

Babies, children and young people's experience of healthcare

[F] Involving parents or carers in healthcare and healthcare decisions

NICE guideline < tbc >

Evidence reviews underpinning recommendations 1.1.2 to 1.1.5 and 1.5.1 to 1.5.5 in the NICE guideline

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Draft for consultation

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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Contents

Involving parents or carers in healthcare and healthcare decisions	6
Review question	6
Introduction	6
Summary of the protocol	6
Methods and process	7
Clinical evidence	7
Summary of studies included in the evidence review.....	8
Quality assessment of studies included in the evidence review	10
Evidence from reference groups and focus groups.....	10
Evidence from national surveys	11
Economic evidence	11
Summary of studies included in the economic evidence review.....	11
Economic model.....	11
The committee’s discussion of the evidence.....	12
Recommendations supported by this evidence review	14
References.....	15
Appendices	16
Appendix A – Review protocol.....	16
Review protocol for review question: How do children and young people want their parents or carers to be involved in their healthcare and decisions about their healthcare?	16
Appendix B – Literature search strategies	25
Literature search strategies for review question: How do children and young people want their parents or carers to be involved in their healthcare and decisions about their healthcare?	25
Databases: Embase/Medline/PsycINFO.....	25
Database: Cochrane Library.....	30
Appendix C – Clinical evidence study selection	35
Study selection for review question: How do children and young people want their parents or carers to be involved in their healthcare and decisions about their healthcare?	35
Appendix D – Clinical evidence tables	36
Evidence tables for review question: How do children and young people want their parents or carers to be involved in their healthcare and decisions about their healthcare?	36
Appendix E – Forest plots.....	48
Forest plots for review question: How do children and young people want their parents or carers to be involved in their healthcare and decisions about their healthcare?	48
Appendix F – GRADE-CERQual tables	49

GRADE-CERQual tables for review question: How do children and young people want their parents or carers to be involved in their healthcare and decisions about their healthcare?	49
Appendix G – Economic evidence study selection.....	53
Economic evidence study selection for review question: How do children and young people want their parents or carers to be involved in their healthcare and decisions about their healthcare?	53
Appendix H – Economic evidence tables.....	54
Economic evidence tables for review question: How do children and young people want their parents or carers to be involved in their healthcare and decisions about their healthcare?	54
Appendix I – Economic evidence profiles	55
Economic evidence profiles for review question: How do children and young people want their parents or carers to be involved in their healthcare and decisions about their healthcare?	55
Appendix J – Economic analysis	56
Economic evidence analysis for review question: How do children and young people want their parents or carers to be involved in their healthcare and decisions about their healthcare?	56
Appendix K – Excluded studies	57
Excluded studies for review question: How do children and young people want their parents or carers to be involved in their healthcare and decisions about their healthcare?	57
Appendix L – Research recommendations	64
Research recommendation for review question: How do children and young people want their parents or carers to be involved in their healthcare and decisions about their healthcare?	64
Appendix M – Evidence from reference groups and focus groups	65
Reference and focus group evidence for review question: How do children and young people want their parents or carers to be involved in their healthcare and decisions about their healthcare?	65
Appendix N – Evidence from national surveys.....	69
Evidence from national surveys for review question: How do children and young people want their parents or carers to be involved in their healthcare and decisions about their healthcare?	69

1 Involving parents or carers in healthcare 2 and healthcare decisions

3 Review question

4 How do children and young people want their parents or carers to be involved in their
5 healthcare and decisions about their healthcare?

6 Introduction

7 Making decisions about healthcare can be challenging for children and young people, and
8 they may want to involve their parent or carer to support them in this process. However,
9 other children and young people may feel they have the confidence to make these decisions
10 on their own and may not welcome parental involvement, or they may want support in only
11 some decisions. Children and young people's preferences may vary depending on a number
12 of factors, for example, their age, understanding of the options, the severity of their illness or
13 as treatment progresses, and how unwell they are feeling on any given day.

14 The aim of this review is to establish how children and young people want their parents or
15 carers to be involved in their healthcare and decisions about their healthcare.

16 Summary of the protocol

17 See Table 1 **Error! Reference source not found.** for a summary of the population,
18 phenomenon of interest and primary outcome characteristics of this review.

19 Table 1: Summary of the protocol

Population	<ul style="list-style-type: none"> • People <18 years-old who have experience of healthcare • 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"> ○ The baby or child of the parent or carer is under-5 years-old, or ○ 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.
Phenomenon of interest	How children and young people want their parents or carers to be involved in their healthcare and making healthcare-related decisions, and the extent to which they want parents and carers to support them.
Primary outcome	<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"> • Child's or young person's understanding (or lack thereof) of condition or impact of potential treatments • Differing needs relative to setting, stage of healthcare (e.g. whether babies, children and young people want their parents to be involved in certain discussions like lifestyle factors) • Feeling actively involved in healthcare and related decisions (feeling of agency) • Impact of child's or young person's condition on their parents or carer emotions and its effect on the latter's decision making • Influence of child's or young person's personal or parental/carer circumstances (e.g. age, capacity to understand, biological parent,



- experience of the healthcare system, health status/condition, language barriers, physical, mental and emotional well-being [including mood])
- Opportunity and being able to articulate for self-advocacy
 - Sharing decision making with parents/carers

1 For further details, see the review protocol in appendix A.

2 **Methods and process**

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

6 **Clinical evidence**

7 **Included studies**

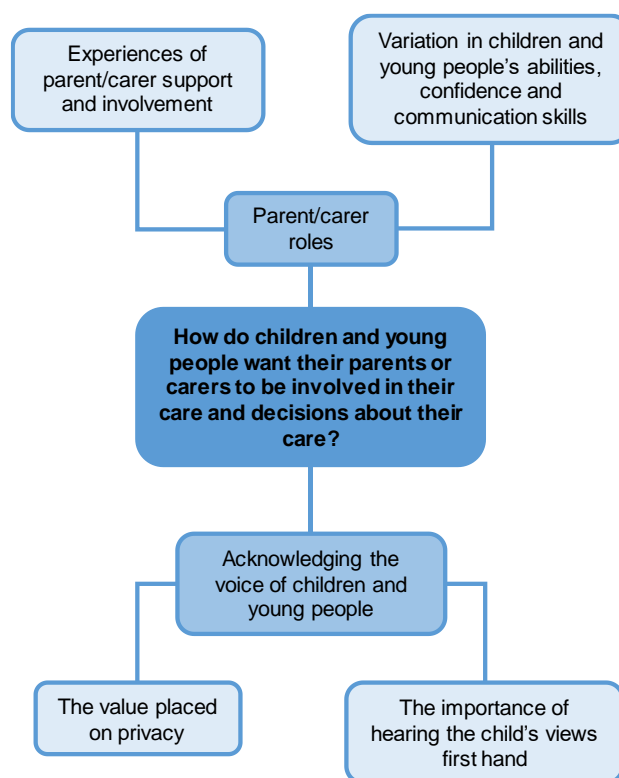
8 This was a qualitative review with the aim of:

- 9 • Understanding how children and young people want their parents or carers to be involved
10 in their healthcare and making healthcare-related decisions.
11 • Understanding the extent to which children and young people want their parents or carers
12 to support them.

13 A systematic review of the literature was conducted using a combined search. Four studies
14 were included in this evidence review: 3 qualitative studies used semi-structured interviews
15 (Harper 2014, Taylor 2010 and Walsh 2011) and 1 systematic review (Lerch 2019).
16 Qualitative studies were conducted in the UK. Of the 9 studies included in the systematic
17 review, 2 were conducted in the UK and 7 were conducted in the US.

18 The included studies are summarised in Table 2.

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

1 **Figure 1: Theme map**

2

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

4 **Excluded studies**5 Studies not included in this review are listed, and reasons for their exclusion are provided in
6 appendix K.7 **Summary of studies included in the evidence review**

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

9 **Table 2: Summary of included studies**

Study	Participants	Methods	Themes
<p>Harper 2014</p> <p>Study design Semi-structured interview</p> <p>Aim of the study To explore young people's experiences of 16-18 mental health services.</p> <p>North West England, UK</p>	<p>N=10 young people</p> <p>Characteristics Age (range): 16-18 years</p> <ul style="list-style-type: none"> • 16 (n)=1 • 17 (n)=5 • 18 (n)=4 <p>Gender (M/F): 3/7</p>	<p>Recruitment Purposive sampling identified by key workers at 16-18 mental health services</p> <p>Data collection Semi-structured interviews</p> <p>Analysis Interpretative phenomenological analysis</p>	<ul style="list-style-type: none"> • Acknowledging the voice of children and young people: The value placed on privacy

Study	Participants	Methods	Themes
<p>Lerch 2019</p> <p>Study design Systematic review</p> <p>Aim of the study To assess the impact of parent-adolescent relationships on illness adherence behaviours during the transition to self-management.</p> <p>Multiple countries</p>	<p>K = 9 studies.</p> <p>Characteristics Range of sample size (n) in included studies:</p> <ul style="list-style-type: none"> • Adolescents, n=11 – 200 • Adolescent-parent dyads, n=10 – 150 • Parents, n=15 – 62 ○ Parent-child opinions were included to understand the process adolescents underwent as they transitioned to self-management for chronic illness 	<p>Recruitment Not applicable.</p> <p>Data collection Authors conducted a systematic literature search of 3 online databases for qualitative, quantitative and mixed-methods studies published in or before June 2017.</p> <p>Analysis Data were extracted according to PRISMA guidelines. No critical appraisal of included studies was performed.</p>	<ul style="list-style-type: none"> • Acknowledging the voice of children and young people: The importance of hearing the child's views first hand • Parent/carer roles: Experiences of parent/carer support and involvement
<p>Taylor 2010</p> <p>Study design Semi-structured interviews</p> <p>Aim of the study To explore the views of children and their parents/carers regarding their involvement in paediatric consultations.</p> <p>North London and Northampton, UK</p>	<p>N=43 children, young people and parents</p> <ul style="list-style-type: none"> • only the views of n=20 children and young people were included in this review <p>Characteristics Median age 10 years (range 7-16 years)</p> <p>Gender of child (M/F): 5/15</p>	<p>Recruitment Consecutive sampling of families attending 1 of 2 paediatric in- and out-patient clinics</p> <p>Data collection Semi-structured interviews with topic guide.</p> <p>Analysis Thematic framework analysis.</p>	<ul style="list-style-type: none"> • Acknowledging the voice of children and young people: The importance of hearing the child's views first hand • Parent/carer roles: Experiences of parent/carer support and involvement • Parent/carer roles: Variation in children and young people's abilities, confidence and communication skills
<p>Walsh 2011</p> <p>Study design Semi-structured interviews</p> <p>Aim of the study To explore young offenders' views of their mental health needs, their history of support and preferences for future support,</p>	<p>N=44 young people (completed a questionnaire)</p> <ul style="list-style-type: none"> • n=6 young people included in this review (were interviewed) <p>Characteristics Age (range): 13-17 years</p> <p>Gender (M/F): 4/2</p>	<p>Recruitment Purposive sampling of mental health services in Suffolk.</p> <p>Data collection Semi-structured interviews informed by earlier questionnaires.</p> <p>Analysis Practical thematic analysis.</p>	<ul style="list-style-type: none"> • Acknowledging the voice of children and young people: The value placed on privacy • Acknowledging the voice of children and young people: The importance of hearing the child's views first hand • Parent/carer roles: Experiences of

Study	Participants	Methods	Themes
and their opinions as to what the barriers are in accessing services effectively. Suffolk, UK			parent/carer support and involvement

1 *F: female; K: number of studies; M: male N/n: number*

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

4 **Quality assessment of studies included in the evidence review**

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

8 Main theme 1: Acknowledging the voice of children and young people

- 9 • Sub-theme 1.1: The value placed on privacy. The overall confidence in this sub-theme
10 was judged to be very low.
- 11 • Sub-theme 1.2: The importance of hearing the child's views first hand. The overall
12 confidence in this sub-theme was judged to be very low.

13 Main theme 2: Parent/carer roles

- 14 • Sub-theme 2.1: Experiences of parent/carer support and involvement. The overall
15 confidence in this sub-theme was judged to be very low.
- 16 • Sub-theme 2.2: Variation in children and young people's confidence and communication
17 skills. The overall confidence in this sub-theme was judged to be very low.

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

20 **Evidence from reference groups and focus groups**

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

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

Age groups	<ul style="list-style-type: none"> • <7 years • 7-11 years • 11-14 years
Areas covered	<ul style="list-style-type: none"> • The role of parents and carers • Other people who can help children and young people
Illustrative quotes	<ul style="list-style-type: none"> • 'I want to make own choices but also need help. Need to make joint decisions' • 'I don't know what to do about my health, so my parents tell me what to do, what to eat etc.' • 'Sometimes might feel like you're in a cage... I don't want them to take control, but sometimes you might feel insecure so you will need your parents to take control then' • Who could help you make decisions about your health?

- 'Parents'
- 'Adult siblings'
- 'Family friends you trust'
- 'Dogs'
- 'Nanna'
- 'Psychologist'
- 'Priest'

1 See the full evidence summary in appendix M.

2 Evidence from national surveys

3 The grey literature review of national surveys of children and young people's experience
4 provided additional evidence for this review. A summary of the findings is presented in Table
5 4.

6 Table 4: Summary of the evidence from national surveys

National surveys	<ul style="list-style-type: none"> • 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 • National Children's Bureau. Listening to children's views on health provision 2012
Areas covered	<ul style="list-style-type: none"> • Age difference in relation to parental involvement • Handover of care for young people with disabilities
Key findings	<ul style="list-style-type: none"> • One young person felt that, if she was younger, she would have preferred her parents to talk to her about the diagnosis rather than the doctor • Young people with disabilities recommended that, as the young person reaches adolescence, the clinician should explore with the family the formal handing over to the young person of their own diagnosis

7 See the full evidence summary in appendix N.

8 Economic evidence

9 Included studies

10 A systematic review of the economic literature was conducted, but no studies were identified
11 which were applicable to this review question. A single economic search was undertaken for
12 all topics included in the scope of this guideline. See supplementary material 6 for details.

13 Excluded studies

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

16 Summary of studies included in the economic evidence review

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

18 Economic model

19 No economic modelling was undertaken for this review because the committee agreed that
20 other topics were higher priorities for economic evaluation.

1 The committee's discussion of the evidence

2 Interpreting the evidence

3 *The outcomes that matter most*

4 This review focused on the preferences of children and young people in relation to the
5 involvement of parents or carers in their healthcare and in decisions relating to their
6 healthcare. To address this issue, the review was designed to include qualitative data, and
7 as a result, the committee could not specify in advance the data that would be located.
8 Instead, they identified the following main themes to guide the review:

- 9 • Child's or young person's understanding (or lack thereof) of condition or impact of
10 potential treatments
- 11 • Differing needs relative to the setting, stage of healthcare
- 12 • Feeling actively involved in healthcare and related decisions (feeling of agency)
- 13 • Impact of child's or young person's condition on their parents' or carers' emotions and its
14 effect on the latter's decision making
- 15 • Influence of child's or young person's personal or parental/carer circumstances
- 16 • Opportunity and being able to articulate for self-advocacy
- 17 • Sharing decision making with parents/carers

18 The evidence review provided data relating to most themes set out in the protocol, and the
19 committee were able to make a number of recommendations in relation to these. Additional
20 themes which emerged from the data were related to privacy.

21 *The quality of the evidence*

22 The evidence was assessed using GRADE-CERQual methodology, and the overall
23 confidence in the findings was very low. The sub-themes were generally downgraded
24 because of methodological limitations of the included studies, assessed using the Critical
25 Appraisal Skills Programme (CASP) checklist. Concerns included unclear recruitment
26 strategies, lack of reflexivity and insufficient rigour during data analysis. The evidence was
27 also downgraded due to the coherence in the study findings, as some findings were a
28 combination of several but related themes. Sub-themes supported by the systematic review
29 were downgraded due to relevance as it included the views of parents and healthcare
30 professionals, as well as participants and therefore the overall population was aged between
31 16 and 48 years (Lerch 2019). However, the study was included because the findings
32 identified were clearly supported by evidence from those participants aged under 18 years.
33 Finally, sub-themes were downgraded for adequacy of data, as some studies only
34 contributed relatively thin data to findings.

35 *Benefits and harms*

36 There was evidence from the systematic review that children and young people had varying
37 preferences regarding their parents' or carers' involvement in their healthcare. Generally,
38 children and young people wanted their own voice to be heard, some said they would be
39 more likely to have an open and honest discussion when their parents or carers were not
40 present, and some had concerns about confidentiality when their parents or carers were
41 present. However, children and young people did appreciate their parents' or carers'
42 involvement or support, as long as it was not over-bearing. The evidence showed that the
43 extent of involvement may depend on a number of factors including the quality of the
44 relationship with parents or carers and the confidence of the children or young people, which
45 in turn may depend on their age, maturity and communication skills. Based on this evidence
46 the committee therefore made recommendations that all children should be given

- 1 opportunities to express their opinions independently, and should be asked how much they
2 wanted their parents or carers to be involved.
- 3 The committee were aware that some parents and carers may not provide their children with
4 enough information or may not discuss healthcare decisions with them. The committee
5 therefore made a recommendation that parents or carers should be encouraged to discuss
6 the extent of their involvement with their children, and that children should be encouraged to
7 develop confidence in making decisions for themselves.
- 8 The committee were aware from their own knowledge and experience that children and
9 young people's need or wish to have their parents or carers involved would vary from day to
10 day – this could depend on what the appointment concerned, how serious the medical
11 condition was, and whether any procedures such as injections were involved. The committee
12 therefore made a recommendation stating this so that it was clear that the discussion about
13 involvement of parents or carers needed to be ongoing and not a one-off conversation.
- 14 The committee discussed the fact that the recommendations are related to support from
15 parents or carers, but that some children or young people (for example care-leavers,
16 unaccompanied migrants) did not always have parents or carers who they could rely on for
17 support. There may also be children and young people whose parents or carers are unable
18 or unwilling to provide support. The committee recognised that in these situations, healthcare
19 professionals would have a responsibility to ensure other sources of support (for example
20 social workers or advocates) were available.
- 21 The committee discussed the potential harms identified by the evidence and from their
22 recommendations. Although the evidence and recommendations focused on the fact that
23 most children want their voices to be heard independently from their parents or carers, the
24 committee discussed that some children and young people may feel pressurised to be seen
25 alone, even when they may not want to be.
- 26 The committee also discussed that parents or carers might withhold information from children
27 and young people, or pass on information that is coloured by their own understanding or
28 experiences, which could lead to healthcare being framed in a negative way for their
29 children.
- 30 The committee discussed that seeing children or young people without their parents would
31 mean that chaperones may be needed and that safeguarding would always need to be
32 prioritised.
- 33 The committee discussed the evidence from the focus groups and reference groups. In all
34 age groups (4 to 7 years, 7 to 11 years and 11 to 14 years) there was a mixture of views on
35 parental involvement, with some children and young people wanting parents and carers to
36 attend appointments and make decisions, while others thought it was easier to see the
37 doctor alone, and that they should be able to make their own decisions. Even some of the
38 youngest children expressed a preference to see a doctor on their own, although others said
39 this would be scary and they wanted someone to be with them. The committee agreed that
40 this evidence backed up the evidence from the systematic review, and that all children
41 (however young) should be given the opportunity to express their own opinions, but that they
42 should also be asked about how much they wanted their parents or carers involved so this
43 could be an individualised decision.
- 44 There was a very small amount of evidence from the grey literature review of national
45 surveys – the committee agreed that this reinforced the information from the systematic
46 review that age impacted on the preferred amount of involvement of parents and carers.

1 Cost-effectiveness and resource use

2 There was no existing economic evidence for this review. The committee discussed that
3 more healthcare professionals' time may be required to implement recommendations in this
4 area. In practice, this may require longer consultation times to discuss parents' or carers'
5 involvement and to see children or young people with their parents or carers, and then
6 separately. However, the overall view was that the recommendations in this area reflect
7 current practice for most services and would have only modest resource implications. These
8 are likely to be justified as they will lead to improvements in children's and young people's
9 experience of care and potentially their quality of life. If children are seen separately from
10 their parents or carers this might necessitate the use of chaperones. Although these were
11 likely to be readily available in settings such as hospital wards and clinics, other settings may
12 not be able to provide chaperones easily, and this may require extra resources, however,
13 chaperone provides safeguards and the committee viewed these as an essential part of the
14 process.

15 Recommendations supported by this evidence review

16 This evidence review supports recommendations 1.1.2 to 1.1.5 and 1.5.1 to 1.5.5 in the
17 NICE guideline.
18

1 **References**

2

3 **Harper 2014**

4 Harper, B., Dickson, J. M., Bramwell, R., Experiences of young people in a 16-18 Mental
5 Health Service, *Child and Adolescent Mental Health*, 19, 90-96, 2014

6 **Lerch 2019**

7 Lerch M F., Thrane S E., Adolescents with chronic illness and the transition to self-
8 management: A systematic review. *Journal of Adolescence*, 72, 152–161, 2019

9 **Taylor 2010**

10 Taylor, S., Haase-Casanovas, S., Weaver, T., Kidd, J., Garralda, E. M., Child involvement in
11 the paediatric consultation: a qualitative study of children and carers' views, *Child: Care,
12 Health and Development*, 36, 678-685, 2010

13

14 **Walsh 2011**

15

16 Walsh, J., Scaife, V., Notley, C., Dodsworth, J., Schofield, G., Perception of need and
17 barriers to access: The mental health needs of young people attending a Youth Offending
18 Team in the UK, *Health and Social Care in the Community*, 19, 420-428, 2011

19

1 Appendices

2 Appendix A – Review protocol

3 Review protocol for review question: How do children and young people want their parents or carers to be involved in their 4 healthcare and decisions about their healthcare?

5 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 want their parents or carers to be involved in their healthcare and decisions about their healthcare?
Objective	The aim of this review is to determine how children and young people want their parents or carers to be involved in their care and making care-related decisions, and the extent to which they want parents and carers to support them.
Searches	<p>The following databases will be searched:</p> <ul style="list-style-type: none"> • CCTR • CDSR • Embase • MEDLINE • MEDLINE IN-Process • PsycINFO <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:</p> <ul style="list-style-type: none"> • 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 the risk of bias • Standard exclusions filter (animal studies/low-level publication types) will be applied <p>For each search (including economic searches), the principal database search strategy is quality assured by a second information specialist using an adaptation of the PRESS 2015 Guideline Evidence-Based Checklist</p>
Condition or domain being studied	<ul style="list-style-type: none"> • Babies, children's and young people's experience of healthcare
Population	<ul style="list-style-type: none"> • People <18 years-old who have experience of healthcare <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"> ○ The baby or child of the parent or carer is under-5 years-old, or ○ 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. <p>Note: Studies where part of the population is <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"> • 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)
Comparator/Reference standard/Confounding factors	Not applicable
Types of study to be included	<ul style="list-style-type: none"> • Systematic reviews of qualitative studies • Studies using qualitative methods: focus groups, semi-structured and structured interviews, observations,

Field	Content
	<ul style="list-style-type: none"> • Surveys conducted using open-ended questions and qualitative analysis of responses <p>Note: Mixed methods 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>STUDY DESIGN</p> <ul style="list-style-type: none"> • Studies using quantitative methods only (including surveys that report only quantitative data) • Surveys using mainly closed questions or which quantify open-ended answers for analysis <p>TOPIC OF STUDY</p> <p>Studies on the following topics will also be excluded:</p> <ul style="list-style-type: none"> • Accessing non-NHS commissioned health promotion interventions • Views and experiences of healthcare professionals and service managers • Views and experiences of people reporting only on social care planning and shared decision making <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"> • Child abuse and maltreatment: <ul style="list-style-type: none"> ○ Child abuse and neglect (NG76) ○ Child maltreatment: when to suspect maltreatment in under 18s (CG89) • Community engagement <ul style="list-style-type: none"> ○ Community engagement (NG44) • Drug misuse in children and young people: <ul style="list-style-type: none"> ○ Alcohol: school-based interventions (PH7) ○ Alcohol-use disorders: diagnosis, assessment and management of harmful drinking and alcohol dependence (CG115) ○ Alcohol-use disorders: prevention (PH24)

Field	Content
	<ul style="list-style-type: none"> ○ Drug misuse prevention: targeted interventions (NG64) ● End of life care for infants, children and young people with life-limiting conditions: planning and management (NG61) ● Immunisations: reducing differences in uptake in under 19s (PH21) ● Oral health promotion: general dental practice (NG30) ● Physical activity and weight management: <ul style="list-style-type: none"> ○ Maternal and child nutrition (PH11) ○ Obesity prevention (CG43) ○ Physical activity for children and young people (PH17) ○ Weight management: lifestyle services for overweight or obese children and young people (PH47) ● Pregnancy, including routine antenatal, intrapartum or postnatal care: <ul style="list-style-type: none"> ○ Antenatal and postnatal mental health: clinical management and service guidance (CG192) ○ Antenatal care for uncomplicated pregnancies (CG62) ○ Intrapartum care for healthy women and babies (CG190) ○ Intrapartum care for women with existing medical conditions or obstetric complications and their babies (NG121) ○ Multiple pregnancy: antenatal care for twin and triplet pregnancies (CG129) ○ Postnatal care up to 8 weeks after birth (CG37) ○ Pregnancy and complex social factors: a model for service provision for pregnant women with complex social factors (CG110) ● Self-harm: <ul style="list-style-type: none"> ○ Self-harm in over 8s: long-term management (CG133) ○ Self-harm in over 8s: short-term management and prevention of recurrence (CG16) ● Sexual health and contraception <ul style="list-style-type: none"> ○ Contraceptive services for under 25s (PH51) ○ Sexually transmitted infections and under-18 conceptions: prevention (PH3) ○ Harmful sexual behaviour among children and young people (NG55) ● Smoking prevention: <ul style="list-style-type: none"> ○ Smoking: preventing uptake in children and young people (PH14) ○ Smoking prevention in schools (PH23)

Field	Content
	<ul style="list-style-type: none"> ○ Stop smoking interventions and services (NG92) ● The transition from children's to adults' services for young people using health or social care services (NG43)
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 BCYP are talking about 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"> ● Child's or young person's understanding (or lack thereof) of condition or impact of potential treatments ● Differing needs relative to setting, stage of healthcare (e.g. whether BCYP want their parents to be involved in certain discussions like lifestyle factors) ● Feeling actively involved in healthcare and related decisions (feeling of agency) ● Impact of child's or young person's condition on their parents or carer emotions and its effect on the latter's decision making ● Influence of child's or young person's personal or parental/carer circumstances (e.g. age, capacity to understand, biological parent, experience of the healthcare system, health status/condition, language barriers, physical, mental and emotional well-being [including mood]) ● Opportunity and being able to articulate for self-advocacy ● Sharing decision making with parents/carers

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"> • Accessing healthcare information (reviewed in RQ 2.1) • Advocacy and support (reviewed in RQ 3.3 and 3.4) • Communication with babies, children and young people, and their parents or carers, including issues regarding confidentiality, treatment etc. (reviewed in RQ 1s) • Using views and experiences of babies, children and young people to improve healthcare services (reviewed in RQ 5.1)
Secondary outcomes (important outcomes)	Not applicable
Data extraction (selection and coding)	<ul style="list-style-type: none"> • 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. • Duplicate screening will not be undertaken for this question. • Full versions of the selected studies will be obtained for assessment. Studies that fail to meet the inclusion criteria once the full version has been checked will be excluded at this stage. Each study excluded after checking the full version will be listed, along with the reason for its exclusion. A standardised form will be used to extract data from studies, 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.
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 Developing NICE guidelines: the manual 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"> • Extracted second-order study themes and related first-order quotes will be synthesised by the reviewer into third-order themes and related sub-themes. • 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.

Field	Content	
	<ul style="list-style-type: none"> 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 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"> <1-year-old (i.e. 364 days-old or less) ≥1 to <12 years-old (i.e. 365 days-old to 11 years and 364 days-old) ≥12 to <18 years-old (i.e. 12 years and 0 days-old to 17 years and 364 days old) <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	

Field	Content		
Anticipated completion date	07 April 2021		
Stage of review at the time of this submission	Review stage	Started	Completed
	Preliminary searches		<input checked="" type="checkbox"/>
	Piloting of the study selection process		<input checked="" type="checkbox"/>
	Formal screening of search results against eligibility criteria		<input checked="" type="checkbox"/>
	Data extraction		<input checked="" type="checkbox"/>
	Risk of bias (quality) assessment		<input checked="" type="checkbox"/>
	Data analysis		<input checked="" type="checkbox"/>
Named contact	<p>5a. Named contact National Guideline Alliance</p> <p>5b. Named contact e-mail Infant&younghealth@nice.org.uk</p> <p>5c. Organisational affiliation of the review 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.		

Field	Content	
Collaborators	Development of this systematic review will be overseen by an advisory committee who will use the review to inform the development of evidence-based recommendations in line with section 3 of Developing NICE guidelines: the manual . Members of the guideline committee are available on the NICE website: https://www.nice.org.uk/guidance/indevelopment/gid-ng10119/documents	
Other registration details	-	
Reference/URL for published protocol	https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42019152442	
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"> • notifying registered stakeholders of publication • publicising the guideline through NICE's newsletter and alerts • issuing a press release or briefing as appropriate, posting news articles on the NICE website, using social media channels, and publicising the guideline within NICE. 	
Keywords	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	[Provide any other information the review team feel is relevant to the registration of the review.]	
Details of final publication	www.nice.org.uk	

1 CASP: Critical Appraisal Skills Programme; CDSR: Cochrane Database of Systematic Reviews; CCTR/CENTRAL: Cochrane Central Register of Controlled Trials; GRADE-
2 CERQual: Grading of Recommendations Assessment, Development and Evaluation – Confidence in the evidence from reviews of qualitative research; NGA: National
3 Guideline Alliance; NHS: National Health Service; NICE: National Institute for Health and Care Excellence

1 Appendix B – Literature search strategies

2 Literature search strategies for review question: How do children and young people want their parents or carers to be involved in their healthcare and decisions about their healthcare?

5 Databases: Embase/Medline/PsycINFO

6 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 diet?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

#	Searches
112	102 not 111
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 psyclit 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 psyclit 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

#	Searches
154	73 and 153
155	154 not 130
156	155 not 129

1 Database: Cochrane Library

2 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*ediatic* 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

#	Search
38	MeSH descriptor: [Mental Health Services] explode all trees
39	MeSH descriptor: [Nutritionists] this term only
40	MeSH descriptor: [Occupational Therapy] this term only
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

#	Search
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
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

#	Search
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 Aug 2020
116	MeSH descriptor: [United Kingdom] explode all trees
117	(national health service* or nhs*):ti,ab,kw
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 (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,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

#	Search
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 Aug 2020

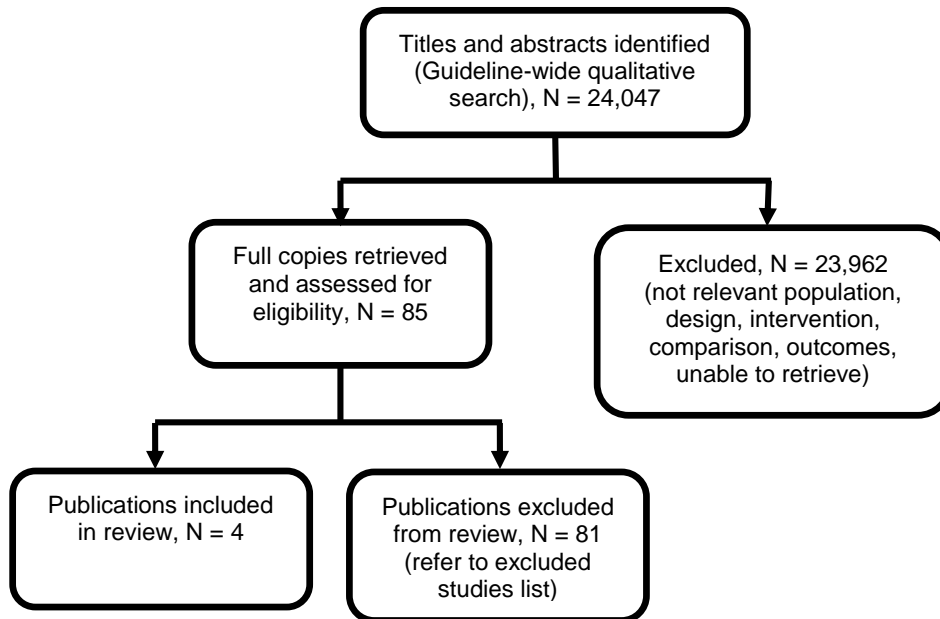
- 1
- 2
- 3

1 Appendix C – Clinical evidence study selection

2 Study selection for review question: How do children and young people want
3 their parents or carers to be involved in their healthcare and decisions about
4 their healthcare?

5 Figure 2: Study selection flow chart

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1 Appendix D – Clinical evidence tables

2 Evidence tables for review question: How do children and young people want their parents or carers to be involved in their 3 healthcare and decisions about their healthcare?

4 Table 6: Evidence tables

Study details	Participants	Methods	Themes and findings	Limitations
<p>Full citation 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</p> <p>Country/ies where the study was carried out North West England, UK</p> <p>Study type Qualitative</p> <p>Aim of the study To explore young people's experiences of the newly-established 16-18 mental health services (16-18 MHS).</p> <p>Study dates</p>	<p>Sample size N=10 young people</p> <p>Characteristics Age: <ul style="list-style-type: none"> • 16 (n)=1 • 17 (n)=5 • 18 (n)=4 </p> <p>Gender (M/F): 3/7</p> <p>Ethnicity: All White-British</p> <p>Inclusion criteria Participants had to: <ul style="list-style-type: none"> • Have prior experience of CAMHS • Have a suitable current mental health status • Be available to participate • Have the mental capacity to consent </p>	<p>Setting 2 specialist NHS 16-18 MHS.</p> <p>Sample selection Purposive sampling. Potential participants were identified by key workers.</p> <p>Data collection Individual semi-structured interviews lasting an average of 45 minutes (ranged from 25-80 minutes). The interview schedule was designed according to prior literature on young people's experiences of 16-18 MHS and modified from another study that investigated the transition from childhood to adulthood. Questions focused on encouraging young people to reflect on their experiences of using 16-18 MHS, and the schedule was used flexibly to allow the young people to talk about areas that were important to them. Researchers used limited prompts to expand their views and experiences. The schedule was</p>	<p>Results summarised under the following themes:</p> <ul style="list-style-type: none"> • Acknowledging the voice of children and young people: Privacy <p>Findings</p> <p>All participants liked the option of a private consultation with their therapist. They were able to disclose more information without the fear of their parents finding out. Young people felt that parents could become over-involved in their healthcare, which lead to the perception that their healthcare services might prioritise their parent's views over their own. This can invalidate self-expression and reduce therapeutic progress.</p>	<p>Limitations (assessed using the CASP checklist for qualitative studies).</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? Yes. Interpretive phenomenological analysis used in order to deeply explore participants' personal experiences and views of a particular event. This approach does not make objective statements about analysed data.</i></p> <p><i>Q4: Was the recruitment strategy appropriate to the aims of the research? Yes. Researchers wanted to recruit a small number of homogenous participants. Key workers from 2 NHS 16-18MHS identified potential participants.</i></p>

Study details	Participants	Methods	Themes and findings	Limitations
<p>Not reported.</p> <p>Source of funding First author received support from the NHS as part of their Clinical Psychology training. No other funding reported.</p>	<p>Exclusion criteria Not reported.</p>	<p>piloted with 2 study participants to ensure relevance and ease of understanding. After review, data from these interviews was included with the final results.</p> <p>Data analysis Interpretative phenomenological analysis (designed to produce a rich idiographic analysis). Data were transcribed, and researchers were familiarised with the data by reading and re-reading. During this process, preliminary analytical findings were noted before line-by-line coding occurred to summarise findings and higher-order codes were identified. Emergent themes were used to determine emergent cluster themes for each participant. Throughout this process, original quotes from transcripts were identified. After themes had been determined for each participant, superordinate themes were identified across all participant interviews whilst continually being checked for coherence against the evolving analysis.</p>		<p>Reasons for non-participation given.</p> <p><i>Q5: Were the data collected in a way that addressed the research issue? Yes. Data collected via semi-structured interviews. Topic guide developed using previous literature and was piloted with 2 initial participants. Examples of questions are provided. The guide was applied flexibly to allow participants to introduce novel views and experiences. However, no mention of data saturation.</i></p> <p><i>Q6: Has the relationship between researcher and participants been adequately considered? No. No description of potential bias/influence between researcher and participants.</i></p> <p><i>Q7: Have ethical issues been taken into consideration? Yes. The study received ethical approval from the National Research Ethics Service. Informed consent obtained before interviews with a 2-week cooling off period to change their mind.</i></p> <p><i>Q8: Was the data analysis sufficiently rigorous? Yes. A very detailed description of analysis and how themes were derived from the raw transcripts. A section detailing</i></p>

Study details	Participants	Methods	Themes and findings	Limitations
				<p>the techniques used to mitigate bias in the analysis, including group discussion of themes, the independent researcher conducted an analysis audit at each stage. Contradictory data is presented and discussed where appropriate, and a good amount of data is presented to support the reported findings. However, no explanation of how the data presented were chosen from the original sample.</p> <p><i>Q9: Is there a clear statement of findings?</i> Yes. A good, detailed explanation of findings within the identified themes, with regular referral back to the original research question. An adequate discussion surrounding evidence both for and against the study's findings, as well as the credibility of findings.</p> <p><i>Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)</i> Can't tell. 1. Yes. Details how the study findings fit in with current literature and the UK population, and how they can be used to inform best practice. Ideas and directions for future research presented. 2. No. Interpretative phenomenological analysis is designed to produce rich data on a homogeneous sample. It is not designed to be generalizable.</p>

Study details	Participants	Methods	Themes and findings	Limitations
				<p><i>Overall judgement of quality: Minor concerns.</i></p> <p>Other information None.</p>
<p>Full citation Lerch, Matthew F., Thrane, Susan E., Adolescents with chronic illness and the transition to self-management: A systematic review. <i>Journal of Adolescence</i>, 72, 152-161, 2019</p> <p>Ref Id 989439</p> <p>Country/ies where the study was carried out Multiple countries</p> <p>Study type Systematic review</p> <p>Aim of the study To assess the impact of parent-adolescent relationships on illness adherence behaviours during the transition to self-management.</p>	<p>Sample size K=9 studies</p> <p>Characteristics</p> <p>Type of study:</p> <ul style="list-style-type: none"> • Qualitative (k)=3 • Quantitative (k)=5 • Mixed methods (k)=1 <p>• Range of sample size: Adolescents (n)=11 – 200</p> <p>• Parent/adolescent dyads (n)=10 – 150</p> <p>• Parents (n)=15 – 62</p> <p>○ Parent-child opinions were included to understand the process adolescents underwent as they transitioned to self-management for chronic illness</p> <p>Study country:</p>	<p>Setting Not applicable.</p> <p>Methodological details A systematic literature search of 3 online databases (The goal of this review was to create a synthesis of existing qualitative and quantitative data on this topic with results organized into themes). A systematic search of PubMed, Cumulative Index to Nursing and Allied Health Literature (CINAHL), and Web of Science were conducted from the earliest database records to early June 2017. Both authors collaborated to refine search terms and conduct database searches. The first author (ML) conducted abstract reviews and a full-text review if an abstract review was inconclusive. These findings were reviewed by the second author (ST). Both authors did full-text reviews of included articles. Discussion and a review of inclusion/exclusion criteria were utilized to resolve differences of opinion between authors. Out of 227 abstracts</p>	<p>Results summarised under the following themes:</p> <ul style="list-style-type: none"> • Acknowledging the voice of children and young people: The importance of hearing the child's views first hand, • Parent/carer roles: Experiences of parent/carer support and involvement <p>Findings</p> <p>3 types of medical-decision making were evaluated.</p> <ul style="list-style-type: none"> • Passive decision making – Defined as allowing the healthcare professionals to choose the plan of care. Preferred by 46% of adolescents. • Shared decision making – Defined as when the healthcare professionals supplied information and insight, collaborating with the family when deciding a treatment plan. Preferred by 37% of adolescents. 	<p>Limitations (assessed using the CASP checklist for systematic reviews).</p> <p>Q1: <i>Did the review address a clearly focused question?</i> Yes.</p> <p>Q2: <i>Did the authors look for the right type of papers?</i> Yes.</p> <p>Q3: <i>Do you think all the important, relevant studies were included?</i> Can't tell. 3 online key databases were used, and the search strategy was devised by authors. Reference lists of included studies and a search of the grey literature were not checked for relevant studies. No restrictions were placed on full-text or language of publication. No mention of personal contact with experts.</p> <p>Q4: <i>Did the review's authors do enough to assess quality of the included studies?</i> No. quality appraisal was reported</p> <p>Q5: <i>If the results of the review have been combined, was it</i></p>

Study details	Participants	Methods	Themes and findings	Limitations
<p>Study dates Search dates: Onset of the database - June 2017</p> <p>Source of funding Not reported.</p>	<ul style="list-style-type: none"> United States (k)=8 UK (k)=1 <p>Area of interest:</p> <ul style="list-style-type: none"> Adolescents with ongoing treatment regimens for chronic illness (k)=9 Adolescents with type 1 diabetes (k)=5 Decision making in adolescents with chronic illness (k)=1 <p>Ethnicity:</p> <ul style="list-style-type: none"> White 72.6% Black 12.3% Mixed or unreported 15.1% <p><i>Only 6 studies reported ethnicity.</i></p> <p>Inclusion criteria Studies had to:</p> <ul style="list-style-type: none"> Include adolescents <ul style="list-style-type: none"> Aged 10–19 years Diagnosed with a chronic illness Address ongoing illness management regimens Discuss parent-child relationships 	<p>screened, 32 full texts were included for the final review, and 9 studies met the inclusion criteria.</p> <p>Data analysis A systematic search of 3 online databases - PubMed, Cumulative Index to Nursing and Allied Health Literature (CINAHL), and Web of Science was conducted from the earliest database records to early June 2017. Both authors collaborated to refine search terms and conduct database searches, reviews of records. Any disagreements were discussed, and an agreement reached. Data were extracted from each study into a tool developed by the first author. Data on study purpose, intervention or measures, outcomes, study design, sample including sexes and ages of participants, illness diagnoses, key findings, and clinical significance were extracted and checked by the second author. While PRISMA guidelines were consulted, a review protocol was not utilized.</p> <p>Quality appraisal of included papers None was performed.</p>	<ul style="list-style-type: none"> Active decision making – Defined as the healthcare professional fulfilling a consultant role while the parent-adolescent dyad selects the care plan. Preferred by 17% of adolescents. <p>Adolescent independent disease management was improved with increased parental support. However, young people reported feeling resentful when they perceived parents as nagging and over-involved. This led to some participants to purposely skip therapy or treatments as a rebellion.</p> <p>Adolescent-parental conflict also affected the success of independent disease management in young people. Difficulties within this relationship were considered a barrier to independence. However, when children and young people built an open and honest line of communication with their parents about their healthcare, they increased the level of trust which supported the transition of care.</p>	<p><i>reasonable to do so?</i> No. Thematic analysis applied to the data, with a good description of the process of combining quantitative and qualitative data, but thin evidence base.</p> <p><i>Q6: What are the overall results of the review?</i> Can't tell. The table presented key characteristics of included studies, details on participant characteristics, study design, and summary of findings - 7 general themes identified. However, descriptions of design, context and qualitative findings were not detailed enough.</p> <p><i>Q7: How precise are the results?</i> Not applicable.</p> <p><i>Q8: Can the results be applied to the local population?</i> Can't tell. The review incorporates data from a wide range of settings and homogenous participants - chronic diseases. However, only 1 study was conducted in the UK. Seven were conducted in the USA, which has a very different healthcare system, where cost plays a large part to access, and this might influence one's ability to express needs.</p>

Study details	Participants	Methods	Themes and findings	Limitations
	<p>Exclusion criteria</p> <ul style="list-style-type: none"> • Primary diagnosis of a mental health condition • Article included children younger than adolescents • Article lacked peer review. 			<p>Q9: <i>Were all important outcomes considered?</i> Not applicable. Themes are driven by data.</p> <p>Q10: <i>Are the benefits worth the harms and costs?</i> Not applicable. Systematic review.</p> <p><i>Overall judgement of quality:</i> Moderate concerns.</p> <p>Other information PRISMA guidelines were consulted, but a review protocol was not utilized.</p>
<p>Full citation 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, <i>Child: care, health and development</i>, 36, 678-685, 2010</p> <p>Country/ies where the study was carried out North London and Northampton, UK</p> <p>Study type</p>	<p>Sample size N=43 participants (from 20 families)</p> <ul style="list-style-type: none"> • n=20 children and young people included in this review • n=17 mothers • n=5 fathers • (1 brother of a patient as interpreter) <p>Characteristics <i>Characteristics reported for children and young people only</i></p> <p>Median age=10 (range 7-16) years</p>	<p>Setting 2 paediatric units (1 in North London, 1 in Northampton).</p> <p>Sample collection A consecutive sampling of families attending participating clinics at 2 paediatric units. Written consent was obtained from the parents and then children.</p> <p>Data collection Semi-structured interviews with parents and children following paediatric consultations. A literature review was used to design an interview guide to study parental and child attitudes towards the child's involvement at various stages of the consultation.</p>	<p>Results summarised under the following themes:</p> <ul style="list-style-type: none"> • Acknowledging the voice of children and young people: The importance of hearing the child's views first hand • Parent/carer roles: Experiences of parent/carer support and involvement; • Parent/carer roles: Variation in children and young people's confidence and communication skills <p>Findings Children and young people believe that a full picture of a child's health can only be gained by hearing their first-hand views and experiences.</p>	<p>Limitations (assessed using the CASP checklist for qualitative studies).</p> <p>Q1: <i>Was there a clear statement of the aims of the research?</i> Yes.</p> <p>Q2: <i>Was a qualitative methodology appropriate?</i> Yes.</p> <p>Q3: <i>Was the research design appropriate to address the aims of the research?</i> Yes. No specific justification is given for qualitative research. Noted that there is a lack of research into paediatric communication, so gaining a better understanding of the family experience is a logical first step.</p>

Study details	Participants	Methods	Themes and findings	Limitations
<p>Qualitative</p> <p>Aim of the study To explore the views of children and their parents/carers to their involvement in paediatric consultations.</p> <p>Study dates Not reported.</p> <p>Source of funding This study was funded by a teaching research grant awarded by Imperial College London.</p>	<p>Gender (M/F): 5/15</p> <p>Ethnicity:</p> <ul style="list-style-type: none"> • n=12 White British • n=1 Black British • n=2 Black African • n=2 Pakistani • n= 2 Asian other • n=1 Mixed <p>Inclusion criteria Participants had to be:</p> <ul style="list-style-type: none"> • Aged 6-16 years • Fluent in English • Accompanied by at least 1 parent • Without learning disability • Well enough to participate in an interview <p>Exclusion criteria Not reported.</p>	<p>Questions were open-ended, with the script allowing for prompts and further exploration of any themes identified. The interview script was refined throughout the study process in response to emerging themes. Children were asked their views first in order to minimise bias from their parents.</p> <p>Data analysis Framework analysis. Interviews were audio-recorded and transcribed verbatim. One researcher read through all transcripts, immersing themselves in the information before the interviews were analysed using a thematic coding framework that was informed by the data. While being coded and charted, the range of responses and themes from each interview was noted. Child and parent answers were first analysed separately (to prevent any cross-over of codes) but charted together, allowing a family analysis to take place. All transcripts were read and analysed by 2 researchers, with another validating the methodology.</p>	<p>Additionally, asking children directly can enhance the child's sense of empowerment and reduce fear. 1 child mentioned that involving children in consultations can serve to reduce the burden of recall in parents.</p> <p>There were several suggestions about how parents and children could collaborate in a consultation, without the negative aspects commonly mentioned. One idea was that adolescents should be seen privately with their healthcare professional, before being seen with their parents. Another suggestion was to train parents in interviewing skills, with the hope that this might stop them over-involving themselves during appointments and allowing their child to take the lead during discussions.</p> <p>Age (both chronological and developmental) and communication skills of the child were identified as factors affecting their ability to be involved in consultations and decision making processes. For example, as children mature, they may wish to be involved in discussions and decisions about later stages of healthcare such as diagnosis and management. The concept of</p>	<p>Q4: <i>Was the recruitment strategy appropriate to the aims of the research?</i> Can't tell. Consecutive recruitment of families at paediatric (both in-patient and out-patient) units. Inclusion criteria well described and matched the aim of the study. However, inadequate information reported for demographic data and no discussion about response rates or non-responders.</p> <p>Q5: <i>Were the data collected in a way that addressed the research issue?</i> Can't tell. Semi-structured interviews were audio-recorded and transcribed. Data saturation was discussed and reached. However, there are several issues with data collection. The setting for data collection was not reported - unsure during reading whether interviews were conducted during the clinic visits or after. An interview guide was used and described as being informed by the literature, but no information given regarding the content. It is noted that the topic guide refined throughout the study but, again, no information was given regarding how. Children were interviewed in the presence of parent/guardian, which may have affected their responses.</p>

Study details	Participants	Methods	Themes and findings	Limitations
			<p>'feeling at ease' was also identified as influencing whether children wish to be involved in consultations.</p>	<p>Q6: <i>Has the relationship between the researcher and participants been adequately considered?</i> No. No description of potential bias/influence between researcher and participants.</p> <p>Q7: <i>Have ethical issues been taken into consideration?</i> Can't tell. Informed consent received from parents and child. Paper states that local research ethic committee approval was granted but no further information.</p> <p>Q8: <i>Was the data analysis sufficiently rigorous?</i> No. Description of the analysis process is very brief, with poor detail of how thematic analysis was utilised. No critical examination of the researcher's role in the process or techniques used to mitigate potential bias and influence during analysis. Contradictory data is not presented or discussed. However, an adequate amount of data was presented to support the reported findings.</p> <p>Q9: <i>Is there a clear statement of findings?</i> Yes. Good, detailed explanation of findings within the identified themes, with regular referral back to the original research question. Good discussion surrounding evidence</p>

Study details	Participants	Methods	Themes and findings	Limitations
				<p>both for and against the study's findings. Tables are used as a good visual description of the differing perspectives of professionals, parents and children throughout the different stages of consultation. Discussion around the credibility of findings.</p> <p>Q10: <i>Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)</i> Yes. 1. Yes. Details how the study findings fit in with current literature and the UK population, and how they can be used to inform best practice. Ideas and directions for future research are identified. 2. Yes. Demographic data show a wide range of participants, increasing transferability. The sample size is a concern, but a good size for a qualitative study.</p> <p><i>Overall judgement of quality:</i> Serious concerns.</p> <p>Other information Views of parents were also reported. However, due to the age of participants, these are outside of our protocol and, where possible, data has not been extracted.</p>
<p>Full citation Walsh, J., Scaife, V., Notley, C., Dodsworth,</p>	<p>Sample size N 44 young people completed a</p>	<p>Setting Mental health services in Suffolk, East of England.</p>	<p>Results summarised under the following themes:</p>	<p>Limitations (assessed using the <u>CASP checklist for qualitative studies</u>).</p>

Study details	Participants	Methods	Themes and findings	Limitations
<p>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</p> <p>Ref Id 910269</p> <p>Country/ies where the study was carried out Suffolk, UK</p> <p>Study type Qualitative</p> <p>Aim of the study To explore young offenders' views of their mental health needs, their history of support and preferences for future support, and their opinions as to what the barriers are in accessing services effectively.</p> <p>Study dates</p>	<p>questionnaire, of whom 6 young people were interviewed n= 6 young people included in this review</p> <p>Characteristics Age (range): 13-17 years</p> <p>Gender (M/F): 4/2</p> <p>Inclusion criteria Participants had to:</p> <ul style="list-style-type: none"> • Have completed questionnaire <p>Exclusion criteria Not reported</p>	<p>Recruitment details Target sample size of 66 participants with wide age-range was targeted to maximise the sample size and gain a representative distribution of views. Participants were recruited from the whole of the Suffolk geographical area.</p> <p>Data collection details All interview participants were aged between 13- and 17-years old. Interviews lasted 30–45 minutes and were structured around the responses the young people had given to their questionnaires. Interviews were tape-recorded.</p> <p>Analysis details Data were qualitatively analysed using a practical thematic analysis method.</p>	<ul style="list-style-type: none"> • Acknowledging the voice of children and young people: The value placed on privacy • Acknowledging the voice of children and young people: The importance of hearing the child's views first hand • Parent/carer roles: Experiences of parent/carer support and involvement <p>Findings Nature/quality of relationship with family, friends, and service professionals central to determining whether young offenders access services. Support from parents/carers sought only if they had 'good' relationship with them (e.g. trust them). Tension between need of young person to be 'grown up' and need for help. Confidentiality/privacy and continuity of care wanted.</p>	<p>Q1: <i>Was there a clear statement of the aims of the research?</i> Yes.</p> <p>Q2: <i>Was a qualitative methodology appropriate?</i> Yes.</p> <p>Q3 <i>Was the research design appropriate to address the aims of the research?</i> Yes. Qualitative design using interviews were used to explore who young people sought help from in the past in relation to any mental health or emotional difficulties, which they would be most likely to seek advice from if problems were experienced in the future, what the barriers might be, and what they understood about mental health problems.</p> <p>Q4: <i>Was the recruitment strategy appropriate to the aims of the research?</i> No. Details on recruitment strategy was not provided, suitable volunteers were identified and approached by caseworkers, suggesting selection bias. Caseload members targeted were screened by workers and considered not to be at risk of harm by participation. Forty-four young people completed and returned questionnaires, and six young people agreed to participate in a follow-up interview.</p>

Study details	Participants	Methods	Themes and findings	Limitations
<p>8-week-period in the summer of 2008</p> <p>Source of funding Grant from the Suffolk Youth Offending Service.</p>				<p>Q5: <i>Were the data collected in a way that addressed the research issue?</i> Yes. Semi-structured interviews were used, but no detailed information on interview guides</p> <p>Q6: <i>Has the relationship between the researcher and participants been adequately considered?</i> No. Descriptions of potential bias/influence between researcher and participants were not described.</p> <p>Q7: <i>Have ethical issues been taken into consideration?</i> Yes. A local University Ethics Committee granted ethical approval for the study. Legal guardian consent was obtained for each participant below 18 years.</p> <p>Q8: <i>Was the data analysis sufficiently rigorous?</i> Yes. Independent researchers developed themes and categories using an iterative approach; disagreements were resolved with consensus, and contrary statements were incorporated in the findings.</p> <p>Q9: <i>Is there a clear statement of findings?</i> Yes. The authors provide a clear discussion of results on structural barriers, poor</p>

Study details	Participants	Methods	Themes and findings	Limitations
				<p>communication and collaboration; supported by literature on broader UK mental health services.</p> <p>Q10: <i>Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)</i> Yes. 1. Yes. Details how the study findings fit in with current literature and the UK population, and how they can be used to inform best practice. Ideas and directions for future research presented. 2. Probably. Good population size for qualitative study and sample had a wide age range.</p> <p><i>Overall judgement of quality:</i> Moderate concerns.</p> <p>Other information None.</p>

CAMHS: Child and Adolescent Mental Health Service; F: Female; K: Number of studies; M: Male; MHS: Mental health service; N/n: Number; NHS: National Health Service

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4 **Appendix E – Forest plots**

5 **Forest plots for review question: How do children and young people want their** 6 **parents or carers to be involved in their healthcare and decisions about their** 7 **healthcare?**

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

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1 Appendix F – GRADE-CERQual tables

2 GRADE-CERQual tables for review question: How do children and young people want their parents or carers to be involved 3 in their healthcare and decisions about their healthcare?

4 Table 7: Evidence summary (GRADE-CERQual) for theme 1: Acknowledging the voice of children and young people

Study information		Description of review finding	CERQUAL Quality assessment				
No of studies	Design		Methodological limitations	Coherence of findings	Adequacy of data	Relevance of evidence	Overall confidence
Sub-theme 1.1: The value placed on privacy							
2 (Harper 2014, Walsh 2011)	Semi-structured interviews	Data from 2 studies showed that young people are concerned about the level of confidentiality offered in consultations, especially regarding parents. When young people have an option to see healthcare professionals alone, they are more likely to disclose more information without fear of parental over-involvement or judgement. <i>'... if I talk to [YOT worker] and then my mum's there and then- so she blurts everything out to my mum, right, then, you know ...' (Walsh 2011, page 425)</i>	Moderate concerns ¹	Minor concerns ²	Moderate concerns ³	No/very minor concerns	VERY LOW
Sub-theme 1.2: The importance of hearing the child's views first hand							
3 (Lerch 2019, Taylor 2010, Walsh 2011)	Semi-structured interviews and systematic review	Data from 3 studies shows that healthcare practitioners should endeavour to get views and experiences first hand from children and young people. Involving them in the consultation can increase a child's sense of empowerment and decrease the burden of parents having to remember events or symptoms. Most families	Serious concerns ⁴	Moderate concerns ⁵	Minor concerns ⁶	Moderate concerns ⁷	VERY LOW

Study information		Description of review finding	CERQUAL Quality assessment				
No of studies	Design		Methodological limitations	Coherence of findings	Adequacy of data	Relevance of evidence	Overall confidence
		believed a complete account of the illness could only be obtained if the child’s view is heard first-hand. Allowances should still be made for the different decision-making styles. Some children prefer passive decision-making, where healthcare professionals devise a care plan based in their expertise. Shared-decision making is another style which is a collaborative approach involving families making decisions as a unit. Alternatively, active decision making allows children to play a bigger role in the consultation and decision-making process. No quotes to support this finding.					

- 1 *1 Evidence was downgraded due to moderate concerns about methodological limitations as per CASP qualitative checklist*
- 2 *2 Evidence was downgraded due to minor concerns about coherence of the evidence, as 1 study did not specifically mention how the desire for privacy related to parental involvement in healthcare decisions*
- 3 *3 Evidence was downgraded for adequacy because studies together offered some rich data*
- 4 *4 Evidence was downgraded due to serious concerns about methodological limitations as per CASP qualitative checklist*
- 5 *5 Evidence was downgraded due to moderate concerns about the coherence of evidence, which included involving children in consultations and decision making*
- 6 *6 Evidence was downgraded for adequacy because studies together offered moderately rich data*
- 7 *7 Evidence was downgraded due to moderate concerns about the relevance of evidence as it contains a systematic review which includes views of children and young people, parents and health professionals from countries with different models of healthcare*
- 8
- 9

10 **Table 8: Evidence summary (GRADE-CERQual) for theme 2: Parent/carers roles**

Study information		Description of theme or finding	CERQUAL Quality assessment				
No of studies	Design		Methodological limitations	Coherence of findings	Adequacy of data	Relevance of evidence	Overall confidence
Sub-theme 2.1: Experiences of parent/carers support and involvement							

Study information		Description of theme or finding	CERQUAL Quality assessment				
No of studies	Design		Methodological limitations	Coherence of findings	Adequacy of data	Relevance of evidence	Overall confidence
3 (Lerch 2019, Taylor 2010, Walsh 2011)	Semi-structured interviews and systematic review	<p>Data from 3 studies shows that children and young people report mixed experiences of parent/carer support in the context of healthcare and related decision making. Good parent/carer support can allow children and young people to develop self-care behaviours in chronic disease management. However, children and young people can perceive this support as parents being overinvolved in healthcare which creates resentment and conflict in the relationship. Additionally, the quality of a child's relationship with their parent/carers impacts their willingness to confide in them and share decision making. Parent/carer acceptance (instead of nagging) and interview skills training for parents are potential mechanisms for increasing parent/carer support.</p> <p><i>'If the doctor would feel like they don't have enough to make them feel completely confident, then they shouldn't tell the child, maybe, like, ask the parent to tell the child or something' (Taylor 2010, page 681)</i></p>	Serious concerns ¹	Minor concerns ²	No/very minor concerns	Moderate concerns ³	VERY LOW
Sub-theme 2.2: Variation in children and young people's abilities, confidence and communication skills							
1 (Taylor 2010)	Semi-structured interviews	<p>Data from 1 study shows that there are variations between children that affect how much they want their parents to be involved in the healthcare decisions. Communication skills, age and maturity</p>	Serious concerns ¹	No/very minor concerns	Serious concerns ⁴	No/very minor concerns	VERY LOW

Study information		Description of theme or finding	CERQUAL Quality assessment				
No of studies	Design		Methodological limitations	Coherence of findings	Adequacy of data	Relevance of evidence	Overall confidence
		<p>can impact children and young's people's ability to participate in consultations. As children get older, they become more confident in taking an active role in their health journey.</p> <p><i>'A 4-year-old is not going to be able to give as detailed a description as perhaps I would or perhaps a 16-year-old would, but the child should always be asked' (Taylor 2010, page 680)</i></p>					

- 1 *1 Evidence was downgraded due to serious concerns about methodological limitations as per CASP qualitative checklist*
- 2 *2 Evidence was downgraded due to moderate concerns about the coherence of evidence, as it included contradictory findings about parents involving themselves in healthcare regimes*
- 3
- 4 *3 Evidence was downgraded due to moderate concerns about the relevance of evidence as it contains a systematic review which includes views of children and young people, parents and health professionals from countries with different models of healthcare.*
- 5
- 6 *4 Evidence was downgraded for adequacy because studies together did not offer rich data*
- 7
- 8

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

2 **Economic evidence study selection for review question: How do children and**
3 **young people want their parents or carers to be involved in their healthcare**
4 **and decisions about their healthcare?**

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

1 **Appendix H – Economic evidence tables**

2 **Economic evidence tables for review question: How do children and young people want their parents or carers to be**
3 **involved in their healthcare and decisions about their healthcare?**

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

5

1 **Appendix I – Economic evidence profiles**

2 **Economic evidence profiles for review question: How do children and young people want their parents or carers to be** 3 **involved in their healthcare and decisions about their healthcare?**

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

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1 **Appendix J – Economic analysis**

2 **Economic evidence analysis for review question: How do children and young**
3 **people want their parents or carers to be involved in their healthcare and**
4 **decisions about their healthcare?**

5 No economic analysis was conducted for this review question.

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1 Appendix K – Excluded studies

2 Excluded studies for review question: How do children and young people want their parents or carers to be involved in their healthcare and decisions about their healthcare?

5 Clinical studies:

6 Table 9: Excluded studies and reasons for their exclusion

Study	Reason for Exclusion
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 did not match protocol. Individual studies checked for inclusion.
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	Phenomenon of interest not in protocol - no themes relating to advocacy and support in healthcare, and views are very parent-centric
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
Actrn., Improving outcomes in mental health for children and families: a study of Enhanced Stepping Stones Triple P, Http://www.who.int/trialsearch/trial2.aspx?Trialid=actrn12618000981224 , 2018	Protocol for ongoing clinical trial
Ahuja, Alka S., Williams, Richard, Telling stories: Learning from patients' and families' experiences of specialist child and adolescent mental health services, <i>International Journal of Consumer Studies</i> , 34, 603-609, 2010	Population not in protocol - 15 parents/carers of patients aged 5-15. Patients only (jointly) participated in 2 of the interviews.
Alderdice, F., Gargan, P., McCall, E., Franck, L., Online information for parents caring for their premature baby at home: A focus group study and systematic web search, <i>Health Expectations</i> , 30, 30, 2018	Phenomenon of interest not in protocol - no themes relating to advocacy and support in healthcare
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 how children want their parents/carers to be involved in their healthcare
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
Allcock, D., Smith, K., Exploring parent views of community matrons, <i>Nursing Times</i> , 110, 21-23, 2014	Study design not in protocol - No qualitative data analysis performed
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> <i>Int J Integr Care</i> , 18, 14, 2018	Population of included studies did not match protocol. Individual studies checked for inclusion.
Allen, N., McFarlane, L., Shanahan, R., Bassett, E. Z. A., Wellcome home: The work of shelter, a charitable organisation in facilitating the discharge of children with medical	Conference abstract

Study	Reason for Exclusion
complexities (CMIC) at birmingham children's hospital, <i>Developmental medicine and child neurology</i> , 59 (Supplement 4), 76, 2017	
Anderson, L., Wilson, J., Williams, G., Cognitive Orientation to daily Occupational Performance (CO-OP) as group therapy for children living with motor coordination difficulties: An integrated literature review, <i>Australian occupational therapy journal</i> , 64, 170-184, 2017	Study design of included studies did not match protocol. Individual studies checked for inclusion.
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
Aranda, K., Coleman, L., Sherriff, N. S., Cocking, C., Zeeman, L., Cunningham, L., Listening for commissioning: A participatory study exploring young people's experiences, views and preferences of school-based sexual health and school nursing, <i>Journal of Clinical Nursing</i> , 27, 375-385, 2018	Phenomenon of interest not in protocol - no themes related to advocacy and support
Arenson, M., Hudson, P. J., Lee, N., Lai, B., The Evidence on School-Based Health Centers: A Review, <i>Lobal Pediatric HealthGlob</i> , 6, 2333794X19828745, 2019	Study design not in protocol - Narrative review.
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	Population and themes not in protocol - Any themes relating to advocacy and support were from parents of children aged 7-11.
Armstrong, V. G., Howatson, R., Parent-infant art psychotherapy: A creative dyadic approach to early intervention, <i>Infant mental health journal</i> , 36, 213-222, 2015	Study design not in protocol - No qualitative data analysis presented.
Ashcraft, L. E., Asato, M., Houtrow, A. J., Kavalieratos, D., Miller, E., Ray, K. N., Parent Empowerment in Pediatric Healthcare Settings: A Systematic Review of Observational Studies, <i>Patient</i> , 12, 199-212, 2019	Population not in protocol - Focuses on parental empowerment within healthcare decision-making rather than how children would like their parent's involved in their healthcare
Ashfield-Watt, P., Philips, A., Dale, P., Hale, M., McDowell, I., Exploring digital arts-based approaches that empower children and young people with Familial Hypercholesterolaemia (FH), <i>Atherosclerosis Supplements</i> , 28, e6, 2017	Conference abstract
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, 215-224, 2017	Phenomenon of interest not in protocol - No themes relating to how children want their parents/carers to be involved in their healthcare
Aston, Hermione Jane, An ecological model of mental health promotion for school communities: Adolescent views about mental health promotion in secondary schools in the UK, <i>International Journal of Mental Health Promotion</i> , 16, 289-307, 2014	Phenomenon of interest not in protocol - Mental health promotion within a secondary school curriculum.
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, <i>BMJ open</i> , 8 (3) (no pagination), 2018	Published protocol for ongoing trial
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, <i>JMIR Mental Health</i> , 5, e10067, 2018	Phenomenon of interest not in protocol - no themes relating to advocacy and support in healthcare

Study	Reason for Exclusion
Cavaleri, Mary A., Olin, S., Kim, Annie, Hoagwood, Kimberly E., Burns, Barbara J., Family support in prevention programs for children at risk for emotional/behavioral problems, <i>Clinical Child and Family Psychology Review</i> , 14, 399-412, 2011	Study design of included studies did not match protocol. Individual studies checked for inclusion.
Dale, H., Watson, L., Adair, P., Moy, M., Humphris, G., The perceived sexual health needs of looked after young people: findings from a qualitative study led through a partnership between public health and health psychology, <i>Journal of Public Health</i> , 33, 86-92, 2011	Phenomenon of interest not in protocol - Sexual health and contraception with no generalizable themes.
Daniels, Karen, Cultural agents creating texts: A collaborative space adventure, <i>Literacy</i> , 48, 103-111, 2014	Setting not in protocol - Early years compulsory education setting
Datt, C., Travers, M., Odell, C., Improving the hospital experience for young people (YP) with autism, <i>Archives of disease in childhood</i> , 102 (Supplement 1), A20, 2017	Conference abstract
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 themes relating to how children want their parents/carers to be involved in their healthcare
Davison, Jo, Zamperoni, Victoria, Stain, Helen J., Vulnerable young people's experiences of child and adolescent mental health services, <i>Mental Health Review Journal</i> , 22, 95-110, 2017	Phenomenon of interest not in protocol - no themes relating to how children want their parents/carers to be involved in their healthcare
Dawson, A., Jackson, D., The primary health care service experiences and needs of homeless youth: a narrative synthesis of current evidence, <i>Contemporary nurse</i> , 44, 62-75, 2013	Phenomenon of interest of included studies did not match protocol. Individual studies checked for inclusion.
Dublon, V. E., Green, S., Benitez-Castillo, M., Edwards, T., Leiva, A., The production of a diabetes information film, by young people who have diabetes, as a means of educating others, <i>Archives of disease in childhood</i> , 103 (Supplement 1), A166, 2018	Conference abstract
Dunn, V., O'Keeffe, S., Stapley, E., Midgley, N., Facing Shadows: working with young people to coproduce a short film about depression, <i>Research Involvement & Engagement</i> , 4, 46, 2018	Study design not in protocol - No qualitative data analysis presented
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 did not match protocol. Individual studies checked for inclusion.
Eaton, Kim, Ohan, Jeneva L., Stritzke, Werner G., Courtauld, Hannah M., Corrigan, Patrick W., Mothers' decisions to disclose or conceal their child's mental health disorder, <i>Qualitative health research</i> , 27, 1628-1639, 2017	Country: Australia
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 how children want their parents/carers to be involved in their healthcare
Edwards, D., Noyes, J., Lowes, L., Haf Spencer, L., Gregory, J. W., An ongoing struggle: A mixed-method systematic review of interventions, barriers and facilitators to achieving optimal self-care by children and young people with Type 1 Diabetes in	Phenomenon of interest of included studies did not match protocol. Individual studies checked for inclusion.

Study	Reason for Exclusion
educational settings, BMC pediatrics, 14 (1) (no pagination), 2014	
Ellis, J., Boger, E., Latter, S., Kennedy, A., Jones, F., Foster, C., Demain, S., Conceptualisation of the 'good' self-manager: A qualitative investigation of stakeholder views on the self-management of long-term health conditions, <i>Social Science and Medicine</i> , 176, 25-33, 2017	Population not in protocol – Participants all over 18 years old
Fargas-Malet, Montserrat, McSherry, Dominic, Pinkerton, John, Kelly, Greg, Home on a care order: Who the children are and what the care order is for, <i>Child & Family Social Work</i> , 22, 813-821, 2017	Phenomenon of interest not in protocol - no themes relating to advocacy and support in healthcare
Fasciano, K., Souza, P., Bielaczyc, A., Englander, S., Building connection and creating community through the development of a young adult cancer conference, <i>Psycho-Oncology</i> , 3), 191-192, 2014	Conference abstract
Fawcett, R., Porritt, K., Stern, C., Carson-Chahhoud, K., Experiences of parents and carers in managing asthma in children: A qualitative systematic review, <i>JB I Database of Systematic Reviews and Implementation Reports</i> , 17, 793-984, 2019	Population of included studies did not match protocol. Individual studies checked for inclusion.
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, <i>Journal of Family Nursing</i> , 19, 431-468, 2013	Population of included studies did not match protocol. Individual studies checked for inclusion.
Franck, L. S., Oulton, K., Bruce, E., Parental involvement in neonatal pain management: an empirical and conceptual update, <i>J Nurs Scholarsh</i> , 44, 45-54, 2012	Parental views of under 5s but poor proxy. Themes are developed around how parents want to be included in their children's care, rather than how they think their child would want them to be involved.
Giambra, B. K., Stiffler, D., Broome, M. E., An integrative review of communication between parents and nurses of hospitalized technology-dependent children, <i>Worldviews on evidence-based nursing / Sigma Theta Tau International, Honor Society of Nursing</i> , 11, 369-375, 2014	Population of included studies did not match protocol. Individual studies checked for inclusion.
Grealish, A., Tai, S., Hunter, A., Morrison, A. P., Qualitative exploration of empowerment from the perspective of young people with psychosis, <i>Clinical Psychology & Psychotherapy</i> , 20, 136-148, 2013	Phenomenon of interest not in protocol - no themes relating to how children want their parents/carers to be involved in their healthcare
Holley, S., Walker, D., Knibb, R., Latter, S., Lioffi, C., Mitchell, F., Radley, R., Roberts, G., Barriers and facilitators to self-management of asthma in adolescents: An interview study to inform development of a novel intervention, <i>Clinical and experimental allergy</i> , 48, 944-956, 2018	Phenomenon of interest not in protocol - no themes relating to how children want their parents/carers to be involved in their healthcare
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	Phenomenon of interest not in protocol - Qualitative analysis of goals set by patients rather than their views on/experiences with goal setting
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	Study design not in protocol - No qualitative data presented. Secondary analysis of goal themes devised by children to

Study	Reason for Exclusion
	build framework for outcomes measurements.
Kohut, Sara Ahola, Stinson, Jennifer, van Wyk, Margaret, Giosa, Lidia, Luca, Stephanie, Systematic review of peer support interventions for adolescents with chronic illness, <i>International Journal of Child and Adolescent Health</i> , 7, 183-197, 2014	Study design of included studies did not match protocol. Individual studies checked for inclusion.
Larkin, M., Boden, Z. V., Newton, E., On the Brink of Genuinely Collaborative Care: Experience-Based Co-Design in Mental Health, <i>Qualitative health research</i> , 25, 1463-1476, 2015	Study design not in protocol - Narrative description and reflection on study with no data presented.
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, <i>Adolescent Health, Medicine and Therapeutics</i> , 9, 121-135, 2018	Population not in protocol - Aged 13 - 24 years old (50% under 18 years) with no way of attaching themes to ages
Lester, H., Marshall, M., Jones, P., Fowler, D., Amos, T., Khan, N., Birchwood, M., Views of young people in early intervention services for first-episode psychosis in England, <i>Psychiatric Services</i> , 62, 882-887, 2011	Population not in protocol - Age 14-35 years (mean male age 21 years, mean female age 23) with no way of attaching themes to ages
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 how children want their parents/carers to be involved in their healthcare
Macdonald, K., Greggans, A., 'Cool friends': an evaluation of a community befriending programme for young people with cystic fibrosis, <i>Journal of Clinical Nursing</i> , 19, 2406-14, 2010	Phenomenon of interest not in protocol - no themes relating to advocacy or support
Mattacola, E., "They Think It's Helpful, but It's Not": a Qualitative Analysis of the Experience of Social Support Provided by Peers in Adolescents with Type 1 Diabetes, <i>International journal of behavioral medicine</i> , 27, 444-454, 2020	Phenomenon of interest not in protocol - No relevant type of support for young people
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	Population of included studies did not match protocol. Individual studies checked for inclusion.
McTavish, J. R., Kimber, M., Devries, K., Colombini, M., MacGregor, J. C. D., Wathen, N., MacMillan, H. L., Children's and caregivers' perspectives about mandatory reporting of child maltreatment: A meta-synthesis of qualitative studies, <i>BMJ open</i> , 9 (4) (no pagination), 2019	Population of included studies did not match protocol. Individual studies checked for inclusion.
Mehmood, A., Cammidge, S., Guy, E., Peckham, D., Duff, A., Evaluation of youth work support for teenagers and young adults with cystic fibrosis, <i>Journal of Cystic Fibrosis</i> , 17 (Supplement 3), S128, 2018	Conference abstract
Mitchell, Wendy, Parents' accounts: Factors considered when deciding how far to involve their son/daughter with learning disabilities in choice-making, <i>Children and Youth Services Review</i> , 34, 1560-1569, 2012	Phenomenon of interest not in protocol - no themes relating to how children want their parents/carers to be involved in their healthcare
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	Parental views of under 5's but poor proxy. Themes are developed around how parents want to be included in their children's care, rather than how

Study	Reason for Exclusion
	they think their child would want them to be involved.
Nightingale, R., Hall, A., Gelder, C., Friedl, S., Brennan, E., Swallow, V., Desirable Components for a Customized, Home-Based, Digital Care-Management App for Children and Young People With Long-Term, Chronic Conditions: A Qualitative Exploration, <i>Journal of medical Internet research</i> , 19, e235, 2017	Phenomenon of interest not in protocol - no themes relating to how children want their parents/carers to be involved in their healthcare
O'Neill, T., Wakefield, J., Fifteen-minute consultation in the normal child: Challenges relating to sexuality and gender identity in children and young people, <i>Archives of Disease in Childhood: Education and Practice Edition</i> , 102, 298-303, 2017	Study design not in protocol - Narrative review with 2 case studies included.
Oulton, K., Sell, D., Kerry, S., Gibson, F., What do children and young people with learning disabilities want from hospital services?, <i>Archives of disease in childhood</i> , 3), A84-A85, 2015	Conference abstract
Petrie, K., McArdle, A., Cookson, J., Powell, E., Poblete, X., 'Let us speak'-children's opinions of doctors, <i>Archives of Disease in Childhood</i> , 102 (Supplement 1), A200-A201, 2017	Conference abstract
Pini, S., Education mentoring for teenagers and young adults with cancer, <i>British journal of nursing (Mark Allen Publishing)</i> , 18, 1316-1319, 2009	Study design not in protocol - Description of the development/implementation of a unique learning mentor with illustrative quotes
Richardson, C., Paslakis, G., Men's experiences of eating disorder treatment: A qualitative systematic review of men-only studies, <i>Journal of psychiatric and mental health nursing</i> , 2020	Population of included studies did not match protocol. Individual studies checked for inclusion.
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, <i>Journal of Adolescent Health</i> , 365-381, 2018	Phenomenon of interest not in protocol - no themes relating to how children want their parents/carers to be involved in their healthcare
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, <i>British Journal of Learning Disabilities</i> , 43, 168-177, 2015	Country: Canada
Robinson, S., Children and young people's views of health professionals in England, <i>Journal of child health care : for professionals working with children in the hospital and community</i> , 14, 310-326, 2010	Publication dates of included studies did not match protocol. Individual studies checked for inclusion.
Rodrigues, S., Melchionda, V., Rodney, K., Coppens, K., Comparing children's and parents' perspectives on hospital care, <i>Archives of disease in childhood</i> , 1), A101, 2014	Conference abstract
Rossiter, C., Levett-Jones, T., Pich, J., The impact of person-centred care on patient safety: An umbrella review of systematic reviews, <i>International journal of nursing studies</i> , 109, 103658, 2020	Population of included studies did not match protocol. Individual studies checked for inclusion.
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
Scott, E., Dale, J., Russell, R., Wolke, D., Young people who are being bullied - do they want general practice support?, <i>BMC family practice</i> , 17, 116, 2016	Phenomenon of interest not in protocol - no themes relating to advocacy and support for healthcare

Study	Reason for Exclusion
Stafford, V., Hutchby, I., Karim, K., O'Reilly, M., "Why are you here?" Seeking children's accounts of their presentation to Child and Adolescent Mental Health Service (CAMHS), <i>Clinical child psychology and psychiatry</i> , 21, 3-18, 2016	Phenomenon of interest not in protocol - no themes relating to advocacy or support for healthcare
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, <i>Health expectations : an international journal of public participation in health care and health policy</i> , 2019	Scoping review: included studies checked for inclusion.
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, <i>BMC endocrine disorders</i> , 11 (no pagination), 2011	Study design of included studies did not match protocol. Individual studies checked for inclusion.
Troy, E., Doltani, D., Harmon, D., The role of a companion attending consultations with the patient. A systematic review, <i>Irish Journal of Medical Science</i> , 188, 743-750, 2019	Population not in protocol - Companions to adult patients only
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, <i>Journal of Genetic Counseling</i> , 23, 409-20, 2014	Parental views of under 5s but poor proxy. Themes are developed around how parents want to tell their child about medical information relating to genetic risks, rather than how and when children want to be informed of these.
Valentine, J. C., Leach, S. M., Fowler, A. P., Stojda, D. K., Macdonald, G., Families and schools together (FAST) for improving outcomes for children and their families, <i>Cochrane Database of Systematic Reviews</i> , 2019, 2019	Study design of included studies did not match protocol. Individual studies checked for inclusion.
Vasey, J., Smith, J., Kirschbaum, M., Chirema, K., Tokenism or true partnership: Parental involvement in the child's acute pain care, <i>Archives of disease in childhood</i> , 101 (Supplement 1), A189, 2016	Conference abstract
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, <i>Journal of Systematic Reviews and Implementation Reports</i> , 12, 204-283, 2014	Population of included studies did not match protocol. Individual studies checked for inclusion.
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, <i>Journal of pediatric oncology nursing : official journal of the Association of Pediatric Oncology Nurses</i> , 1043454220919711, 2020	Population of included studies did not match protocol. Individual studies checked for inclusion.

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2 Economic studies

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

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1 **Appendix L – Research recommendations**

- 2 **Research recommendation for review question: How do children and young**
- 3 **people want their parents or carers to be involved in their healthcare and**
- 4 **decisions about their healthcare?**
- 5 No research recommendations were made for this review question.

1 Appendix M – Evidence from reference groups and focus groups

2 Reference and focus group evidence for review question: How do children and young people want their parents or carers to be involved in their healthcare and decisions about their healthcare?

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

5 Table 10: Evidence from reference groups and focus groups

Age < 7 years	Age 7-11 Years	Age 11-14 years	Overall quality of the evidence
<ul style="list-style-type: none"> • ‘When I have my head cut open, my mum was there with me. It was nice because my mummy loves me’ • Would you want to talk to a doctor or nurse on your own? <ul style="list-style-type: none"> ○ ‘Yes because I think they are going to be very kind. If she was worried they would not be kind, she would want to be with someone else, but trust they will be kind.’ ○ ‘Yes, because your mum might interrupt’ ○ ‘Yes, because the doctor wouldn’t hurt me’ ○ Yes, because if it might hurt, our mums can always cuddle us’ ○ ‘It’s scary on your own’ ○ ‘No because I would feel scared and a bit lonely. I would want mummy and daddy with [me].’ 	<ul style="list-style-type: none"> • How do you want your parents to be involved in your healthcare? <ul style="list-style-type: none"> ○ ‘Let your parents come into appointments/injections with you’ ○ ‘Parents being allowed into appointments with you’ • Parents and carers should help you make decisions: <ul style="list-style-type: none"> ○ Agree: <ul style="list-style-type: none"> - ‘Good for them to choose for you’ - ‘Mum says I’m going to be fine’ - ‘You should get help to make your health decisions because you could be wrong’ - ‘I don’t know what I’m doing, if I think something is right, I ask my parents ‘is it right or wrong?’ and sometimes they tell me I’m wrong’ - ‘I want to make own choices but also need help. Need to make joint decisions’ ○ Unsure: 	<ul style="list-style-type: none"> • Parents/carers should help you make decisions: <ul style="list-style-type: none"> ○ Agree: <ul style="list-style-type: none"> - ‘Parents can help talk it through with you, they can help you make good decisions – point out the good things about your decisions and the bad things’ - ‘They can help explain it to us’ - ‘Easier to ask parents than doctors because you just trust your parents’ - ‘Parents made you, they should have a say in what happens – but this is just a say, not forcing you to have decisions’ ○ Disagree: – <ul style="list-style-type: none"> - ‘Sometimes having them involved makes it more difficult. You have to 	<ul style="list-style-type: none"> • Low

Age < 7 years	Age 7-11 Years	Age 11-14 years	Overall quality of the evidence
<ul style="list-style-type: none"> ○ 'I would like to go with someone because if I went on my own I would feel scared – would want my mummy, daddy and my brother' ○ 'Want my mum with me because what if a stranger came in and the doctor was in a different room? Wouldn't want to be left on my own if the doctor went out the room' ● I like it when doctors talk to my parents more than me: <ul style="list-style-type: none"> ○ Agree (7/18) <ul style="list-style-type: none"> - 'Because our parents might tell [the doctor] something important' - 'Because you don't want to be there all by yourself' - 'The doctor might be telling them something important and they will know' ○ Disagree (11/18) ● When I see the doctor I want my mum or dad to be with me: <ul style="list-style-type: none"> ○ Agree (11/15) <ul style="list-style-type: none"> - 'I feel comfortable because my mum is with me and I can sit on her lap' - 'I don't like it there when the doctors check my mouth so if I get scared, I need my mummy to help me with the 	<ul style="list-style-type: none"> - 'Don't know, sometimes I would and sometimes I wouldn't' - 'Parents have more experience – things can go wrong if forced' - 'I'm in the middle because you want to make your own choices but your parents do too, so you want to listen to them but you think you're right at the same time – and I don't know if they know the answer or not. Has to be a bit of me and a bit of them' ○ Disagree: <ul style="list-style-type: none"> - 'Will change when I get older, I have to learn to progress' ● Parents/carers should make decisions for you: <ul style="list-style-type: none"> ○ Agree: <ul style="list-style-type: none"> - 'Rather not do it myself, parents know what I need' - 'I don't know what to do about my health, so my parents tell me what to do, what to eat etc.' - 'This might change as I get older when I will feel more happy but now I want parents to help me, I might want them to make decisions for me when I get older too' - 'Sometimes might feel like you're in a cage... I don't want them to take control, but sometimes you might feel insecure so you will need your parents to take control then' - 'If you didn't like it or unsure, helpful for them to choose for you' 	<p>make your own mistakes. And they start nattering on about everything, so you don't get to make the choice in the end'</p> <ul style="list-style-type: none"> ● Parents/carers should make decisions for you: <ul style="list-style-type: none"> ○ Agree <ul style="list-style-type: none"> - 'In case you do something wrong" - 'I make loads of mistakes, so my mum picks me up and helps me going' ○ Unsure <ul style="list-style-type: none"> - 'We should make our own decisions but they should have an input on what happens' - 'Parents and the actual person it is happening to should have an equal say' - 'It is your choice, but if something is too complicated or if it will scare you but it will help you a lot, if it has to happen, but if it is just up to you, you might chose not to do it but it could be vital' ○ Disagree: <ul style="list-style-type: none"> - 'Because you should be able to make your own decisions' 	

Age < 7 years	Age 7-11 Years	Age 11-14 years	Overall quality of the evidence
<p>scared... and my daddy can help drop me off there'</p> <ul style="list-style-type: none"> - 'Makes me feel safe' <ul style="list-style-type: none"> o Disagree (3/15) - 'I want my friends to come and take care of me instead' 	<ul style="list-style-type: none"> o Unsure: <ul style="list-style-type: none"> - 'Sometimes it gets annoying so they make you do what you don't want to do' - 'They might not choose the best thing' o Disagree: <ul style="list-style-type: none"> - 'I know what's right and what's wrong, they make decisions, not what I want' - 'When I want to play and my dad says no so I take care of myself when I'm outside' - 'I like having independence, I want to do it on my own.' • Who should the healthcare professionals explain things to? <ul style="list-style-type: none"> o 'Explain to my parents' (x5) o 'Explain to me and my parents' (x5) o 'Explain things to me' (x2) • Who could help you make decisions about your health? <ul style="list-style-type: none"> o 'Mummy' o 'Daddy' o 'Someone in my class' o 'Friends' o 'Doctor' o 'Grandpa' o 'Dogs' o 'Nanna' 	<ul style="list-style-type: none"> - 'If I was two years younger, I would be more in agree [parents should make decisions for you] as two years ago I was only 9 and couldn't speak up for myself. In 2 years I have gained more confidence' - 'You develop a sense of individuality' - 'For some people it would have been important to make their own decisions at any age' - 'In difficult circumstances e.g. parent dying, it can be much harder to make decisions – or when decisions feel too big to make' <ul style="list-style-type: none"> • Who could help you make decisions about your health? <ul style="list-style-type: none"> o 'Parents' o 'Adult siblings' o 'Family friends you trust' o 'Teacher' o 'Grandparent' o 'Psychologist' o 'Priest' o 'Carers/guardians' o 'Health care worker' o 'Group leaders' o 'School nurse' 	

Age < 7 years	Age 7-11 Years	Age 11-14 years	Overall quality of the evidence
	<ul style="list-style-type: none"> • When I go and see the dentist, I like it when someone comes in with me <ul style="list-style-type: none"> ○ 3 agreed <ul style="list-style-type: none"> - 'I want my mum with me and she did it last time' - 'I don't like being alone and last time my mum came with me when I had a tooth out' - 'I don't like the dentist' • I like it when the doctors speak to my parents before they speak to me <ul style="list-style-type: none"> ○ 5 agreed <ul style="list-style-type: none"> - 'Because I want to know what the doctor is like first' ○ 5 disagreed <ul style="list-style-type: none"> - 'I would like to know what is happening' 	<ul style="list-style-type: none"> ○ 'First aiders' ○ 'Uncle and aunts' ○ 'NHS' 	

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1 Appendix N – Evidence from national surveys

2 Evidence from national surveys for review question: How do children and young people want their parents or carers to be 3 involved in their healthcare and decisions about their healthcare?

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

5 Table 11: Evidence from national surveys

Survey	Findings	Overall quality of the evidence
Care Quality Commission. Children and young people's inpatient and day case survey 2018	<ul style="list-style-type: none"> No relevant findings were identified for this question 	<ul style="list-style-type: none"> N/A
Picker Institute. Children and Young People's Patient Experience Survey 2018.	<ul style="list-style-type: none"> No relevant findings were identified for this question 	<ul style="list-style-type: none"> N/A
Picker Institute. Paediatric Emergency Department Survey 2015 and Children and Young People's Outpatient Survey 2015	<ul style="list-style-type: none"> No relevant findings were identified for this question 	<ul style="list-style-type: none"> N/A
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"> No relevant findings were identified for this question 	<ul style="list-style-type: none"> N/A
Opinion Matters. Declare your care survey 2018	<ul style="list-style-type: none"> No relevant findings were identified for this question 	<ul style="list-style-type: none"> N/A
Association for Young People's Health.	<ul style="list-style-type: none"> No relevant findings were identified for this question 	<ul style="list-style-type: none"> N/A

Survey	Findings	Overall quality of the evidence
Young people's views on involvement and feedback in healthcare 2014		
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"> No relevant findings were identified for this question 	<ul style="list-style-type: none"> N/A
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>AGE DIFFERENCE IN RELATION TO PARENTAL INVOLVEMENT:</p> <ul style="list-style-type: none"> 1 teenager reported that she would have felt differently about her parents' involvement when she was younger. <p>Quote:</p> <p>'I think it's really important that you can influence things that affect your care, because some things affect you but not others. I think it's important to take into consideration what each person wants. I feel that maybe if I'd been younger I would have preferred my parents to talk to me (about the diagnosis), rather than some doctor I didn't know.' (F15)</p>	<ul style="list-style-type: none"> Low
HM Inspectorate of Prisons. Children in Custody 2016-2017	<ul style="list-style-type: none"> No relevant findings were identified for this question 	<ul style="list-style-type: none"> N/A
National Children's Bureau. Listening to children's views on health provision 2012	<p>HANDOVER OF CARE FOR ADOLESCENT DISABLED YOUNG PEOPLE:</p> <ul style="list-style-type: none"> Disabled young people aged 15-21 recommended that, as the young person reaches adolescence, the clinician should explore with the family the formal handing over to the young person of their own diagnosis. 	<ul style="list-style-type: none"> Moderate
Picker Institute/NHS England/Bliss. Neonatal Survey 2014	<ul style="list-style-type: none"> No relevant findings were identified for this question 	<ul style="list-style-type: none"> N/A

Survey	Findings	Overall quality of the evidence
<p><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>		

1 N/A: not applicable

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