 0-17 with no way of discerning age.
Amin, A., Oragui, E., Khan, W., Puri, A., Psychosocial considerations of perioperative care in children, with a focus on effective management strategies, <i>Journal of perioperative practice</i> , 20, 198-202, 2010	Narrative review
Amsalem, D., Hasson-Ohayon, I., Gothelf, D., Roe, D., Subtle ways of stigmatization among professionals: The subjective experience of consumers and their family members, <i>Psychiatric rehabilitation journal</i> , 41, 163-168, 2018	Population not in protocol - no way of identifying age of participant
Anderson, C., Lupfer, A., Shattuck, P. T., Barriers to receipt of services for young adults with autism, <i>Pediatrics</i> , 141, S300-S305, 2018	Population not in protocol - young adults with autism who had left high school in the past 15 years.
Anderson, C., Roy, T., Patient experiences of taking antidepressants for depression: A secondary qualitative analysis, <i>Research in Social and Administrative Pharmacy</i> , 9, 884-902, 2013	Outcomes not in protocol - No qualitative data for under 18s
Anderson, E. S., Ford, J. S., Learning to listen: A patient led innovation to improve student's communication with patient feedback, <i>Medical education</i> , supplement, 2), 118-119, 2011	Conference abstract
Angelopoulou, M. V., Oulis, C. J., Kavvadia, K., School-based oral health-education program using experiential learning or traditional lecturing in adolescents: a clinical trial, <i>International dental journal</i> , 64, 278-284, 2014	Outcomes not in protocol - No qualitative data.
Angold, A., Erkanli, A., Copeland, W., Goodman, R., Fisher, P. W., Costello, E. J., Psychiatric diagnostic interviews for children and adolescents: A comparative study, <i>Journal of the American Academy of Child and Adolescent Psychiatry</i> , 51, 506-517, 2012	Outcomes not in protocol - No qualitative data
Anonymous,, The development and analysis of feedback from a pilot chronic pain group at the Royal Manchester Children's Hospital, <i>Rheumatology (united kingdom)</i> , 56 (Supplement 7), vii30, 2017	Conference abstract
Ansmann, L., Kowalski, C., Ernstmann, N., Ommen, O., Pfaff, H., Patients' perceived support from physicians and the role of hospital characteristics, <i>International Journal for Quality in Health Care</i> , 24, 501-8, 2012	Outcomes not in protocol – No qualitative data
Antao, V., Evaluation of post-diagnostic support to families and children with autism spectrum disorder, <i>Developmental medicine and child neurology</i> , 4), 69, 2010	Conference abstract
Anttila, A., Rappaport, D. I., Tijerino, J., Zaman, N., Sharif, I., Interpretation Modalities Used on Family-Centered Rounds: Perspectives of Spanish-Speaking Families, <i>Hospital Pediatrics</i> , 7, 492-498, 2017	Unclear population - Views of parents with age of children not reported.
Arai, L., Bettany-Saltikov, J., Hamilton, S., Findings from a small-scale, exploratory content analysis of information provided to AIS patients and their parents from NHS Scoliosis Hospital Clinics, <i>Scoliosis</i> . Conference: 9th International Conference on	Conference abstract

Study	Reason for Exclusion
Conservative Management of Spinal Deformities SOSORT, 8, 2012	
Archibald, Mandy, Scott, Shannon, Hartling, Lisa, Mapping the waters: A scoping review of the use of visual arts in pediatric populations with health conditions, <i>Arts &amp; Health: An International Journal of Research, Policy and Practice</i> , 6, 5-23, 2014	Scoping review. Included studies checked for inclusion.
Arheiam, A., Albadri, S., Laverty, L., Harris, R., Reasons for low adherence to diet-diaries issued to pediatric dental patients: A collective case study, <i>Patient Preference and Adherence</i> , 12, 1401-1411, 2018	Outcomes not in protocol - No qualitative data for under 18s
Arheiam, A., Brown, S. L., Burnside, G., Higham, S. M., Albadri, S., Harris, R. V., The use of diet diaries in general dental practice in England, <i>Community dental health</i> , 33, 267-273, 2016	Population not in protocol - Views of healthcare professionals
Armitage, S., Swallow, V., Kolehmainen, N., Ingredients and change processes in occupational therapy for children: a grounded theory study, <i>Scandinavian journal of occupational therapy</i> , 24, 208-213, 2017	Phenomenon of interest not in protocol – No themes relating to shared planning or decision making
Armoiry, Xavier, Sturt, Jackie, Phelps, Emma Elizabeth, Walker, Clare-Louise, Court, Rachel, Taggart, Frances, Sutcliffe, Paul, Griffiths, Frances, Atherton, Helen, Digital clinical communication for families and caregivers of children or young people with short- or long-term conditions: Rapid review, <i>Journal of Medical Internet Research Vol 20(1)</i> , 2018, ArtID e5, 20, 2018	Narrative review. Included studies checked for inclusion.
Armoogum, J., Cathcart, E., Cazenove, E., Knott, C., Mathambo, N., Tomsitt, L., Vevers, J., Wall, M., Bridging the gap: Giving information to young people undergoing bone marrow transplants using modern media, <i>Bone Marrow Transplantation</i> , 1), S421, 2011	Conference abstract
Arnab, Sylvester, Brown, Katherine, Clarke, Samantha, Dunwell, Ian, Lim, Theodore, Suttie, Neil, Louchart, Sandy, Hendrix, Maurice, de Freitas, Sara, The development approach of a pedagogically-driven serious game to support Relationship and Sex Education (RSE) within a classroom setting, <i>Computers &amp; Education</i> , 69, 15-30, 2013	Description of health education tool development
Arnott, J., Hesselgreaves, H., Nunn, A. J., Peak, M., Pirmohamed, M., Smyth, R. L., Turner, M. A., Young, B., Enhancing Communication about Paediatric Medicines: Lessons from a Qualitative Study of Parents' Experiences of Their Child's Suspected Adverse Drug Reaction, <i>Plos one</i> , 7 (10) (no pagination), 2012	Phenomenon of interest not in protocol - No themes relating to shared planning or decision making
Arnott, J., Nunn, A. J., Mannix, H., Peak, M., Pirmohamed, M., Smyth, R. L., Turner, M. A., Young, B., Communicating with parents following a suspected adverse drug reaction in a child: Who says what and when?, <i>Archives of disease in childhood</i> , 3), A10-A11, 2015	Conference abstract
Arnott, J., Turner, M. A., Hesselgreave, H., Nunn, A. J., Peak, M., Pirmohamed, M., Smyth, R. L., Young, B., Parents' experiences of adverse drug reactions in children: Qualitative study, <i>Pharmacoepidemiology and Drug Safety</i> , 21 (1), 112, 2012	Conference abstract
Aronson, P. L., Shapiro, E. D., Niccolai, L. M., Fraenkel, L., Shared Decision-Making with Parents of Acutely Ill Children: A Narrative Review, <i>Academic pediatrics</i> , 18, 3-7, 2018	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Ashcraft, L. E., Asato, M., Houtrow, A. J., Kavalieratos, D., Miller, E., Ray, K. N., Parent Empowerment in Pediatric Healthcare	Population of included studies not in protocol. Included studies checked for inclusion.

Study	Reason for Exclusion
Settings: A Systematic Review of Observational Studies, Patient, 12, 199-212, 2019	
Aslam, A., Children's preference in selecting an emollient of their choice, British journal of dermatology, 1), 116, 2009	Conference abstract
Aston, Hermione J., Lambert, Nathan, Young people's views about their involvement in decision-making, Educational Psychology in Practice, 26, 41-51, 2010	Setting not in protocol - Shared decision making in education only
Aston, J., Terry, D., Nusgen, U., Champaneri, N., Prescribed antimicrobial therapy: What parents/carers are told and what they would like to know, Archives of Disease in Childhood. Conference: 18th Neonatal and Paediatric Pharmacists Group, NPPG Annual Conference. Liverpool United Kingdom. Conference Publication:, 98, 2013	Conference abstract
Aston, J., Wilson, K. A., Terry, D. R. P., The treatment-related experiences of parents, children and young people with regular prescribed medication, International journal of clinical pharmacy, 41, 113-121, 2019	Unclear population - Views of parents with no way of discerning age of children
Aston, J., Wilson, K., Terry, D., Starting a new medicine study, Archives of disease in childhood, 101 (9), A28, 2016	Conference abstract
Atkins, E., Colville, G., John, M., Finding the way to a 'new normal': Families' recovery in the year after a paediatric intensive care admission, Pediatric critical care medicine, 1), A3-A4, 2011	Conference abstract
Aubegeau-Williams, P., Brierley, J., Consent in paediatric intensive care: A qualitative study of parental & professional views, Archives of Disease in Childhood. Conference: Great Ormond Street Hospital Conference, GOSH, 102, 2017	Conference abstract
Audrey, S., Batista Ferrer, H., Ferrie, J., Evans, K., Bell, M., Yates, J., Roderick, M., Macleod, J., Hickman, M., Impact and acceptability of self-consent procedures for the school-based human papillomavirus vaccine: A mixed-methods study protocol, BMJ open, 8 (3) (no pagination), 2018	Published protocol
Azevedo, Avds, Lanconi, A. C. Junior, Crepaldi, M. A., Nursing team, family and hospitalized child interaction: an integrative review, Ciencia & Saude ColetivaCienc, 22, 3653-3666, 2017	Population of included studies not in protocol. Included studies checked for inclusion.
Azzopardi, L. M., Serracino-Inglott, A., Zarb-Adami, M., Portanier, F. S., Evaluation of patient information leaflets for non-prescription medicines, International journal of pharmacy practice, 2), 81-82, 2010	Conference abstract
Babbage, C., Jackson, G. M., Nixon, E., Desired Features of a Digital Technology Tool for Self-Management of Well-Being in a Nonclinical Sample of Young People: Qualitative Study, JMIR Mental Health, 5, e10067, 2018	Phenomenon of interest not in protocol - No themes relating to shared planning or decision making
Badri, P., Saltaji, H., Flores-Mir, C., Amin, M., Factors affecting children's adherence to regular dental attendance: a systematic review, Journal of the American Dental Association (1939), 145, 817-828, 2014	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Bailey, J. V., Webster, R., Hunter, R., Freemantle, N., Rait, G., Michie, S., Estcourt, C., Anderson, J., Gerressu, M., Stephenson, J., et al., The Men's Safer Sex (MenSS) trial: protocol for a pilot randomised controlled trial of an interactive digital intervention to increase condom use in men, BMJ open, 5, e007552, 2015	Published protocol
Baird, Jennifer, Davies, Betty, Hinds, Pamela S., Baggott, Christina, Rehm, Roberta S., What impact do hospital and unit-based rules have upon patient and family-centered care in the pediatric intensive care unit?, Journal of pediatric nursingJ Pediatr Nurs, 30, 133-142, 2015	Population not in protocol - age >18 years old.

Study	Reason for Exclusion
Baker, Erika, Baibazarova, Eugenia, Ktistaki, Georgia, Shelton, Katherine H., van Goozen, Stephanie H., Development of fear and guilt in young children: Stability over time and relations with psychology, <i>Development and psychopathology</i> , 24, 833-845, 2012	Outcomes not in protocol - No qualitative data
Balato, N., Megna, M., Di Costanzo, L., Balato, A., Ayala, F., Educational and motivational support service: a pilot study for mobile-phone-based interventions in patients with psoriasis, <i>British journal of dermatology</i> , 168, 201-205, 2013	Outcomes not in protocol - No qualitative data.
Bancroft, V., Ganesan, V., Pistrang, N., Murphy, T., How adolescents and their parents understand and manage paediatric stroke, <i>Developmental Medicine and Child Neurology</i> , 3), 14-15, 2010	Conference abstract
Banks, J., Cramer, H., Sharp, D. J., Shield, J. P., Turner, K. M., Identifying families' reasons for engaging or not engaging with childhood obesity services: a qualitative study, <i>Journal of child health care</i> , 18, 101-110, 2014	Population not in protocol - parental views of children >5 years old. Children present in some interviews but no way of identifying which themes used data from them
Barber, S., Bekker, H., Marti, J., Pavitt, S., Khambay, B., Meads, D., Development of a Discrete-Choice Experiment (DCE) to Elicit Adolescent and Parent Preferences for Hypodontia Treatment, <i>Patient</i> , 12, 137-148, 2019	Description of questionnaire development with no qualitative data presented.
Barber, S., Pavitt, S., Meads, D., Khambay, B., Bekker, H., Assessment of information resources for people with hypodontia, <i>Bdj Open</i> , 4, 18001, 2018	Population not in protocol - views and experiences of healthcare professionals
Boyden, P., Muniz, M., Laxton-Kane, M., Listening to the views of children with learning disabilities: An evaluation of a learning disability CAMHS service, <i>Journal of Intellectual Disabilities</i> , 17, 51-63, 2013	Phenomenon of interest not in protocol - No themes relating to shared planning or decision making
Brodsgaard, A., Pedersen, J. T., Larsen, P., Weis, J., Parents' and nurses' experiences of partnership in neonatal intensive care units: A qualitative review and meta-synthesis, <i>Journal of Clinical Nursing</i> , 28, 3117-3139, 2019	Phenomenon of interest not in protocol - No themes relating to shared planning or decision making
Brown, Freddy Jackson, Guvenir, Jane, The experiences of children with learning disabilities, their carers and staff during a hospital admission, <i>British Journal of Learning Disabilities</i> , 37, 110-115, 2009	Phenomenon of interest not in protocol – No themes relating to shared planning or decision making
Byron et al, "You learn from each other": LGBTIQ Young People's Mental Health Help-seeking and the RAD Australia Online Directory. , 2016	Country: Australia
Cameron, M. A., Schleien, C. L., Morris, M. C., Parental presence on pediatric intensive care unit rounds, <i>J Pediatr</i> , 155, 522-8, 2009	Country: USA
Can text messages increase safer sex behaviours in young people? Intervention development and pilot randomized controlled trial, <i>Health technology assessment</i> . 20 (57) (pp 1-81), 2016. Date of publication: august 2016., 2016	Phenomenon of interest not in protocol – No themes relating to shared planning or decision making
Chaturvedi, Surabhi, Accessing psychological therapies: Homeless young people's views on barriers and facilitators, <i>Counselling and Psychotherapy Research</i> , 16, 54-63, 2016	Population not in protocol - Age 16-25 with no further information.
Coker, T. R., Sareen, H. G., Chung, P. J., Kennedy, D. P., Weidmer, B. A., Schuster, M. A., Improving access to and utilization of adolescent preventive health care: the perspectives of adolescents and parents, <i>J Adolesc Health</i> , 47, 133-42, 2010	Country: USA

Study	Reason for Exclusion
Comp, D., Improving parent satisfaction by sharing the inpatient daily plan of care: an evidence review with implications for practice and research, <i>Pediatric nursing</i> , 37, 237-242, 2011	Population of included studies not in protocol. Included studies checked for inclusion.
Coyne, I., Amory, A., Kiernan, G., Gibson, F., Children's participation in shared decision-making: children, adolescents, parents and healthcare professionals' perspectives and experiences, <i>Eur J Oncol Nurs</i> , 18, 273-80, 2014	Country: Ireland
Coyne, I., Children, parents, and healthcare professionals' perspectives on children's participation in shared decision making, <i>European Journal of Oncology</i> , 15, 275-276, 2011	Conference abstract
Coyne, I., Gallagher, P., Participation in communication and decision-making: children and young people's experiences in a hospital setting, <i>J Clin Nurs</i> , 20, 2334-43, 2011	Country: Ireland
Coyne, I., Kirwan, L., Ascertaining children's wishes and feelings about hospital life, <i>J Child Health Care</i> , 16, 293-304, 2012	Country: Ireland
Crowley, Making it matter: improving the health of homeless young people., 2012	Unclear population - age 16-25 with no further information on participants
Curtis-Tyler, K., Facilitating children's contributions in clinic? Findings from an in-depth qualitative study with children with Type 1 diabetes, <i>Diabetic medicine</i> , 29, 1303-1310, 2012	Phenomenon of interest not in protocol - No themes relating to shared planning or decision making
Daley, A. M., Polifroni, E. C., Sadler, L. S., "Treat Me Like a Normal Person!" A Meta-Ethnography of Adolescents' Expectations of Their Health Care Providers, <i>Journal of pediatric nursing</i> , 36, 70-83, 2017	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Daniels, Karen, Cultural agents creating texts: A collaborative space adventure, <i>Literacy</i> , 48, 103-111, 2014	Phenomenon of interest not in protocol - No qualitative information for shared planning or decision making
Davey, A., Asprey, A., Carter, M., Campbell, J. L., Trust, negotiation, and communication: young adults' experiences of primary care services, <i>BMC family practice</i> , 14, 202, 2013	Population not in protocol - participants aged 18-25 years old.
Davies, Adam, Randall, Duncan, Perceptions of children's participation in their healthcare: A critical review, <i>Issues in comprehensive pediatric nursing</i> , 38, 202-221, 2015	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Davies, E. B., Buchanan, H., An exploratory study investigating children's perceptions of dental behavioural management techniques, <i>International journal of paediatric dentistry</i> , 23, 297-309, 2013	Outcomes not in protocol - No qualitative data.
Davies, Karen E., Marshall, Julie, Brown, Laura J., Goldbart, Juliet, Co-working: Parents' conception of roles in supporting their children's speech and language development, <i>Child Language Teaching and Therapy</i> , 33, 171-185, 2017	Phenomenon of interest not in protocol - No qualitative information for shared planning or decision making
Davies-House, A., Ball, N., Balmer, C., Meeting and greeting in the clinical setting - are we doing what patients want?, <i>British dental journal</i> , 222, 457-461, 2017	Outcomes not in protocol - No qualitative data
Day, E. R., Jones, L., Langner, R., Stirling, L. C., Hough, R., Bluebond-Langner, M., Teenagers' perspectives on their decisional involvement in the context of interactions with healthcare professionals, <i>Archives of disease in childhood</i> , 102 (Supplement 1), A2, 2017	Conference abstract
Day, Emma, Jones, Louise, Langner, Richard, Bluebond-Langner, Myra, Current understanding of decision-making in adolescents	Phenomenon of interest of included studies not in

Study	Reason for Exclusion
with cancer: A narrative systematic review, Palliative Medicine, 30, 920-934, 2016	protocol. Included studies checked for inclusion.
de Anstiss and Ziaian, Mental health help-seeking and refugee adolescents: Qualitative findings from a mixed-methods investigation, Aust Psychol, 45, 29-37, 2010	Country: Australia
De Vries MC, Bresters D, Kaspers GJL, et al, What constitutes the best interest of a child? Views of parents, children, and physicians in a pediatric oncology setting., AJOB Prim Res, 4, 1-10, 2012	Country: The Netherlands
Dean, L. A., An exploration of the experiences of young people who have been nursed on adult wards, Archives of disease in childhood, 1), A76, 2012	Conference abstract
Dean, L., Black, S., Exploring the experiences of young people nursed on adult wards, British journal of nursing (Mark Allen Publishing), 24, 229-236, 2015	Phenomenon of interest not in protocol - No qualitative information for shared planning or decision making
Deldar, K., Bahaadinbeigy, K., Tara, S. M., Teleconsultation and clinical decision making: A systematic review, Acta Informatica Medica, 24, 286-292, 2016	Population not in protocol - focus on medical professional views
DeLemos, D., Chen, M., Romer, A., Brydon, K., Kastner, K., Anthony, B., Hoehn, K. S., Building trust through communication in the intensive care unit: HICCC, Pediatric Critical Care Medicine, 11, 378-384, 2010	Unclear population - Parents with no way of ascertaining age of child.
Dewlett, S., Polychronakis, T., Ng, G. Y. T., Look who's talking: How well are we communicating with parents in the neonatal unit? A patient survey, Intensive Care Medicine, 37, S419-S420, 2011	Conference abstract
Dhital, R., Whittlesea, C. M., Norman, I. J., Milligan, P., Community pharmacy service users' views and perceptions of alcohol screening and brief intervention, Drug and Alcohol Review, 29, 596-602, 2010	Unclear population - age of respondents not given.
Diagnosis, assessment, and treatment of childhood eczema in primary care: cross-sectional study, BJGP open, 1, 2017	Study design not in protocol - No qualitative data
Dibley, L., Czuber-Dochan, W., Duncan, J., Artom, M., Burch, J., Wade, T., Verjee, A., Cann, D., Warusavitarne, J., Norton, C., Decision-making about emergency and planned stoma surgery for IBD: A qualitative exploration of patient and clinician perspectives, Journal of Crohn's and Colitis, 11 (Supplement 1), S487-S488, 2017	Conference abstract
Dickens, G., Picchioni, M., A systematic review of the terms used to refer to people who use mental health services: user perspectives, The International journal of social psychiatry, 58, 115-122, 2012	Population of included studies not in protocol. Included studies checked for inclusion.
Dodoo, T., Murhad, Y., Batchelor, H. K., Stirling, H. F., Supporting young people to take their medication, Archives of Disease in Childhood, 102, A51, 2017	Conference abstract
Donnellan, D., Murray, C., Harrison, J., An investigation into adolescents' experience of cognitive behavioural therapy within a child and adolescent mental health service, Clinical Child Psychology and Psychiatry, 18, 199-213, 2013	No generalizable themes - specifically investigating attitudes to cognitive behavioural therapy
Dovey-Pearce, Gail, Price, Christine, Wood, Helen, Scott, Tracy, Cookson, Jennifer, Corbett, Sally, Young people (13 to 21) with disabilities in transition from childhood to adulthood: An exploratory, qualitative study of their developmental experiences and health care needs, Educational and Child Psychology, 29, 86-100, 2012	Population not in protocol - age 13-21 with 82% over 16. No way of discerning age in results.
Downing, J., Gleeson, H., Clayton, P. E., Davis, J. R. E., Dimitri, P., Wales, J., Young, B., Callery, P., Communication with young	No generalizable themes - investigating if a forensic

Study	Reason for Exclusion
people in paediatric and adult endocrine consultations: an intervention development and feasibility study, <i>BMC Endocrine Disorders</i> , 17, 33, 2017	interview protocol aids < 18 years old with verbalising emotional reactions.
Drake, E. K., Urquhart, R., The Experiences of Young Adults Living with Metastatic/Advanced Cancer: A Scoping Review, <i>Journal of Adolescent and Young Adult Oncology</i> , 9, 145-156, 2020	Scoping review. Included studies checked for inclusion.
Drewett, O., Hann, G., Price, N., Tipper, C., Devereux, E., A qualitative study to explore the use of the RCPCH epilepsy passport, <i>Archives of disease in childhood</i> , 102 (Supplement 1), A150, 2017	Conference abstract
Duckett, Paul, Kagan, Carolyn, Sixsmith, Judith, Consultation and participation with children in healthy schools: Choice, conflict and context, <i>American Journal of Community Psychology</i> , 46, 167-178, 2010	Educational experiences of children and young adults.
Dugdale, E., Gerrard, G., Priestley, L., Mariappan, L., Choong, E. S., Follow up of low risk thyroid cancer patients by specialist nurse phone consultations rather than via clinic visits, <i>European Thyroid Journal</i> , 1), 165-166, 2014	Conference abstract
Dunne, A., Carolan, R., Swords, L., Fortune, G., Patient and family perspectives of paediatric psychogenic non-epileptic seizures: A systematic review, <i>Seizure</i> , 71, 279-285, 2019	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Duran, C., Curtis-Tyler, K., Exploring children's healthcare experiences of haematopoietic stem cell transplantation (HSCT)-a small scale study for service improvement, <i>Bone Marrow Transplantation</i> , 1), S257, 2016	Conference abstract
Edbrooke-Childs, J., Edridge, C., Averill, P., Delane, L., Hollis, C., Craven, M. P., Martin, K., Feltham, A., Jeremy, G., Deighton, J., Wolpert, M., A Feasibility Trial of Power Up: Smartphone App to Support Patient Activation and Shared Decision Making for Mental Health in Young People, <i>JMIR MHealth and UHealth</i> , 7, e11677, 2019	Phenomenon of interest not in protocol - No themes relating to shared planning or decision making
Edbrooke-Childs, J., Jacob, J., Argent, R., Patalay, P., Deighton, J., Wolpert, M., The relationship between child- and parent-reported shared decision making and child-, parent-, and clinician-reported treatment outcome in routinely collected child mental health services data, <i>Clinical Child Psychology &amp; Psychiatry</i> , 21, 324-38, 2016	Study design not in protocol - No qualitative data
Edwards, M., Lawson, C., Rahman, S., Conley, K., Phillips, H., Uings, R., What does quality healthcare look like to adolescents and young adults? Ask the experts!, <i>Clinical Medicine, Journal of the Royal College of Physicians of London</i> , 16, 146-151, 2016	Unclear population - Age of participants 17-25 with no way of discerning age of individual quotes.
Egbunike, J. N., Shaw, C., Porter, A., Button, L. A., Kinnersley, P., Hood, K., Bowden, S., Bale, S., Snooks, H., Edwards, A., Streamline triage and manage user expectations: lessons from a qualitative study of GP out-of-hours services, <i>British Journal of General Practice</i> , 60, e83-97, 2010	Unclear population - No way of determining age source of data.
El Miedany, Y., Lotfy, H., El Aroussy, N., Mekki, D., Nasef, S. I., Hassan, W., El Deriny, G., Farag, Y., Eissa, M., Almedany, S., El Gaafary, M., Facilitating patient centred care: The development of illustrated multidimensional patient reported outcome measure for children with juvenile idiopathic arthritis, <i>Annals of the rheumatic diseases</i> , 77 (Supplement 2), 502, 2018	Conference abstract



Study	Reason for Exclusion
Elwell, L., Grogan, S., Coulson, N., Adolescents living with cancer: the role of computer-mediated support groups, <i>Journal of health psychology</i> , 16, 236-248, 2011	Unclear population - Age of study population not reported.
Ely, B., Chen Lim, M., Becker, E., Wilson Jr, B., The pain experience of hospitalized youth: Assessment and management preferences, <i>Journal of Pain</i> , 1), S3, 2016	Conference abstract
Ely, E., Chen-Lim, M. L., Carpenter, K. M., Wallhauser, E., Friedlaender, E., Pain Assessment of Children with Autism Spectrum Disorders, <i>Journal of developmental and behavioral pediatrics</i> : JDBP, 37, 53-61, 2016	Phenomenon of interest not in protocol – No themes relating to shared planning or decision making
Epstein, E. G., Arechiga, J., Dancy, M., Simon, J., Wilson, D., Alhusen, J. L., Integrative Review of Technology to Support Communication With Parents of Infants in the NICU, 46, 357-366, 2017	Duplicate
Epstein, Elizabeth G., Arechiga, Jaqueline, Dancy, Margaret, Simon, Jordan, Wilson, Daniel, Alhusen, Jeanne L., Integrative review of technology to support communication with parents of infants in the NICU, <i>Journal of Obstetric, Gynecologic, &amp; Neonatal Nursing: Clinical Scholarship for the Care of Women, Childbearing Families, &amp; Newborns</i> , 46, 357-366, 2017	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Epstein, Elizabeth Gingell, Sherman, Jessica, Blackman, Amy, Sinkin, Robert A., Testing the feasibility of Skype and FaceTime updates with parents in the neonatal intensive care unit, <i>American Journal of Critical Care</i> , 24, 290-296, 2015	Outcomes not in protocol - No qualitative data.
Evans, J., Rose, D., Flach, C., Csipke, E., Glossop, H., McCrone, P., Craig, T., Wykes, T., VOICE: developing a new measure of service users' perceptions of inpatient care, using a participatory methodology, <i>Journal of Mental Health</i> , 21, 57-71, 2012	Outcome not in protocol - validity study of experience measure
Evans, N., Experiences of a child and adolescent mental health service, <i>Nursing Children and Young People</i> , 29, 41-45, 2017	Phenomenon of interest not in protocol - no themes relating to access or continuity of healthcare
Everley, S., Children's understanding of physical activity and health, <i>Obesity facts</i> , 10 (Supplement 1), 227, 2017	Conference abstract
Fangstrom, Karin, Sarkadi, Anna, Lucas, Steven, Calam, Rachel, Eriksson, Maria, "And they gave me a shot, it really hurt"- Evaluative content in investigative interviews with young children, <i>Children and Youth Services Review</i> , 82, 434-443, 2017	No generalizable themes - investigating if a forensic interview protocol aids babies, children and young people with verbalising emotional reactions.
Fawcett, R., Porritt, K., Stern, C., Carson-Chahhoud, K., Experiences of parents and carers in managing asthma in children: A qualitative systematic review, <i>JBIC Database of Systematic Reviews and Implementation Reports</i> , 17, 793-984, 2019	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Fazel, M., Garcia, J., Stein, A., The right location? Experiences of refugee adolescents seen by school-based mental health services, <i>Clinical Child Psychology and Psychiatry</i> , 21, 368-380, 2016	Phenomenon of interest not in protocol – No themes relating to shared planning or decision making
Flynn, D., Knoedler, M.A., Hess, E.P., Murad, M.H., Erwin, P.J., Montori, V.M., Thomson, R.G., Engaging patients in health care decisions in the emergency department through shared decision-making: A systematic review, <i>Academic Emergency Medicine</i> , 19, 959-967, 2012	Study design of included studies not in protocol. Included studies checked for inclusion.
Fortier, M. A., Chorney, J. M., Rony, R. Y. Z., Perret-Karimi, D., Rinehart, J. B., Camilon, F. S., Kain, Z. N., Children's desire for	Phenomenon of interest not in protocol – No themes relating

Study	Reason for Exclusion
perioperative information, Anesthesia and Analgesia, 109, 1085-1090, 2009	to shared planning or decision making
Foster, M. J., Whitehead, L., Maybee, P., Cullens, V., The parents', hospitalized child's, and health care providers' perceptions and experiences of family centered care within a pediatric critical care setting: a metasynthesis of qualitative research, Journal of Family Nursing, 19, 431-468, 2013	Population of included studies not in protocol. Included studies checked for inclusion.
Foster, Mandie Jane, Whitehead, Lisa, Maybee, Patricia, Cullens, Victoria, The parents', hospitalized child's, and health care providers' perceptions and experiences of family centered care within a pediatric critical care setting: A metasynthesis of qualitative research, Journal of Family Nursing, 19, 431-468, 2013	Duplicate
Franck, L. S., Oulton, K., Bruce, E., Parental involvement in neonatal pain management: an empirical and conceptual update, J Nurs Scholarsh, 44, 45-54, 2012	No generalizable themes - parental experience of communicating pain.
Franck, L. S., Oulton, K., Nderitu, S., Lim, M., Fang, S., Kaiser, A., Parent involvement in pain management for NICU infants: A randomized controlled trial, Pediatrics, 128, 510-518, 2011	Study design not in protocol - No qualitative data
Freer, Y., McIntosh, N., Teunisse, S., Anand, K. J., Boyle, E. M., More information, less understanding: a randomized study on consent issues in neonatal research, Pediatrics, 123, 1301-1305, 2009	Study design not in protocol - No qualitative data.
Gates, M., Shulhan-Kilroy, J., Featherstone, R., MacGregor, T., Scott, S. D., Hartling, L., Parent experiences and information needs related to bronchiolitis: A mixed studies systematic review, Patient Education and Counseling, 102, 864-878, 2019	Study design of included studies not in protocol. Included studies checked for inclusion.
Giambra, B. K., Stiffler, D., Broome, M. E., An integrative review of communication between parents and nurses of hospitalized technology-dependent children, Worldviews on evidence-based nursing / Sigma Theta Tau International, Honor Society of Nursing, 11, 369-375, 2014	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Gondek, D., Edbrooke-Childs, J., Velikonja, T., Chapman, L., Saunders, F., Hayes, D., Wolpert, M., Facilitators and Barriers to Person-centred Care in Child and Young People Mental Health Services: A Systematic Review, Clinical Psychology & Psychotherapy, 24, 870-886, 2017	Study design of included studies not in protocol. Included studies checked for inclusion.
Graham, R., Pemstein, D., & Curley, M. , Experiencing the pediatric intensive care unit: Perspective from parents of children with severe antecedent disabilities. , Critical Care Medicine, 37, 2064-2070, 2009	Country: USA
Grainger, H., Joyce, C., Beuschel, S., Davies, A., Shreeve, K., Super blood! development of a child patient information leaflet, Transfusion Medicine, 2), 45, 2014	Conference abstract
Grealish, A., Tai, S., Hunter, A., Morrison, A. P., Qualitative exploration of empowerment from the perspective of young people with psychosis, Clinical Psychology & Psychotherapy, 20, 136-148, 2013	Phenomenon of interest not in protocol – No themes relating to shared planning or decision making
Gregory, J. W., UK: Communication in patient-centered care, Pediatric diabetes, 18), 8, 2013	Conference abstract
Grist, Rebecca, Porter, Joanna, Stallard, Paul, Mental health mobile apps for preadolescents and adolescents: A systematic review, Journal of medical internet research, 19, 153-166, 2017	Outcomes not in protocol - No qualitative data.
Guest, J., Cheal, H., Welcome to Ward 3 at the Great North children's hospital-a fun guide to your first two days with us (DVD	Conference abstract

Study	Reason for Exclusion
format patient family information), Bone Marrow Transplantation, 1), S519, 2016	
Gund A, Sjoqvist BA, Wigert H, Hentz E, Lindecrantz K, Bry K, A randomized controlled study about the use of eHealth in the home health care of premature infants, Neonatal Intensive Care, 26, 42-50, 2013	Country: Sweden
Gurung, G., Richardson, A., Wyeth, E., Edmonds, L., Derrett, S., Child/youth, family and public engagement in paediatric services in high-income countries: A systematic scoping review, Health expectations : an international journal of public participation in health care and health policy, 23, 261-273, 2020	Scoping review. Included studies checked for inclusion.
Gutman, T., Hanson, C. S., Bernays, S., Craig, J. C., Sinha, A., Dart, A., Eddy, A. A., Gipson, D. S., Bockenbauer, D., Yap, H. K., Groothoff, J., Zappitelli, M., Webb, N. J. A., Alexander, S. I., Goldstein, S. L., Furth, S., Samuel, S., Blydt-Hansen, T., Dionne, J., Michael, M., Wenderfer, S. E., Winkelmayr, W. C., Currier, H., McTaggart, S., Walker, A., Ralph, A. F., Ju, A., James, L. J., Carter, S., Tong, A., Child and Parental Perspectives on Communication and Decision Making in Pediatric CKD: A Focus Group Study, American Journal of Kidney Diseases, 72, 547-559, 2018	Countries: Australia, Canada and USA
Hajivassiliou, E. C., Hajivassiliou, C. A., Informed consent in primary dental care: patients' understanding and satisfaction with the consent process, British dental journal, 219, 221-224, 2015	Population not in protocol - adults with capacity.
Hamama, Liat, Ronen, Tammie, Children's drawings as a self-report measurement, Child & Family Social Work, 14, 90-102, 2009	Country: Israel
Hamann, J., Kohl, S., McCabe, R., Buhner, M., Mendel, R., Albus, M., Bernd, J., What can patients do to facilitate shared decision making? A qualitative study of patients with depression or schizophrenia and psychiatrists, Social psychiatry and psychiatric epidemiology, 51, 617-625, 2016	Population not in protocol - Adult population only, aged 18-65 years old.
Harper, B., Dickson, J. M., Bramwell, R., Experiences of young people in a 16-18 Mental Health Service, Child and Adolescent Mental Health, 19, 90-96, 2014	Phenomenon of interest not in protocol – No themes relating to shared planning or decision making
Harper, Ben, Dickson, Joanne M., Bramwell, Ros, Experiences of young people in a 16-18 Mental Health Service, Child and Adolescent Mental Health, 19, 90-96, 2014	Duplicate
Hartling, L., Scott, S., Pandya, R., Johnson, D., Bishop, T., Klassen, T. P., Storytelling as a communication tool for health consumers: development of an intervention for parents of children with croup. Stories to communicate health information, BMC pediatrics, 10, 64, 2010	Narrative description of intervention development.
Harvey, M. E., Redshaw, M. E., Analysis of audio-recordings of discussions between parents and clinicians regarding scanning results, Archives of Disease in Childhood: Fetal and Neonatal Edition, 99, A57, 2014	Conference abstract
Heath, G., Greenfield, S., Redwood, S., The meaning of 'place' in families' lived experiences of paediatric outpatient care in different settings: A descriptive phenomenological study, Health and Place, 31, 46-53, 2015	Outcome not in protocol - No themes relating to shared planning or decision making
Heinemann, A. B., Hellstrom-Westas, L., Hedberg Nyqvist, K., Factors affecting parents' presence with their extremely preterm infants in a neonatal intensive care room, Acta Paediatr, 102, 695-702, 2013	Country: Sweden

Study	Reason for Exclusion
Hemsley, B., Bastock, K., Baladin, S., Davidson, B., Scarinci, N., Worrall, L., Communication during hospitalization: The path to better healthcare for children and adults with cerebral palsy, <i>Developmental Medicine and Child Neurology</i> , 54, 31-32, 2012	Conference abstract
Hill, C., Knafelz, K. A., Santacroce, S. J., Family-Centered Care From the Perspective of Parents of Children Cared for in a Pediatric Intensive Care Unit: An Integrative Review, <i>Journal of pediatric nursing</i> , 16, 2017	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Hill, J., Masding, M. G., The development of an innovative mobile phone App for Type 1 diabetes alcohol education, <i>Diabetic medicine</i> , 1), 112, 2013	Conference abstract
Hinton, D., Kirk, S., Paediatric multiple sclerosis: A qualitative study of families' diagnosis experiences, <i>Archives of disease in childhood</i> , 100, 623-629, 2015	Outcome not in protocol - No themes relating to shared planning or decision making
Hughes, B., O'Brien, M. R., Flynn, A., Knighting, K., The engagement of young people in their own advance care planning process: A systematic narrative synthesis, <i>Palliative Medicine</i> , 32, 1147-1166, 2018	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Hughes, V. C., Phillips, S., Exploring the pre-hospitalisation needs of parents of children with cystic fibrosis, <i>Journal of Cystic Fibrosis</i> , 13, S115, 2014	Conference abstract
Hunt, A., Brown, E., Coad, J., Staniszewska, S., Hacking, S., Chesworth, B., Chambers, L., 'Why does it happen like this?' Consulting with users and providers prior to an evaluation of services for children with life limiting conditions and their families, <i>Journal of child health care : for professionals working with children in the hospital and community</i> , 19, 320-333, 2015	Phenomenon of interest not in protocol – No themes relating to shared planning or decision making
Ignatowicz, Agnieszka, Slowther, Anne-Marie, Elder, Patrick, Bryce, Carol, Hamilton, Kathryn, Huxley, Caroline, Forjaz, Vera, Sturt, Jackie, Griffiths, Frances, Ethical implications of digital communication for the patient-clinician relationship: Analysis of interviews with clinicians and young adults with long term conditions (the LYNC study), <i>BMC Medical Ethics Vol 19 2018</i> , ArtID 11, 19, 2018	Unclear protocol - clinicians and patients (16-24 years old) with chronic physical and mental health conditions. No way of determining source of data.
Ion, R., Cropper, J., Walters, H., Involving young people in decision making about sequential cochlear implantation, <i>Cochlear Implants International</i> , 14, S44-S47, 2013	Outcomes not in protocol - No qualitative data
Jacob, J., Edbrooke-Childs, J., Holley, S., Law, D., Wolpert, M., Horses for courses? A qualitative exploration of goals formulated in mental health settings by young people, parents, and clinicians, <i>Clinical child psychology and psychiatry</i> , 21, 208-223, 2016	No generalizable themes - individual goal examples used.
Jacob, J., Edbrooke-Childs, J., Law, D., Wolpert, M., Measuring what matters to patients: Using goal content to inform measure choice and development, <i>Clinical Child Psychology and Psychiatry</i> , 22, 170-186, 2017	Outcomes not in protocol - No qualitative data
Jansen, R., Reid, M., Caregivers of adolescents with mental health issues using communication technology: a systematic review, <i>JMIR mHealth and uHealth</i> , 2020	Population of included studies not in protocol. Included studies checked for inclusion.
Jefferies, K., Haest, J., Edge, J., Admission pack for newly diagnosed diabetes: Help or hindrance?, <i>Archives of disease in childhood</i> , 1), A120, 2012	Conference abstract
Jenkins, Peter, Having confidence in therapeutic work with young people: Constraints and challenges to confidentiality, <i>British Journal of Guidance &amp; Counselling</i> , 38, 263-274, 2010	Narrative review
Joanne, C., Deepa, P., Emily, W., Vanessa, M., An evaluation of the views of adolescent patients with a learning disability and their	Conference abstract

Study	Reason for Exclusion
carers on a medicines information leaflet, Archives of Disease in Childhood. Conference: 22nd Annual Conference of the Neonatal and Paediatric Pharmacists Group. United Kingdom, 103, 2018	
Jobbins, A., Baily, C., Wilkinson, G., Menzies, J., Mildner, R., Adolescents in PICU: Are we meeting their needs?, Pediatric critical care medicine, 1), A37-A38, 2011	Conference abstract
Kean, S., Children and young people visiting an adult intensive care unit, Journal of advanced nursing, 66, 868-877, 2010	Phenomenon of interest not in protocol - Reports experiences of babies, children and young people visiting family members in intensive care unit
Kerri, O., Byron, P., Improving strategies to better support adolescents with cancer: The creation of an "adolescent-friendly oncology ward", Pediatric Blood and Cancer, 53 (5), 751-752, 2009	Conference abstract
Kew, K. M., Malik, P., Aniruddhan, K., Normansell, R., Shared decision-making for people with asthma, Cochrane Database of Systematic Reviews, 2017	Duplicate
Kew, K. M., Malik, P., Aniruddhan, K., Normansell, R., Shared decision-making for people with asthma, Cochrane Database of Systematic Reviews, 2017 (10) (no pagination), 2017	Outcomes not in protocol - No qualitative data.
Latour, Jos M., van Goudoever, Johannes B., Schuurman, Beatrix Elink, Albers, Marcel J. I. J., van Dam, Nicolette A. M., Dullaart, Eugenie, van Heerde, Marc, Verlaat, Carin W. M., van Vught, Elise M., Hazelzet, Jan A., A qualitative study exploring the experiences of parents of children admitted to seven Dutch pediatric intensive care units, Intensive care medicine/Intensive Care Med, 37, 319-325, 2011	Country: The Netherlands
Law, H., Gee, B., Dehmahdi, N., Carney, R., Jackson, C., Wheeler, R., Carroll, B., Tully, S., Clarke, T., What does recovery mean to young people with mental health difficulties?-"It's not this magical unspoken thing, it's just recovery", Journal of Mental Health, 2020	Phenomenon of interest not in protocol - No themes relating to shared planning or decision making
Lawrence, M., Young adults' experience of stroke: a qualitative review of the literature, British journal of nursing (Mark Allen Publishing), 19, 241-248, 2010	Population not in protocol - Adults 18-65
Lawton, J., Waugh, N., Noyes, K., Barnard, K., Harden, J., Bath, L., Stephen, J., Rankin, D., Improving communication and recall of information in paediatric diabetes consultations: A qualitative study of parents' experiences and views, BMC pediatrics, 15 (1) (no pagination), 2015	Population not in protocol - parents of children with Type 1 diabetes. Only 2 quotes gave age of patients, both over 5.
Lea, S., Martins, A., Morgan, S., Cargill, J., Taylor, R. M., Fern, L. A., Online information and support needs of young people with cancer: A participatory action research study, Adolescent Health, Medicine and Therapeutics, 9, 121-135, 2018	Unclear population - Age range 13-24, no way of determining source of data
Lerch, Matthew F., Thrane, Susan E., Arnett, Babler Baucom Bishay Borus Dashiff Gaston Heath Hilliard Kayle King Knopf Miller Polfuss Sanders Sawicki Seiffge-Krenke Skinner Stevens Vygotsky Williams, Adolescents with chronic illness and the transition to self-management: A systematic review, Journal of Adolescence, 72, 152-161, 2019	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Levin, A. B., Fisher, K. R., Cato, K. D., Zurca, A. D., October, T. W., An Evaluation of Family-Centered Rounds in the PICU: Room for Improvement Suggested by Families and Providers, Pediatric critical care medicine : a journal of the Society of Critical Care	Country: USA

Study	Reason for Exclusion
Medicine and the World Federation of Pediatric Intensive and Critical Care Societies <i>Pediatr Crit Care Med</i> , 16, 801-7, 2015	
LGBT Youth Scotland et al, Life in Scotland for LGBT young people: Health Report, 2013	Grey literature survey
Lindberg, Birgitta, Axelsson, Karin, Öhrling, Kerstin, Taking care of their baby at home but with nursing staff as support: The use of videoconferencing in providing neonatal support to parents of preterm infants, <i>Journal of Neonatal Nursing</i> , 15, 47-55, 2009	Country: Sweden
Lion, K. C., Kieran, K., Desai, A., Hencz, P., Ebel, B. E., Adem, A., Forbes, S., Kraus, J., Gutman, C., Horn, I., Audio-Recorded Discharge Instructions for Limited English Proficient Parents: A Pilot Study, <i>Joint Commission Journal on Quality and Patient Safety</i> , 45, 98-107, 2019	Outcomes not in protocol - no qualitative data.
Lioffi, C., Noble, G., Franck, L. S., How parents make sense of their young children's expressions of everyday pain: A qualitative analysis, <i>European journal of pain (united kingdom)</i> , 16, 1166-1175, 2012	Phenomenon of interest not in protocol – No themes relating to shared planning or decision making
Lipstein, E. A., Brinkman, W. B., Britto, M. T., What is known about parents' treatment decisions? A narrative review of pediatric decision making, <i>Medical decision making : an international journal of the Society for Medical Decision Making</i> , 32, 246-258, 2012	Narrative review
Little, P., White, P., Kelly, J., Everitt, H., Gashi, S., Bikker, A., Mercer, S., Verbal and non-verbal behaviour and patient perception of communication in primary care: An observational study, <i>British journal of general practice</i> , 65, e357-e365, 2015	Outcomes not in protocol - No qualitative data
Livesley, J., Long, T., Children's experiences as hospital in-patients: Voice, competence and work. Messages for nursing from a critical ethnographic study, <i>International journal of nursing studies</i> , 50, 1292-1303, 2013	Phenomenon of interest not in protocol - No themes relating to shared planning or decision making
Loewenstein, K., Barroso, J., Phillips, S., The Experiences of Parents in the Neonatal Intensive Care Unit: An Integrative Review of Qualitative Studies Within the Transactional Model of Stress and Coping, <i>The Journal of perinatal &amp; neonatal nursing</i> , 33, 340-349, 2019	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Lowes, L., Eddy, D., Channon, S., McNamara, R., Robling, M., Gregory, J. W., The experience of living with type 1 diabetes and attending clinic from the perception of children, adolescents and carers: analysis of qualitative data from the DEPICTED study, <i>Journal of pediatric nursing</i> , 30, 54-62, 2015	Phenomenon of interest not in protocol - No themes relating to shared planning or decision making
Macdonald, M. E., Liben, S., Carnevale, F. A., Cohen, S. R., An office or a bedroom? Challenges for family-centered care in the pediatric intensive care unit, <i>J Child Health Care</i> , 16, 237-49, 2012	Country: Canada
Martin-Kerry, J. M., Knapp, P., Atkin, K., Bower, P., Watt, I., Stones, C., Higgins, S., Sheridan, R., Preston, J., Horton Taylor, D., Baines, P., Young, B., Supporting children and young people when making decisions about joining clinical trials: Qualitative study to inform multimedia website development, <i>BMJ open</i> , 9 (1) (no pagination), 2019	Population not in protocol - age of protocol range from 6-19 which no way of discerning age of quotes
Masoumi, M., Shahhosseini, Z., Self-care challenges in adolescents: A comprehensive literature review, <i>International Journal of Adolescent Medicine and Health</i> , 31, 0152, 2019	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.

Study	Reason for Exclusion
Mc Manus, V., Savage, E., Cultural perspectives of interventions for managing diabetes and asthma in children and adolescents from ethnic minority groups, <i>Child: Care, Health and Development</i> , 36, 612-622, 2010	Population of included studies not in protocol. Included studies checked for inclusion.
McCormack, A., Norrish, S., Parker, L., Frampton, I., Consulting with young people about healthcare. Part 2: Experience of long-term health conditions, <i>Pediatric Health</i> , 4, 167-175, 2010	Phenomenon of interest not in protocol - No themes relating to shared planning or decision making
McKenna, K., Collier, J., Hewitt, M., Blake, H., Parental involvement in paediatric cancer treatment decisions, <i>Eur J Cancer Care (Engl)</i> , 19, 621-30, 2010	Outcomes not in protocol - No qualitative data
McMillan, S. S., Wilson, B., Stapleton, H., Wheeler, A. J., Young people's experiences with mental health medication: A narrative review of the qualitative literature, <i>Journal of Mental Health</i> , 2020	Narrative review. Included studies checked for inclusion.
McPherson, G., Jefferson, R., Kissoon, N., Kwong, L., Rasmussen, K., Toward the inclusion of parents on pediatric critical care unit rounds, <i>Pediatric critical care medicine : a journal of the Society of Critical Care Medicine and the World Federation of Pediatric Intensive and Critical Care Societies</i> <i>Pediatr Crit Care Med</i> , 12, e255-61, 2011	Country: Canada
Miller, V. A., Parent-child collaborative decision making for the management of chronic illness: a qualitative analysis, <i>Fam Syst Health</i> , 27, 249-66, 2009	Country: USA
Mimmo, L., Harrison, R., Taking time to care: Meta narrative review of the experience of parents with a child with intellectual disability in hospital, <i>Journal of Intellectual Disability Research</i> , 63, 812, 2019	Conference abstract
Mimmo, L., Woolfenden, S., Travaglia, J., Harrison, R., Partnerships for safe care: A meta-narrative of the experience for the parent of a child with Intellectual Disability in hospital, <i>Health Expectations</i> , 22, 1199-1212, 2019	Population of included studies not in protocol. Included studies checked for inclusion.
Nair, T., Savulescu, J., Everett, J., Tonkens, R., Wilkinson, D., Settling for second best: when should doctors agree to parental demands for suboptimal medical treatment?, <i>Journal of medical ethics</i> , 43, 831-840, 2017	Outcomes not in protocol – Empirical and ethical analyses only
Neill, S. J., Jones, C. H., Lakhanpaul, M., Roland, D. T., Thompson, M. J., Parents' help-seeking behaviours during acute childhood illness at home: A contribution to explanatory theory, <i>Journal of child health care : for professionals working with children in the hospital and community</i> , 20, 77-86, 2016	Phenomenon of interest not in protocol – No themes relating to shared planning or decision making
Neill, S. J., Jones, C. H., Lakhanpaul, M., Roland, D. T., Thompson, M. J., Parent's information seeking in acute childhood illness: what helps and what hinders decision making?, <i>Health expectations : an international journal of public participation in health care and health policy</i> , 18, 3044-3056, 2015	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Neill, S., Roland, D., Jones, C. H. D., Thompson, M., Lakhanpaul, M., Information resources to aid parental decision-making on when to seek medical care for their acutely sick child: A narrative systematic review, <i>BMJ open</i> , 5 (12) (no pagination), 2015	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Nelson, P. A., Kirk, S. A., Parents' perspectives of cleft lip and/or palate services: A qualitative interview, <i>Cleft Palate-Craniofacial Journal</i> , 50, 275-285, 2013	No generalizable themes - experiences of cleft lip and/or palate services.
Ngo-Metzger, Q., Hayes, G. R., Yunan, Chen, Cygan, R., Garfield, C. F., Improving communication between patients and providers using health information technology and other quality improvement strategies: focus on low-income children, <i>Medical</i>	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.

Study	Reason for Exclusion
Care Research & Review Med Care Res Rev, 67, 246S-267S, 2010	
Nicholls, S. G., Southern, K. W., Parental selection and use of information when learning about newborn bloodspot screening, <i>Pediatric Pulmonology</i> , 46, 427, 2011	Conference abstract
Nik-Hussin, N. M. H., Saleem, Y., Sivayoham, E., Rothera, M. P., A survey of parent's attitudes towards viewing intraoperative photographs used as an educational tool, <i>International journal of pediatric otorhinolaryngology</i> , 73, 585-588, 2009	Outcomes not in protocol - no qualitative data
Obeysekera, M., Tanney, K., Picture books to improve the quality of communication in newborn intensive care, <i>Archives of Disease in Childhood</i> , 102, A88, 2017	Conference abstract
Ochieng, B. M., Black African migrants: the barriers with accessing and utilizing health promotion services in the UK, <i>European Journal of Public Health</i> , 23, 265-269, 2013	Population not in protocol - > 18 years old.
October, Tessie W., Fisher, Kiondra R., Feudtner, Chris, Hinds, Pamela S., The parent perspective: "being a good parent" when making critical decisions in the PICU, <i>Pediatric critical care medicine : a journal of the Society of Critical Care Medicine and the World Federation of Pediatric Intensive and Critical Care Societies</i> <i>Pediatr Crit Care Med</i> , 15, 291-298, 2014	Country: USA
O'Hare, L., Santin, O., Winter, K., McGuinness, C., The reliability and validity of a Child and Adolescent Participation in Decision-Making Questionnaire, <i>Child: care, health and development</i> , 42, 692-698, 2016	Outcomes not in protocol - no qualitative data.
O'Reilly, Michelle, Karim, Khalid, Taylor, Helen, Dogra, Nisha, Parent and child views on anonymity: 'I've got nothing to hide', <i>International Journal of Social Research Methodology: Theory &amp; Practice</i> , 15, 211-223, 2012	Phenomenon of interest not in protocol - No themes relating to shared planning or decision making
Oulton, K., Wray, J., Carr, L., Hassiotis, A., Jewitt, C., Kerry, S., Tuffrey-Wijne, I., Gibson, F., Pay More Attention: a national mixed methods study to identify the barriers and facilitators to ensuring equal access to high-quality hospital care and services for children and young people with and without learning disabilities and their families, <i>BMJ open</i> , 6, 2016	Published protocol, no experimental data
Page, C. J., Dunkley, L., Edgerton, J., Hawley, D., Tattersall, R. S., Don't lose your HEADSS in the adolescent clinic: An evaluation of how an adolescent rheumatology service counsels young people's issues, <i>Rheumatology (United Kingdom)</i> , 3, iii6, 2014	Conference abstract
Palatability of hypoallergenic formulas for cow's milk allergy and healthcare professional recommendation, <i>Pediatric allergy and immunology</i> , 29, 857-862, 2018	Population not in protocol - Healthcare providers views only
Pallotta-Chiarolli, Maria, Martin, Erik, 'Which Sexuality? Which Service?': Bisexual Young People's Experiences with Youth, Queer and Mental Health Services in Australia, <i>Journal of LGBT Youth</i> , 6, 199-222, 2009	Country: Australia
Pellerin-Leblanc, A. A., Derynck, M., Dow, K., Improving communication in the NICU: Parental perceptions and knowledge about resident physicians, <i>Paediatrics and Child Health (Canada)</i> , 23 (Supplement 1), e47-e48, 2018	Conference abstract
Pepper, D., Rempel, G., Austin, W., Ceci, C., Henderson, L., More than information: a qualitative study of parents' perspectives on neonatal intensive care at the extremes of prematurity, <i>Advances in Neonatal Care</i> , 12, 303-309, 2012	Country: Canada



Study	Reason for Exclusion
Petrie, K., McArdle, A., Cookson, J., Powell, E., Poblete, X., 'Let us speak'-children's opinions of doctors, Archives of Disease in Childhood, 102 (Supplement 1), A200-A201, 2017	Conference abstract
Pini, S., Education mentoring for teenagers and young adults with cancer, British journal of nursing (Mark Allen Publishing), 18, 1316-1319, 2009	Phenomenon of interest not in protocol – No themes relating to shared planning or decision making
Pyke-Grimm, Kimberly A., Franck, Linda S., Kelly, Katherine Patterson, Halpern-Felsher, Bonnie, Goldsby, Robert E., Kleiman, Ari, Rehm, Roberta S., Albritton, Alsous Barakat Bhatia Bhatia Bleyer Bluebond-Langner Britto Britto Broome Broome Butow Coccia Coyne Coyne Coyne Coyne Day de Vries Dunsmore Ellis Hinds Jacobs Joffe Kelly Knopf Lyon Martenson Masera Miller Miller Miller Moher Noblit Pace Pearce Pluye Read Ruhe Ruhe Smith Snethen Spinetta Stegenga Stewart Tenniglo Unguru Unguru Weaver Whittemore Young Zwaanswijk Zwaanswijk, Treatment decision-making involvement in adolescents and young adults with cancer, Oncology Nursing Forum, 46, E22-E37, 2019	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Pyke-Grimm, Kimberly A., Franck, Linda S., Kelly, Katherine Patterson, Halpern-Felsher, Bonnie, Goldsby, Robert E., Kleiman, Ari, Rehm, Roberta S., Treatment decision-making involvement in adolescents and young adults with cancer, Oncology Nursing Forum, 46, E22-E37, 2019	Duplicate record - Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Read, N., Schofield, A., Autism: are mental health services failing children and parents?, The journal of family health care, 20, 120-124, 2010	Phenomenon of interest not in protocol - No qualitative data for under 18s.
Redley, M., Prince, E., Bateman, N., Pennington, M., Wood, N., Croudace, T., Ring, H., The involvement of parents in healthcare decisions where adult children are at risk of lacking decision-making capacity: A qualitative study of treatment decisions in epilepsy, Journal of intellectual disability research, 57, 531-538, 2013	Population not in protocol - Parents' views with no way of discerning age of child
Rennick, J., Lambert, S., Childerhose, J., Campbell-Yeo, M., Fillion, F., & Johnston, C., Mothers' experiences of a touch and talk nursing intervention to optimize pain management in the PICU: A qualitative descriptive study. , Intensive & Critical Care Nursing, 27, 151-157, 2011	Country: Canada
Richards, C. A., Starks, H., O'Connor, M. R., Doorenbos, A. Z., Elements of Family-Centered Care in the Pediatric Intensive Care Unit: An Integrative Review, Journal of hospice and palliative nursing : JHPN : the official journal of the Hospice and Palliative Nurses Association, 19, 238-246, 2017	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Richardson, C., Paslakis, G., Men's experiences of eating disorder treatment: A qualitative systematic review of men-only studies, Journal of psychiatric and mental health nursing, 2020	Population of included studies not in protocol. Included studies checked for inclusion.
Riddell, R., Lewis, A., Tuthill, D., PN for children-information leaflet, Archives of disease in childhood, 101 (9), A13, 2016	Conference abstract
Robards, F., Kang, M., Usherwood, T., Sancu, L., How Marginalized Young People Access, Engage With, and Navigate Health-Care Systems in the Digital Age: Systematic Review, Journal of Adolescent Health, 365-381, 2018	Phenomenon of interest not in protocol - No themes relating to shared planning or decision making
Robert, Marie, Leblanc, Line, Boyer, Thierry, When satisfaction is not directly related to the support services received: Understanding parents' varied experiences with specialised services for children with developmental disabilities, British Journal of Learning Disabilities, 43, 168-177, 2015	Country not in protocol: Canada

Study	Reason for Exclusion
Robertson, A. O., Tadic, V., Rahi, J. S., Transition from paediatric to adult ophthalmology services: what matters most to young people with visual impairment, <i>Eye</i> , 32, 406-414, 2018	Phenomenon of interest not in protocol - child to adult healthcare transition.
Rosenthal, S. A., Nolan, M. T., A Meta-Ethnography and Theory of Parental Ethical Decision Making in the Neonatal Intensive Care Unit, <i>Jognn-Journal of Obstetric Gynecologic and Neonatal Nursing</i> , 42, 492-502, 2013	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Rubin, S.E., McKee, M.D., Campos, G., O'Sullivan, L.F., Delivery of confidential care to adolescent males, <i>Journal of the American Board of Family Medicine: JABFM</i> , 23, 728-735, 2010	Country: USA
Russell, G., Sawyer, A., Rabe, H., Abbott, J., Gyte, G., Duley, L., Ayers, S., Parents' views on care of their very premature babies in neonatal intensive care units: a qualitative study, <i>BMC Pediatrics</i> , 14, 230, 2014	Population not in protocol - strongly on parent's views only. Not a good proxy for unders 5s.
Saaltink, R., MacKinnon, G., Owen, F., Tardif-Williams, C., Protection, participation and protection through participation: young people with intellectual disabilities and decision making in the family context, <i>J Intellect Disabil Res</i> , 56, 1076-86, 2012	Country: Canada
Sanders, C., Pritchard, E., Bray, L., McKenna, J., Exploring young people's expectations and experiences of discussing sexual and relationship health with professionals in a children's hospital, <i>Journal of clinical nursing</i> , 20, 1705-1712, 2011	Outcomes not in protocol - no qualitative data
Sayal, Kapil, Mills, Jonathan, White, Kate, Merrell, Christine, Tymms, Peter, Predictors of and barriers to service use for children at risk of ADHD: Longitudinal study, <i>European child &amp; adolescent psychiatry</i> , 24, 545-552, 2015	Outcomes not in protocol - no qualitative data.
Schaeuble, K., Haglund, K., Vukovich, M., Adolescents' preferences for primary care provider interactions, <i>J Spec Pediatr Nurs</i> , 15, 202-10, 2010	Country: USA
Scholefield, B., Gosney, J., Callens, C., Duncan, H., Morris, K., Draper, H., Consultation with children regarding deferred consent in emergency care research, <i>Pediatric critical care medicine</i> , 1), A44, 2011	Conference abstract
Sharkey, S., Lloyd, C., Tomlinson, R., Thomas, E., Martin, A., Logan, S., Morris, C., Communicating with disabled children when inpatients: barriers and facilitators identified by parents and professionals in a qualitative study, <i>Health expectations : an international journal of public participation in health care and health policy</i> , 19, 738-750, 2016	Phenomenon of interest not in protocol - No themes relating to shared planning or decision making
Sime, D., 'I think that Polish doctors are better': Newly arrived migrant children and their parents' experiences and views of health services in Scotland, <i>Health and Place</i> , 30, 86-93, 2014	Phenomenon of interest not in protocol – No themes relating to shared planning or decision making
Sisson, Helen, Jones, Catriona, Williams, Rhona, Lachanudis, Lisa, Metaethnographic synthesis of fathers' experiences of the neonatal intensive care unit environment during hospitalization of their premature infants, <i>Journal of Obstetric, Gynecologic, &amp; Neonatal Nursing: Clinical Scholarship for the Care of Women, Childbearing Families, &amp; Newborns</i> , 44, 471-480, 2015	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Smith, L. A. M., Critoph, D. J., Hatcher, H. M., How Can Health Care Professionals Communicate Effectively with Adolescent and Young Adults Who Have Completed Cancer Treatment? A Systematic Review, <i>Journal of Adolescent and Young Adult Oncology</i> , 2020	Population of included studies not in protocol. Included studies checked for inclusion.
Stafford, V., Hutchby, I., Karim, K., O'Reilly, M., "Why are you here?" Seeking children's accounts of their presentation to Child	Phenomenon of interest not in protocol – No themes relating

Study	Reason for Exclusion
and Adolescent Mental Health Service (CAMHS), Clinical child psychology and psychiatry, 21, 3-18, 2016	to shared planning or decision making
Starkman, Harold, Fisher, Kathleen, Pilek, Nicole L., Lopez-Henriquez, Gloria, Lynch, Laura, Bilkins-Morgis, Briana L., Listening to adolescents with uncontrolled diabetes, their parents and medical team, Families, systems & health : the journal of collaborative family healthcare, 37, 30-37, 2019	Country not in protocol: USA
Stenberg, U., Haaland-Overby, M., Koricho, A. T., Trollvik, A., Kristoffersen, L. G. R., Dybvig, S., Vagan, A., How can we support children, adolescents and young adults in managing chronic health challenges? A scoping review on the effects of patient education interventions, Health expectations : an international journal of public participation in health care and health policy, 2019	Scoping review. Included studies checked for inclusion.
Stickney, C. A., Ziniel, S. I., Brett, M. S., Truog, R. D., Family participation during intensive care unit rounds: goals and expectations of parents and health care providers in a tertiary pediatric intensive care unit, J Pediatr, 165, 1245-1251.e1, 2014	Country: USA
Sullivan, V., de Sa, J., Hamlyn, E., Baraitser, P., How can we facilitate online disclosure of safeguarding concerns in under 18s to support transition from online to face-to-face care?, International Journal of STD and AIDS, 31, 553-559, 2020	Phenomenon of interest not in protocol - No themes relating to shared planning or decision making
Sunderland, E., Wood, K., Barwick, S., What do looked after young people think about the specialist health services they use?, Archives of disease in childhood, 3), A184, 2015	Conference abstract
Sutcliffe, P., Martin, S., Sturt, J., Powell, J., Griffiths, F., Adams, A., Dale, J., Systematic review of communication technologies to promote access and engagement of young people with diabetes into healthcare, BMC endocrine disorders, 11 (no pagination), 2011	Outcomes not in protocol - No qualitative data.
Sviryzdenka, N., Ronzoni, P., Dogra, N., Meaning and barriers to quality care service provision in Child and Adolescent Mental Health Services: Qualitative study of stakeholder perspectives, BMC health services research, 17, 151, 2017	Phenomenon of interest not in protocol - No themes relating to shared planning or decision making
Taylor, S., Haase-Casanovas, S., Weaver, T., Kidd, J., Garralda, E. M., Child involvement in the paediatric consultation: a qualitative study of children and carers' views, Child: care, health and development, 36, 678-685, 2010	Phenomenon of interest not in protocol - No themes relating to shared planning or decision making
Templeton, Lorna, Novak, Claire, Wall, Sarah, Young people's views on services to help them deal with parental substance misuse, Drugs: Education, Prevention & Policy, 18, 172-178, 2011	Phenomenon of interest not in protocol – No themes relating to shared planning or decision making
Ulph, F., Cullinan, T., Qureshi, N., Kai, J., Informing children of their newborn screening carrier result for sickle cell or cystic fibrosis: qualitative study of parents' intentions, views and support needs, Journal of Genetic Counseling, 23, 409-20, 2014	Phenomenon of interest not in protocol – No themes relating to shared planning or decision making
Van Cleave, A., Roosen-Runge, M., Miller, A., Karkazis, K., Magnus, D., Quality of communication in interpreted versus non-interpreted pediatric ICU family meetings, Critical Care Medicine, 1), A177, 2013	Conference abstract
Van De Vijver, M., Bertaud, S., Nailor, S., Marais, G., Baby diaries: A tool to improve parental communication in the neonatal unit, Archives of Disease in Childhood, 99, A81-A82, 2014	Conference abstract
van de Vijver, M., Evans, M., A tool to improve communication in the neonatal unit, BMJ Quality Improvement ReportsBMJ qual, 4, 2015	Study design not in protocol - close ended, yes/no questionnaire

Study	Reason for Exclusion
Waite-Jones, J. M., Majeed-Ariss, R., Smith, J., Stones, S. R., Van Rooyen, V., Swallow, V., Young People's, Parents', and Professionals' Views on Required Components of Mobile Apps to Support Self-Management of Juvenile Arthritis: Qualitative Study, JMIR MHealth and UHealth, 6, e25, 2018	Phenomenon of interest not in protocol – No themes relating to shared planning or decision making
Wales, Jackie, Brewin, Nicola, Raghavan, Raghu, Arcelus, Jon, Exploring barriers to South Asian help-seeking for eating disorders, Mental Health Review Journal, 22, 40-50, 2017	Population not in protocol – adults >18 years old
Walsh, J., Scaife, V., Notley, C., Dodsworth, J., Schofield, G., Perception of need and barriers to access: The mental health needs of young people attending a Youth Offending Team in the UK, Health and Social Care in the Community, 19, 420-428, 2011	Phenomenon of interest not in protocol – No themes relating to shared planning or decision making
Watts, R., Zhou, H., Shields, L., Taylor, M., Munns, A., Ngune, I., Family-centered care for hospitalized children aged 0-12 years: A systematic review of qualitative studies, JBI Database of Systematic Reviews and Implementation Reports, 12, 204-283, 2014	Phenomenon of interest not in protocol – No themes relating to shared planning or decision making.
White, B., Tuschl, K., Walker, J., Segal, T., Viner, R. M., Confidentiality, consent and privacy: A challenge even in a specialist young person unit, Archives of disease in childhood, 1), A65, 2010	Conference abstract
Whittingham, Koa, Boyd, Roslyn N., Sanders, Matthew R., Colditz, Paul, Parenting and prematurity: Understanding parent experience and preferences for support, Journal of Child and Family Studies, 23, 1050-1061, 2014	Country: Australia
Wiering, B. M., Noordman, J., Tate, K., Zwaanswijk, M., Elwyn, G., De Bont, E. S. J. M., Beishuizen, A., Hoogerbrugge, P. M., Van Dulmen, S., Sharing decisions during diagnostic consultations; an observational study in pediatric oncology, Patient Education and Counseling, 99, 61-67, 2016	Outcomes not in protocol - No qualitative data
Wong et al, Risk discourse and sexual stigma: Barriers to STI testing, treatment and care among young heterosexual women in disadvantaged neighbourhoods in Toronto, Can J Hum Sex, 21, 75-89, 2012	Country: Canada
Wood, D., Geoghegan, S., Ramnarayan, P., Davis, P. J., Pappachan, J. V., Goodwin, S., Wray, J., Eliciting the experiences of the adolescent-parent dyad following critical care admission: a pilot study, European Journal of Pediatrics, 177, 747-752, 2018	Phenomenon of interest not in protocols - No themes relating to shared planning or decision making
Wyatt, K. D., Prutsky Lopez, G., Domecq Garces, J. P., Erwin, P., Brinkman, W. B., Montori, V. M., LeBlanc, A., Study protocol: a systematic review of pediatric shared decision making, Systematic reviews, 2, 48, 2013	Published protocol
Yamaji, Noyuri, Suto, Maiko, Takemoto, Yo, Suzuki, Daichi, Lopes, Katharina da Silva, Ota, Erika, Supporting the Decision Making of Children With Cancer: A Meta-synthesis, Journal of pediatric oncology nursing : official journal of the Association of Pediatric Oncology Nurses, 1043454220919711, 2020	Population of included studies not in protocol. Included studies checked for inclusion.
Ye, Jiali, Rust, George, Fry-Johnson, Yvonne, Strothers, Harry, E-mail in patient-provider communication: A systematic review, Patient Education and Counseling, 80, 266-273, 2010	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.

### **Economic studies**

No economic evidence was identified for this review. See supplementary material 6 for details.

## **Appendix L – Research recommendations**

**Research recommendations for review question: How do children and young people, and the parents and carers of babies and young children, prefer to be involved and supported in planning their healthcare and making informed, shared decisions about their health?**

No research recommendations were made for this review question.

## Appendix M – Evidence from reference groups and focus groups

**Reference and focus group evidence for review question: How do children and young people, and the parents and carers of babies and young children, prefer to be involved and supported in planning their healthcare and making informed, shared decisions about their health?**

Methods for the reference and focus groups and details of how input was obtained from the children and young people are described in Supplement 4.

**Table 11: Evidence from focus groups and reference groups**

Age < 7 years	Age 7-11 Years	Age 11-14 years	Overall quality of the evidence
<p>There was no evidence from this group for this question</p>	<ul style="list-style-type: none"> <li>• Let you be honest</li> <li>• I like giving my opinion because:                             <ul style="list-style-type: none"> <li>○ 'I like giving my opinion for subjects that I like, it shows I love them if I give my opinion'</li> <li>○ 'I like talking about opinions; it could help the person that you're speaking to so they can understand you'</li> <li>○ 'It is better to tell them more about my opinion'</li> <li>○ '[They] need to understand what is wrong with you'</li> </ul> </li> <li>• I may not like giving opinion because:                             <ul style="list-style-type: none"> <li>○ 'I don't want to be picked on'</li> <li>○ 'Some days I want to share more than other days'</li> <li>○ 'I just don't like to [give my opinion] sometimes but sometimes I want to share more'</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• I like giving my opinion because:                             <ul style="list-style-type: none"> <li>○ 'So I'm not left out'</li> <li>○ 'I like people to know my opinion because otherwise... they won't know it. People might not take my thoughts into account, they might not do what I think is right to me'</li> <li>○ 'Because I think my opinion matters'</li> </ul> </li> <li>• I feel comfortable asking a nurse or a doctor a question if I don't understand because:                             <ul style="list-style-type: none"> <li>○ 'I have to go see a doctor every half a year and I do feel comfortable, I enjoy seeing the same doctor every time'</li> <li>○ [One commented] 'I've never been in that situation'</li> </ul> </li> <li>• I don't feel comfortable asking a nurse or a doctor a question if I don't understand because:</li> </ul>	<ul style="list-style-type: none"> <li>• Low</li> </ul>

Age < 7 years	Age 7-11 Years	Age 11-14 years	Overall quality of the evidence
	<ul style="list-style-type: none"> <li>○ ‘Don’t know, might feel like you know what it is but you’re not sure, might hurt in some places but don’t know how you feel’</li> <li>○ ‘Mum and dad might help but they might not know as well as me’</li> <li>● I don’t like giving my opinion because:                             <ul style="list-style-type: none"> <li>○ ‘Opinions can be personal/ secretive, can be rude, thinking that I don’t want to share, I could get into trouble’</li> </ul> </li> <li>● I like being listened to because:                             <ul style="list-style-type: none"> <li>○ ‘I like people listening to my ideas, I want to share how you are feeling’</li> <li>○ ‘Some people listen well and some don’t’</li> <li>○ ‘Being listened to is better than anything – they can listen to you whether it’s an emergency or not’</li> </ul> </li> <li>● I don’t like being listened to because:                             <ul style="list-style-type: none"> <li>○ ‘People can say no’</li> <li>○ ‘Some things you want to share and others you don’t’</li> <li>○ ‘If in a rush or you are a bad [very ill] patient or if in an emergency /bleeding out, being listened to is less important’</li> </ul> </li> <li>● I am happy asking questions in hospital or of school nurse because:                             <ul style="list-style-type: none"> <li>○ ‘Depends what it’s about, something to do with health then they can help you’</li> <li>○ ‘They aren’t expecting you to know anything’</li> <li>○ ‘Sometimes you don’t even know if you’re sick’</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>○ ‘I just don’t like asking questions – there’s nothing they could do to make me feel more comfortable and I don’t think this will change as I get older’</li> <li>○ Curiosity kills the cat</li> <li>● I like to make decisions about my health and body because:                             <ul style="list-style-type: none"> <li>○ ‘It’s all about confidence and independence – I should have a say in what happens to me’</li> <li>○ ‘It’s your body so you should choose what to do with it’</li> <li>○ ‘You need to be able to make decisions about what happens to you’</li> <li>○ ‘It’s fine for people to talk through it with you, but if you don’t want to do it then you should tell them’</li> <li>○ ‘You don’t always have to agree with everything they are saying, but they can still be a part of it – because you will know what helps you even if they don’t’</li> <li>○ [one was unsure and said] ‘I don’t care what happens to my body’ [then thought about it more and decided it was more important to them]</li> </ul> </li> <li>● Only adults get to make decisions about their child’s health care:                             <ul style="list-style-type: none"> <li>○ All disagreed with this statement</li> <li>○ ‘It’s your decision, it is not up to adults to overpower you with what they say’</li> <li>○ ‘It’s our bodies we should get a say in what happens’</li> </ul> </li> <li>● How comfortable asking questions and say how feeling if in hospital or from school nurse:</li> </ul>	



Age < 7 years	Age 7-11 Years	Age 11-14 years	Overall quality of the evidence
	<ul style="list-style-type: none"> <li>○ 'If you tell a doctor, they can help you better, in case you have a really bad infection or something'</li> <li>○ 'People would have asked them questions before'</li> <li>○ 'Would be scared if they did not tell you information'</li> <li>● I am unsure about asking questions in hospital or of school nurse because:                             <ul style="list-style-type: none"> <li>○ 'I might be scared if you ask a question'</li> <li>○ 'They could hurt you'</li> </ul> </li> <li>● I am NOT happy asking questions in hospital or of school nurse because:                             <ul style="list-style-type: none"> <li>○ 'Embarrassing, wouldn't ask anyone'</li> <li>○ 'Nervous to say it out loud'</li> <li>○ 'I don't really like talking to nurses or doctors... just how I feel'</li> <li>○ You're used to your teacher as you see them every day, but you don't see the doctors every day, doctors you don't know them as well so you could get really nervous'</li> <li>○ 'Something might be really, really important but you can feel embarrassed telling them'</li> <li>○ You don't want to talk to everybody, some days just feel like that'</li> <li>○ 'Sometimes you are tired, if you've had a seizure or something, so you might just want to listen or go to sleep... harder when you're not well'</li> <li>○ 'Sometimes I feel nervous asking questions'</li> <li>○ 'Ask your parents and then they ask for you'</li> </ul> </li> <li>● I like to make decisions about my own body/health because:</li> </ul>	<ul style="list-style-type: none"> <li>○ 'The setting makes a difference but also the person makes a difference'</li> <li>● What questions would you want to ask if having appendix out:                             <ul style="list-style-type: none"> <li>○ 'What's the appendix?'</li> <li>○ 'How soon would it be taken out?'</li> <li>○ 'What is the process/operation?'</li> <li>○ 'How long the recovery?'</li> <li>○ 'Where will it be done?'</li> <li>○ 'Will I survive?'</li> <li>○ 'Will I wake up?'</li> <li>○ 'Will I have to be asleep for long?'</li> <li>○ 'How long to fall asleep?'</li> <li>○ 'Will it hurt?'</li> <li>○ 'Am I allowed to eat/drink before the operation?'</li> <li>○ 'When will I go back to school/college?'</li> </ul> </li> <li>● What questions would you want to ask if having tooth taken out:                             <ul style="list-style-type: none"> <li>○ 'Will I still get braces? And what will I do if there is a gap?'</li> <li>○ 'Will I be asleep/anaesthetic?'</li> <li>○ 'Why do I need it out?'</li> <li>○ 'How long until it will get sore?'</li> <li>○ 'What if squeamish and scared of blood?'</li> <li>○ 'What happens if you pull out the wrong tooth?'</li> <li>○ 'Adult tooth vs children's tooth – different?'</li> </ul> </li> </ul>	

Age < 7 years	Age 7-11 Years	Age 11-14 years	Overall quality of the evidence
	<ul style="list-style-type: none"> <li>○ 'If you don't want injections tell them to stop'</li> <li>○ 'I like being healthy, but I prefer to look after myself'</li> <li>○ 'If you had a tummy ache and mum and dad did not believe you it's not about your mum and dad deciding'</li> <li>● I am unsure about making decisions about my own body/health because:                             <ul style="list-style-type: none"> <li>○ 'I ask a lot of questions, understand what is happening'</li> <li>○ 'When you're a ten year old kid like me, you might be quite unaware of things so you might need your parent or guardian or to help you in those times'</li> <li>○ 'Parents may know better; I like a little help but mostly do it by myself'</li> </ul> </li> <li>● I don't like making decisions about my own body/health because:                             <ul style="list-style-type: none"> <li>○ 'Doctors and nurses can make better decisions'</li> <li>○ 'Parents may know better'</li> <li>○ 'Sometimes in my own interest'</li> <li>○ 'If you were about to have lunch, I would just eat chocolate and chips. This is not good for you. Your mum would know what's best for you'</li> </ul> </li> <li>● What questions would you want to ask if having an injection in a GP surgery:                             <ul style="list-style-type: none"> <li>○ 'Why would I need it?'</li> <li>○ 'Why two?'</li> <li>○ 'Will it hurt?'</li> <li>○ 'No, thank you'</li> <li>○ I might scream'</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>○ 'Will I be able to talk?'</li> <li>○ 'Accept it'</li> <li>○ 'Question it/ask why –because didn't say you have to, only they want to'</li> <li>● What questions would you want to ask if taking a new prescription medicine:                             <ul style="list-style-type: none"> <li>○ 'Ingredients – allergies?'</li> <li>○ 'How many times to take it?'</li> <li>○ 'Why nurse not doctor? Doctor for all prescriptions?'</li> <li>○ 'Side effects – will it make you put on weight?'</li> <li>○ 'Will I have to wake up in night to take it?'</li> <li>○ 'Dosage/strength – overdose?'</li> <li>○ 'What happens if you miss a dose?'</li> <li>○ 'Does it taste horrible? Nice or not?'</li> <li>○ 'How can I take it - chewing, swallowing whole or liquid like calpol dissolvable?'</li> <li>○ 'How to collect medicine?'</li> <li>○ 'What happens if it makes me sick?'</li> </ul> </li> <li>● What questions would you want to ask if having an X-ray [for a broken arm]:                             <ul style="list-style-type: none"> <li>○ 'When will I have the X-ray?'</li> <li>○ 'How does x-ray machine work?'</li> <li>○ 'Will I need a cast? And when will it come off?'</li> <li>○ 'How long will it take?'</li> <li>○ 'How long to recover?'</li> <li>○ 'How sore will it be?'</li> </ul> </li> </ul>	

Age < 7 years	Age 7-11 Years	Age 11-14 years	Overall quality of the evidence
	<ul style="list-style-type: none"> <li>○ ‘What’s it filled with?’</li> <li>○ ‘Feel uncomfortable with my parents there’</li> <li>○ ‘Squeeze someone’s [hand] and don’t look’</li> <li>○ ‘What’s the problem?’</li> <li>○ ‘Where on my body?’</li> <li>○ ‘Have you told my parents?’</li> <li>○ ‘Might be very painful’</li> <li>○ ‘Why and where?’</li> <li>● What questions would you want to ask if having an X-ray                             <ul style="list-style-type: none"> <li>○ ‘Why do I need one?’</li> <li>○ ‘Will it hurt?’ [multiple responses like this]</li> <li>○ ‘What will it actually do?’</li> <li>○ ‘What part of my body is broken?’</li> <li>○ ‘Worried about something being broken’</li> <li>○ ‘Do my parents know?’</li> <li>○ ‘It’s ok, not that bad’</li> <li>○ ‘It’s not as bad as having an operation’</li> <li>○ ‘Is that the place it actually hurts?’</li> <li>○ ‘Just a quick scan, like a picture’</li> <li>○ ‘Are you strict?’</li> <li>○ ‘Will I have to have surgery after?’</li> <li>○ ‘What’s going to happen?’</li> <li>○ ‘Easier if you’ve seen a friend have it happen – you know they are fine’</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>○ ‘Will my arm hurt if I move it?’</li> <li>○ ‘What will happen if badly injured?’</li> <li>○ ‘If arm falls off?’</li> <li>○ ‘Will have to exercise my arm?’</li> <li>○ ‘How often will they have to go back?’</li> <li>○ ‘How will I do work if broken?’</li> <li>● Shared healthcare decision-making scenario #1: Joy is 7, lives with her mum, dad, twin sister:                             <ul style="list-style-type: none"> <li>○ ‘Parent to make vital decision’</li> <li>○ ‘Parent will explain things more clearly and comfortably for her’</li> <li>○ ‘Will need quite a lot of support because of her age’</li> <li>○ ‘Moral support for injections/other medical support’</li> <li>○ ‘Little bit of help with decision but should still get to make her own decisions – they could check up on her’</li> <li>○ ‘May feel nervous and intimidated – lots of people, big hospitals etc.’</li> <li>○ ‘Would help to have a young children’s area for under 10s for appointments etc.’</li> <li>○ ‘A nurse who is really good with children – nice, easy words so don’t have to ask questions as much, help with all stages’</li> </ul> </li> <li>● Shared healthcare decision-making scenario #2: Mike is 11 and he lives in a children’s home with eight other children and a golden retriever                             <ul style="list-style-type: none"> <li>○ ‘Guardian would need an input too ‘</li> </ul> </li> </ul>	

Age < 7 years	Age 7-11 Years	Age 11-14 years	Overall quality of the evidence
	<ul style="list-style-type: none"> <li>○ ‘Doctor – bring animals round, Wi-Fi needs to be really good, go on your phone, sometimes in too much pain to go on your phone if you get a headache.’</li> <li>● What questions would you want to ask if having appendix out:                             <ul style="list-style-type: none"> <li>○ ‘I don’t want to die’</li> <li>○ ‘Will I die?’</li> <li>○ ‘I wouldn’t feel comfortable asking questions’</li> <li>○ ‘What is my appendix? Where is my appendix?’</li> <li>○ ‘Some young people wouldn’t feel comfortable asking this ‘because I don’t know him’, but others would feel comfortable asking as it isn’t a personal thing’</li> <li>○ ‘If your appendix burst what happens?’</li> <li>○ ‘I would want to ask and listen – What are you actually going to do? Will it ever be uninfected?’</li> <li>○ ‘What is going to sleep going to be like?’</li> <li>○ ‘Please don’t kill me’</li> <li>○ ‘Will you be careful?’</li> <li>○ Sub-question: Would you tell them if you were scared? 4 said they would feel comfortable saying this, 1 some of the time/depends, 2 wouldn’t feel comfortable saying this</li> </ul> </li> <li>● What questions would you want to ask if seeing a GP/talking to a therapist once a week about fear of spiders:                             <ul style="list-style-type: none"> <li>○ ‘Why once a week?’</li> <li>○ ‘Is it that important – some people just like spiders and some don’t’</li> <li>○ ‘Am I allowed to bring a friend or family member?’</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>○ ‘Dog could be a therapy dog to help keep him calm and feel comforted ‘</li> <li>○ ‘Little bit of help but enough independence so he knows what to do when he is older’</li> <li>○ ‘[Would need] most support with actual intervention, e.g. injection, medicine, examination to help understand what is happening and moral support’</li> <li>○ ‘[Would need] most help with next step decisions’                             <ul style="list-style-type: none"> <li>- Step 1: foster parents do it, the doctors, the receptionist, ask the date, where it may be</li> <li>- Step 2: a foster parent to say what they need to say, tell them the name of patient, time, which GP?</li> <li>- Step 3: think about allergies, e.g. dog, cat, peanuts, nuts, don’t want people butting in, may want to be in room by themselves. If old enough, talk about what strange things have happened</li> <li>- Step 4: may need to explain more, show what medication there may be</li> <li>- Step 5: do the medication, get the place ready, tell foster parent, get qualified person</li> <li>- Step 6: having medication, getting diagnosed, visiting doctor every so often, visiting dentist every 6 months</li> </ul> </li> <li>● Shared healthcare decision-making scenario #3: Sarah is 13 and he lives with her mum, nana and an older sister who is 20                             <ul style="list-style-type: none"> <li>○ ‘Step 3 most important – sharing thoughts’</li> <li>○ ‘Book appointments on own’</li> </ul> </li> </ul>	

Age < 7 years	Age 7-11 Years	Age 11-14 years	Overall quality of the evidence
	<ul style="list-style-type: none"> <li>○ 'What time do you want us there?'</li> <li>○ 'Why is it necessary?'</li> <li>○ 'Is there something else more important?'</li> <li>○ 'Why am I here?'</li> <li>○ 'Different with physical and mental health'</li> <li>● What questions would you want to ask if at the dentist/GP/hospital, having a tooth out:                             <ul style="list-style-type: none"> <li>○ 'It might hurt'</li> <li>○ 'Would I be put to sleep?'</li> <li>○ 'When you go to sleep, when you wake up are you still feeling tired?'</li> <li>○ 'Will anaesthetic make you go weird and why?'</li> <li>○ One boy explained that his mouth and lips went weird and droopy afterwards but he hadn't been told in advance this was going to happen – he didn't mind because he thought it was funny but thought if it had been something bad, more scary he would not have wanted to know in advance 'because then I'd say 'get off me!' and be running away'</li> <li>○ 'Is it a big bit or a small bit?'</li> <li>○ 'Is it a baby tooth or big tooth?'</li> <li>○ 'Why do you have to take it out?'</li> <li>○ 'Will I get it back as an adult tooth?'</li> <li>○ 'Will I die? – worried'</li> <li>○ 'I would say 'I feel fine'</li> <li>○ 'Will one grow back?'</li> <li>○ 'Will I get a fake tooth?'</li> <li>○ 'Do you have to take the tooth out now?'</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>○ 'She might want her sister there when booking but might want to be on her own in the appointment'</li> <li>○ 'More support from her mum to help her understand what the doctor is saying'</li> <li>○ 'Talk through with friends'</li> <li>○ 'More/most things by herself (probably) because mature'</li> <li>○ 'Individually and independence more support'</li> <li>○ 'Moral support important'</li> <li>○ 'More support 5-7 '</li> <li>○ 'Mum to come in and explain if she has a question'</li> <li>○ 'Mum and nan to give more support with decision making ultimate decision is hers'</li> </ul>	

Age < 7 years	Age 7-11 Years	Age 11-14 years	Overall quality of the evidence
	<ul style="list-style-type: none"> <li>○ ‘Could I have something different, like a filling?’</li> <li>○ ‘Will it help the pain?’</li> <li>● General feedback about asking questions:                             <ul style="list-style-type: none"> <li>○ Some more comfortable asking parents questions/talking to them</li> <li>○ Some more comfortable asking doctors, nurse questions/talking to them</li> <li>○ Writing question’s down asking them is also a good option – some of the young people said this would make a big difference if they were too nervous to say it out loud, some disagreed:                                     <ul style="list-style-type: none"> <li>- ‘I don’t like writing’</li> <li>- ‘I would rather ask them in person so it goes quicker so you don’t have to wait for them to read it and write it down’</li> <li>- ‘The worry will be over faster’ [if you ask]</li> </ul> </li> </ul> </li> </ul>		

## Appendix N – Evidence from national surveys

### Evidence from national surveys for review question: How do children and young people, and the parents and carers of babies and young children, prefer to be involved and supported in planning their healthcare and making informed, shared decisions about their health?

Methods for the grey literature review of national surveys and details of the surveys included are described in Supplement 5.

**Table 12: Evidence from national surveys**

Survey	Findings	Overall quality of the evidence
Association for Young People's Health. Young people's views on involvement and feedback in healthcare 2014	<ul style="list-style-type: none"> <li>No relevant findings were identified for this question</li> </ul>	<ul style="list-style-type: none"> <li>N/A</li> </ul>
Care Quality Commission. Children and young people's inpatient and day case survey 2018	<p>INVOLVEMENT IN CARE:</p> <ul style="list-style-type: none"> <li>46% of 8-15 year olds felt very involved in their care; 15% said they had not been involved</li> <li>74% parents of 0-7 year olds said they were given enough information to be involved in decisions about their child's care</li> </ul>	<ul style="list-style-type: none"> <li>Low</li> </ul>
Child Outcomes Research Consortium. Child- and Parent-reported Outcomes and Experience from Child and Young People's Mental Health Services 2011-2015	<ul style="list-style-type: none"> <li>No relevant findings were identified for this question</li> </ul>	<ul style="list-style-type: none"> <li>N/A</li> </ul>
Health and Social Care Information Centre. Children's Dental Health Survey 2013. (Country specific report for England, published 2015)	<ul style="list-style-type: none"> <li>No relevant findings were identified for this question</li> </ul>	<ul style="list-style-type: none"> <li>N/A</li> </ul>

Survey	Findings	Overall quality of the evidence
HM Inspectorate of Prisons. Children in Custody 2016-2017	<ul style="list-style-type: none"> <li>No relevant findings were identified for this question</li> </ul>	<ul style="list-style-type: none"> <li>N/A</li> </ul>
National Children's Bureau. Listening to children's views on health provision 2012	<p>INVOLVEMENT IN DECISIONS ABOUT CARE:</p> <ul style="list-style-type: none"> <li>Disabled young people aged 15 to 21 recommended that consultations with all health professionals must place the young person at the centre. Every effort should be made to enable children to make a contribution to the consultation and any decisions made should take into account any preferences expressed by the young person.</li> </ul>	<ul style="list-style-type: none"> <li>Moderate</li> </ul>
Opinion Matters. Declare your care survey 2018	<ul style="list-style-type: none"> <li>No relevant findings were identified for this question</li> </ul>	<ul style="list-style-type: none"> <li>N/A</li> </ul>
Picker Institute. Children and Young People's Patient Experience Survey 2018.	<ul style="list-style-type: none"> <li>No relevant findings were identified for this question</li> </ul>	<ul style="list-style-type: none"> <li>N/A</li> </ul>
Picker Institute. Paediatric Emergency Department Survey 2015 and Children and Young People's Outpatient Survey 2015	<p>INVOLVEMENT IN CARE (OUTPATIENTS):</p> <ul style="list-style-type: none"> <li>55% children and young people aged 8-16 (for whom hospital admission was needed) said they did not have a say in what would happen to them in hospital</li> </ul>	<ul style="list-style-type: none"> <li>Low</li> </ul>
Picker Institute/NHS England/Bliss. Neonatal Survey 2014  <i>Results for individual questions were converted into scores on a scale of 1 to 100, with 100 representing the best possible outcome (the scores are not percentages).</i>	<p>INVOLVEMENT IN DECISIONS ABOUT BABY'S CARE:</p> <ul style="list-style-type: none"> <li>Did the neonatal staff include you in discussions about your baby's care and treatment? Score = 78</li> <li>Were you told about changes in your baby's condition or care? Score = 89</li> </ul>	<ul style="list-style-type: none"> <li>Moderate</li> </ul>



Survey	Findings	Overall quality of the evidence
	<ul style="list-style-type: none"> <li>When a ward round was taking place, were you allowed to be present when your baby was being discussed? Score = 80</li> </ul>	
<p>Word of Mouth Research and Point of Care Foundation.                      An options appraisal for obtaining feedback on the experiences of children and young people with cancer 2018</p>	<p><b>INVOLVEMENT IN DECISIONS ABOUT CARE:</b></p> <ul style="list-style-type: none"> <li>Three teenagers aged 13 to 17 reported that the presumption that children and young people with cancer would be especially concerned to ensure that they were fully involved in all aspects of their treatment and care was not so clear cut. Two said that they had been too ill to even consider the notion of wanting control over decision making. Instead, they reported that they had been very willing to entrust all matters to do with their medical condition to their parents and the medical staff.</li> <li>Seven other teenagers aged 13 to 17 took a different view and were very keen that the views and wishes of young people like themselves should be sought and acted upon.</li> </ul> <p>Quotes:</p> <p>'To be honest, I was so out of it, physically and things, really sick all the time, that I wasn't thinking like that... I just went with what they (parents/medical staff) decided...' (M17)</p> <p>'It was really important to me that I was involved fully in the decisions about treatment. I was made very aware of everything that was going on. At the end of the day it's your body, your life and once you reach a certain age you should be able to make decisions for yourself.' (M16)</p>	<ul style="list-style-type: none"> <li>Low</li> </ul>

*N/A: not applicable; NHS: National Health Service*