National Institute for Health and Care Excellence

FINAL

Babies, children and young people's experience of healthcare

[J] Improving experience of healthcare

NICE guideline NG204

Evidence reviews underpinning recommendations 1.6.1 to 1.6.5 and 1.9.9 and research recommendations in the NICE guideline

August 2021

Final

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

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Improving experience of healthcare

Review question

What factors are important to babies, children and young people to improve their experience of healthcare services? (Qualitative)

Introduction

There are many factors that influence a baby, child or young person's experience of healthcare. While some surveys in recent years have actively sought the views and opinions of children and young people, they are not routinely included in local or national experience surveys, priority is given to adults' experiences, or parents' views are often considered to be acceptable proxies. This means that chances are missed to improve experience of healthcare for this age group.

The aim of this qualitative review was to identify what factors are important to children and young people, and the parents or carers of babies and young children, when considering how their experience of healthcare could be improved. In particular, it was designed to highlight factors that had not been identified at the scoping stage and not covered by other review questions in the guideline.

Summary of the protocol

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

Table 1: Summary of the protocol

Population	• 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 ○ 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	Experience of healthcare, in particular factors important to babies, children and young people in order to improve their experience of healthcare services.
Primary outcomes	Themes identified from the focus groups will form the primary outcome, as well as themes identified from national qualitative surveys. The following themes from the literature search will be included (although additional themes may be identified): • Food provision at the healthcare facility • General ambience and security • Pain-related themes • Recognition of symptoms • Quality of life in general While we will attempt to draw out themes indicating which factors babies, children and young people consider the most

	important, this will require the evidence to explicitly state this in their findings.

For further details see the review protocol in appendix A.

Methods and process

This evidence review was developed using the methods and process described in Developing NICE guidelines: the manual. Methods for this review question are described in the review protocol in appendix A and the methods supplement.

Clinical evidence

Included studies

This was a qualitative review with the aim of:

- Understanding what factors are important to babies, children and young people for improving their experience of healthcare.

A systematic review of the literature was conducted using a combined search. Seven qualitative studies were included in this review: Ali 2017, Brady 2009, Carlton 2013, Fletcher 2011, Gibson 2012, Heath 2015 and Law 2020. Data collection methods included focus groups (Ali 2017), face-to-face interviews (Brady 2009, Carlton 2013, Heath 2015, Gibson 2012 and Law 2020) or a combination of both (Fletcher 2011). Three studies used an additional creative or art-based mode of collection alongside these methods (Brady 2009, Fletcher 2011 and Gibson 2012).

This review question was designed to find any issues important to babies, children and young people that had not been identified during scoping, or as part of the other reviews conducted for this guideline. As such, the themes that were identified included a variety of topics and do not fit into a common framework. It was decided that a thematic map was not the most appropriate way to present an overview of the findings. The following themes were identified through analysis of the included studies:

- Theme 1: Benefits and harms of a diagnosis
- Theme 2: Community connections
- Theme 3: Hospital food
- Theme 4: Pain management
- Theme 5: Physical appearance of healthcare staff
- Theme 6: Religion as a source of support
- Theme 7: Side-effects of treatment
- Theme 8: Healthcare workers’ uniforms
- Theme 9: Boredom while waiting

The included studies are summarised in Table 6.

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

Excluded studies

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

Summary of studies included in the evidence review

Summaries of the studies that were included in this review are presented in Table 6.

Table 2: Summary of included studies

Study	Population	Method	Themes
Ali 2017 **Study design** Focus groups **Aim of the study** To explore UK Pakistani young people's views of barriers and facilitators to accessing mental health services in Peterborough, as well designing actions to improve access to these services. Peterborough, UK	N=33 young people **Characteristics** Age (range): 11-19 years • It was not possible to establish how many participants were ≥18 years old. • Themes have been downgraded for relevance where applicable Gender (M/F): 17/16	**Recruitment** Recruited from local schools, madrasas (Islamic religious education institutions) and youth groups. **Data collection** Focus groups **Analysis** Framework approach	• Religion as a source of support • Community connections
Brady 2009 **Study design** Drawings and semi-structured interviews **Aim of the study** To explore inpatient children's views of what characteristics make good nurses and bad nurses, in order to inform nursing practice. Southeast England, UK	N=22 children **Characteristics** Age (range): 7- 12 years Gender (M/F): 11/11	**Recruitment** Participants recruited from inpatient hospital wards. **Data collection** Drawings and semi-structured interviews. **Analysis** Constant comparative approach based on grounded theory.	• Physical appearance of healthcare staff • Healthcare workers' uniforms
Carlton 2013 **Study design** Semi-structured interviews **Aim of the study** Overall, to develop a paediatric disease specific health related quality of life questionnaire for amblyopia (commonly	N=59 children **Characteristics** Mean age: 6 years 3 months (range 3 years 9 months - 9 years 11 months) Gender (M/F): 36/23	**Recruitment** Opportunistic recruitment after appointments at eye clinics. **Data collection** Semi-structured interviews. **Analysis** Thematic content analysis using Framework.	• Side-effects of treatment

Study	Population	Method	Themes
known as lazy eye). This paper reports on the identification of potential items for inclusion in the CAT-QOL (Child Amblyopia Treatment –Quality of Life) questionnaire. Sheffield, UK			
Fletcher 2011 **Study design** Draw and write/tell with individual interviews or focus groups **Aim of the study** To reflect children and young people's involvement in the development of a new undergraduate nursing curriculum and in service developments in 2 children's hospitals. South of England, UK	N=69 children and young people • Arm 1: n=61 • Arm 2: n=8 **Characteristics** *Arm 1* Age (n): • Pre-school: 8 • School age <11 years old: 28 • Young people >11 years old: 25 Gender (M/F): 25/36 *Arm 2* No demographics reported.	**Recruitment** • Arm 1: Families approached during hospital admission. • Arm 2: Contacted through Connexions. **Data collection** 'Draw and write/draw and tell technique. • Arm 1: Individual interviews • Arm 2: Focus groups **Analysis** Thematic analysis.	• Pain management
Gibson 2012 **Study design** Scrapbooking/diaries with interviews **Aim of the study** To explore the experience of children and their families regarding food intake and management of nutrition while receiving chemotherapy. London, UK	N=13 children **Characteristics** Age, (n): • 4-6 years: 5 • 7-12 years: 8 Gender (M/F): 5/8	**Recruitment** Eligible participants introduced to the research team by healthcare staff **Data collection** Scrapbooking or personal diaries with interviews. **Analysis** Inductive thematic analysis	• Hospital food
Heath 2015 **Study design** Semi-structured interviews	N=14 children and young people • Hospital outpatient: n=8	**Recruitment** Purposive sampling of families in waiting area of paediatric clinic.	• Boredom while waiting • Community connections

Study	Population	Method	Themes
Aim of the study To explore paediatric outpatient care as experienced by patients and parents, focusing on the impact of healthcare setting. Birmingham, UK	• Community clinic outpatient: n=6 **Characteristics** Not reported.	**Data collection** Semi-structured interviews. **Analysis** Descriptive phenomenology	
Law 2020 **Study design** Semi-structured interviews **Aim of the study** To understand young people's concept of mental health recovery. East Anglia and Greater Manchester, UK	N=23 young people • < 18 years: n=15 • > 18 years: n=8 **Characteristics** Age (years, n): • 14-17: 15 • 18-21: 5 • 22-25: 3 Gender (M/F/non-binary): 4/18/1	**Recruitment** Convenience sampling of 2 regional mental health services. **Data collection** Semi-structured interviews **Analysis** Thematic analysis	• Benefits and harms of a diagnosis

F: Female; M: Male; N/n: Number

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

Quality assessment of studies included in the evidence review

A summary of the strength of evidence (overall confidence), assessed using GRADE-CERQual is presented according to the main themes.

- Theme 1: Benefits and harms of a diagnosis. The overall confidence in this theme was judged to be very low.
- Theme 2: Community connections. The overall confidence in this theme was judged to be very low.
- Theme 3: Hospital food. The overall confidence in this theme was judged to be very low.
- Theme 4: Pain management. The overall confidence in this theme was judged to be very low.
- Theme 5: Physical appearance of healthcare staff. The overall confidence in this theme was judged to be very low.
- Theme 6: Religion as a source of support. The overall confidence in this theme was judged to be very low.
- Theme 7: Side-effects of treatment. The overall confidence in this theme was judged to be very low.
- Theme 8: Healthcare workers’ uniforms. The overall confidence in this theme was judged to be very low.

- Theme 9: Boredom while waiting. The overall confidence in this theme was judged to be very low.

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

Evidence from reference groups and focus groups

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

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

Age groups	• <7 years • 7-11 years • 11-14 years
Areas covered	• Factors important to babies, children and young people to improve their experience in healthcare services
Illustrative quotes	• 'I love games' • 'I like it feeling comfy' • 'I don't like the doctors because they have to do injections and vets have to do injections for your pets' • 'Experienced staff doing things right' • 'No needles' • 'Getting right prescription' • 'Avoid sensory overload' • 'Not bland' [about food] • 'Not being expected to do something you physically can't do'

See the full evidence summary in appendix M.

Evidence from national surveys

The grey literature review of national surveys provided additional evidence for this review. A summary of the findings is presented in Table 4.

Table 4: Summary of the evidence from national surveys

National surveys	• Care Quality Commission. Children and young people's inpatient and day case survey 2018 • Picker Institute/NHS England/Bliss. Neonatal Survey 2014 • 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
Areas covered	• Food and drink • Pain • Admissions to neonatal care
Key findings	• Perceptions about hospital food were mixed, although most young people and parents and carers of babies said they liked hospital food • When experiencing pain, most young people felt that staff did everything they could to help • Most parents and carers of babies in the neonatal unit reported that they were given enough support (generally, for breastfeeding and to formula fed the baby) and enough feeding equipment

	• Parents and carers of babies in the neonatal unit reported that they were able to see their baby as soon as they wanted, but they were not always able to take a photography of their baby

See the full evidence summary in appendix N.

Economic evidence

Included studies

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

Excluded studies

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

Summary of studies included in the economic evidence review

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

Economic model

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

The committee's discussion of the evidence

Interpreting the evidence

The outcomes that matter most

This review focused on the views and opinions of babies, children and young people about what factors would improve their healthcare experience. To address this issue, the review was designed to include qualitative data and as a result the committee could not specify in advance the data that would be located. Instead they identified the following main themes to guide the review, although the list was not intended to be exhaustive:

- Food provision
- General ambience and feeling of security
- Pain-related themes
- Recognition of symptoms
- Quality of life in general

This review found data on 2 of these themes (food provision and pain) but did not identify any evidence regarding recognition of symptoms or quality of life or feelings of security. Additional themes were identified including ‘Appearance of healthcare professionals and their uniforms’, ‘Religion as a source of support’, the ‘Benefits and harms of a diagnosis’, ‘Side-effects of treatments’, ‘Community connections’ and ‘Boredom while waiting’.

The committee were able to make a number of recommendations in relation to these themes.

The quality of the evidence

The quality of the evidence for this review was assessed using GRADE-CERQual. The quality of the methodology of the individual studies was assessed using the Critical Skills Appraisal Programme (CASP) checklist.

The overall quality of evidence was judged to be very low. Review findings were generally low quality because of the methodological limitations of the included studies, for example a lack of information on recruitment methods and lack of consideration of researcher’s biases in the analysis. The evidence was also downgraded due to a lack of coherence in the data, including themes that were identified in different contexts within the same study. Review evidence was downgraded for relevance because some themes were only described in certain study ages, studies were only investigating specific healthcare conditions, or they included participants over 18 years old. However, the main reason for downgrading evidence was due to lack of adequacy of data. Many themes only had 1 study, and these studies only contributed thin evidence.

Benefits and harms

The committee considered the results of this review in combination with the results from the corresponding quantitative review on this same topic. The committee noted that both reviews had identified a number of factors which children and young people considered were important to their healthcare experience, but which had not specifically been addressed by other review questions in the guideline. The committee therefore considered each of the factors in turn and discussed whether it reflected their own knowledge and experience of what children and young people see as important, whether it was necessary or possible to make recommendations, or whether the importance of the factor to children and young people could be addressed by making amendments to recommendations that had already been made.

The first factor identified in this review was the benefits and harms of a diagnosis. The committee noted that the evidence had shown that some children and young people said that being given a diagnosis felt like being labelled, but others felt the benefits of having a diagnosis (and therefore treatment where necessary) outweighed the potential harms. The committee agreed that children and young people should be informed about their diagnosis, but that this had already been included in the recommendations about information and therefore they did not need to make a separate recommendation.

The second factor identified in the review was community connections. The committee discussed that the recommendations they had made on access already suggested that it may be preferable to see children and young people in their community (for example at a school or youth centre) rather than in a clinical environment. Another aspect of the evidence from this review suggested that cultural sensitivity was important. The committee recognised its importance but agreed that this was already covered in their recommendations on communication, information, privacy and confidentiality, maintaining usual activities and access to healthcare and therefore it was not necessary to make separate recommendations on this.

The third factor identified was hospital food. The committee noted that this had also been identified as important in the quantitative part of this review. The committee agreed that poor food could impair a child or young person’s experience of healthcare and that good nutrition was important to healing and a healthy lifestyle. The committee therefore agreed to make a recommendation on the importance of balanced, healthy food. They noted from their own knowledge and experience that having a choice of food to appeal to different tastes was important and that menu options which had been developed in conjunction with children and young people was likely to increase the chances of child or young person being able to choose food that they could enjoy and that was nutritionally and culturally appropriate. The committee noted that stakeholder feedback from children and young people had identified that flexible availability of food was important, with snacks accessible outside scheduled meal-times. The committee therefore made a recommendation to state this. The committee also discussed breast-feeding as a separate issue. There was evidence from the national surveys that parents appreciated support to continue breastfeeding, and the committee were aware that support for breastfeeding in the first six weeks was covered in the NICE guideline on postnatal care, but that after this period, babies or mothers who needed to access healthcare, may still require support. The committee therefore added to their recommendation about food, that breast and bottle feeding should also be supported also.

The fourth factor identified was pain management. The committee agreed that adequate pain management was very important to healthcare experience and quality of life, but also recognised that it was not within the scope of this guideline to advise on specific strategies or treatments for pain. However, the committee agreed that the guideline could address the fear and anxiety about pain, and advise on strategies to reduce this, particularly as anxiety about injections had been mentioned on numerous occasions in the evidence from the reference and focus groups. The committee agreed that it was particularly important that children and young people were believed when they reported pain, and that pain was adequately assessed. Based on their knowledge and experience the committee therefore made recommendations to minimise fear and anxiety about pain.

The fifth and eighth factors identified in this review related to the physical appearance of healthcare staff and their uniforms and the committee considered these factors together. The evidence had identified that children and young people preferred staff to look professional and efficient, neat and clean, with names and identification badges. The committee discussed the role of uniforms for healthcare staff, and agreed that they did make it easier for children and young people (and their parents or carers) to identify staff, and that different colours of uniforms were helpful to allow different roles to be identified quickly. The committee discussed that some of the disadvantages of uniforms were that they could be frightening for some children and that less formal uniforms (for example, polo shirts) were worn in some settings to try and overcome this. The committee agreed that the ability to identify staff was the most important aspect, that wearing name badges was current practice, and that uniforms could also help with this. However, the committee were aware that the requirements and choice of uniform would vary greatly between settings, and so they included these as suggestions in a recommendation but did not agree to make a specific recommendation that uniforms should always be worn.

The committee agreed that some healthcare clothing such as gowns, masks, visors, or personal protective equipment (PPE) could be very frightening for children, and anything covering the face had the added disadvantage that children and young people could not recognise staff, could not see their facial expressions, or see if they were smiling. Face coverings may also hinder communication for all children and young people, but especially for those who rely on lip reading or facial cues. The committee agreed that it was important to highlight these issues in a recommendation.

The sixth factor was religious support. The committee discussed that this would vary greatly but that some children and young people may have some kind of religious, spiritual or cultural aspect to their life, and that in times of illness this may provide support. The committee therefore agreed that it was important to include this in the recommendations on maintaining usual activities, and expanded the recommendations they had already made to encompass this aspect.

The seventh factor was side-effects of treatment. The committee agreed that it was important to discuss this but noted that they had already included this in their recommendations on information, and therefore it was not necessary to make another recommendation.

The ninth and final factor was boredom while waiting. The committee noted that this had also been identified as important in the quantitative part of this review. The committee discussed that they had already made recommendations about the availability of toys and age-appropriate activities in the environment section of the guideline, and they therefore agreed to amend the wording of this recommendation to include the fact that it was important that children or young people were given options to occupy them while waiting for healthcare. The committee also noted that, based on the evidence from the quantitative review, they had already included recommendations in the information section about keeping people informed about waiting times.

In addition to the nine themes or factors identified by the systematic review of the literature, the committee reviewed the evidence from the focus and reference groups and the evidence from national surveys. The 4-7 years old focus groups had identified that being kept occupied while waiting was important, food and pain were mentioned briefly, and the children liked being able to identify healthcare staff by their uniforms or the fact that they had stethoscopes. The 7-11 and 11-14 year olds had identified a wider range of factors including food, pain, having procedures done quickly, efficiently and correctly by trained staff and getting the right diagnosis. The committee agreed that this evidence reinforced the evidence from the literature review and all these factors were already covered by their recommendations. The national surveys also identified that food and drink were areas where children and young people and their parents or carers were not always positive about, and 21% of children aged 8 to 15 years in one survey reported that their pain was not always dealt with satisfactorily. The committee agreed that this backed up the evidence from the literature review and was already covered in the recommendations they had made on these topics.

Cost effectiveness and resource use

There was no existing economic evidence for this review. The overall view was that the recommendations in this area (providing quality hospital food, reducing anxiety about pain, the physical appearance of healthcare staff, ensuring religious support) reflect current practice and are not expected to result in resource implications. The committee discussed that some recommendations may potentially require additional consultation time to implement, for example preparing children and young people for interventions or procedures, engaging in therapeutic play and distraction techniques. However, for most services, these would have only modest resource implications, if any, which are justifiable as such care is likely to lead to improvements in children’s and young people’s experience of healthcare and potentially their quality of life.

Recommendations supported by this evidence review

This evidence review supports recommendations 1.6.1 to 1.6.5 and 1.9.9 and the research recommendation on the factors that are important to babies, children and young people to improve their experience of healthcare.

References

Ali 2017

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Law 2020

Law, H., Gee, B., Dehmahdi, N., Carney, R., Jackson, C., Wheeler, R., Carroll, B., Tully, S., Clarke, T., What does recovery mean to young people with mental health difficulties?-"It's not this magical unspoken thing, it's just recovery", Journal of Mental Health, 2020

Review question

What factors are important to babies, children and young people to improve their experience of healthcare? (Quantitative)

Introduction

Babies, children and young people are not routinely included in healthcare experience surveys. It is not therefore possible to use this source to determine what factors will improve their experience of healthcare. While some information can be extrapolated from results of adult surveys, the factors important to those under 18 years may be very different to adults. This has been demonstrated in surveys that have found different responses from children and young people and from their parents or carers. Certain groups of babies, children and young people will also have specific needs and priorities (for example looked after children, young offenders, children with chronic illnesses, or those needing assistance to communicate).

The aim of this quantitative review is to identify what factors are important to children and young people, and the parents or carers of babies and young children, when considering how their experience of healthcare could be improved.

Summary of the protocol

See Table 5 for a summary of the Population, Intervention, Comparison and Outcome (PICO) characteristics of this review.

Table 5: Summary of the protocol (PICO table)

Population	• People <18 years old who have experience of healthcare • Studies that use the responses of parents or carers as proxies for their child will be included only if they are responding on behalf of their child or charge, and: ○ 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 healthcare as proxies for their child.
Intervention	Any regional or UK-wide survey or closed-question questionnaire that measures or rates which factors babies, children or young people judge to be important for improving their experience of healthcare.
Comparison	Not applicable
Outcome	**Critical** • Factors important to experience of healthcare

For further details see the review protocol in appendix A.

Methods and process

This evidence review was developed using the methods and process described in Developing NICE guidelines: the manual. Methods for this review question are described in the review protocol in appendix A and the methods supplement.

Clinical evidence

Included studies

This was a quantitative review with the aim of:

- Determining the important factors to improve healthcare experiences for babies, children and young people.

A systematic review of the literature was conducted. Two studies were included for this review: 1 was a regional survey of adolescent's healthcare preferences in an accident and emergency (A&E) unit (Bryans 2018) and 1 national survey of paediatric experiences as hospital outpatients (Hopwood 2011).

The included studies are summarised in Table 6.

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

Excluded studies

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

Summary of studies included in the evidence review

Summaries of the studies that were included in this review are presented in Table 6.

Table 6: Summary of included studies.

Study	Population	Survey	Outcomes
Bryans 2018 **Study design** Cross-sectional survey **Aim of the study** To determine the factors of emergency healthcare that are important to young people, and use these to inform future A&E services. UK	N=2,904 emergency department attendees Respondents: n=254 (216 questionnaires, 38 interviews) **Characteristics** Age in years [range (mean)]: 12-16 (13.8) Gender (M/F): 133/121	To determine the factors of emergency healthcare that are important to young people, and to use these to inform future A&E services. Questionnaires distributed to adolescents attending the emergency departments of Royal Hospital for Sick Children (12 years old) and The Royal Infirmary Edinburgh (13-16 years old).	Overall response rate: 8.8% Ranking of factors: • Cleanliness, feeling comfortable, clear explanation, staff communication, seen quickly, privacy, confidentiality, choice in treatment, treated by same doctor, treated with same age, entertainment
Hopwood 2011 **Study design** Cross-sectional survey **Aim of the study** To design a paediatric questionnaire	N=11,900 recent paediatric outpatients (n=850 from each of 14 NHS trusts) Respondents: n=3,783 questionnaires **Characteristics** Not reported	The study aimed to design a paediatric questionnaire to obtain reliable feedback from young people as hospital outpatients. Questionnaire was aimed at parents for patients aged 7 and under, and at children and young people themselves if aged 8 and over.	Overall response rate: 33% • Young people response rate: 32% • Parental response rate: 34% Overall experience of care Agreement with reported experience:

Study	Population	Survey	Outcomes
to obtain reliable feedback from young people as hospital outpatients. UK			• Waiting times, age-related activities, pre-appointment information, information on medicines, parking, food and drink, communication, involvement in decisions, privacy, cleanliness

A&E: Accident and Emergency; F: females; M: male; N: number; NHS: National Health Service

Summary of the evidence

Bryans 2018 reports on a regional survey that was conducted with young people (12-16 years old) attending two Edinburgh Accident and Emergency (A&E) departments. Questionnaires were distributed upon arrival to A&E and were completed in the waiting room. The results of 3 questions were presented in the paper.

For the first of the questions, young people were asked to score a list of factors from 1 to 5 on a Likert scale, according to their importance in affecting their healthcare experience (where 1 = least important, 5 = most important). The paper identified which factors were most important overall by adding together the percentage of respondents who selected either a 4 or 5 on the Likert scale. The results of this ranking are shown in Table 7.

Cleanliness was rated the most important factor in an A&E setting (94.8% rated this as 4 or 5). This was followed by feeling comfortable (91.2% rated 4 or 5), clear explanation (90.8% rated 4 or 5), staff communication (90.4% rated 4 or 5), seen quickly (89.6% rated 4 or 5), privacy (85.9% rated 4 or 5) and confidentiality (83.8% rated 4 or 5). Choice in treatment and treated by the same doctor were rated 4 or 5 by 62.4% and 50.2% of the young people respectively. The 2 factors with lowest importance for young people in an A&E setting were being treated with patients of the same age (25.8% rated 4 or 5) and availability of entertainment (17.0% rated 4 or 5).

Table 7: Importance of healthcare service factors for young people attending A&E

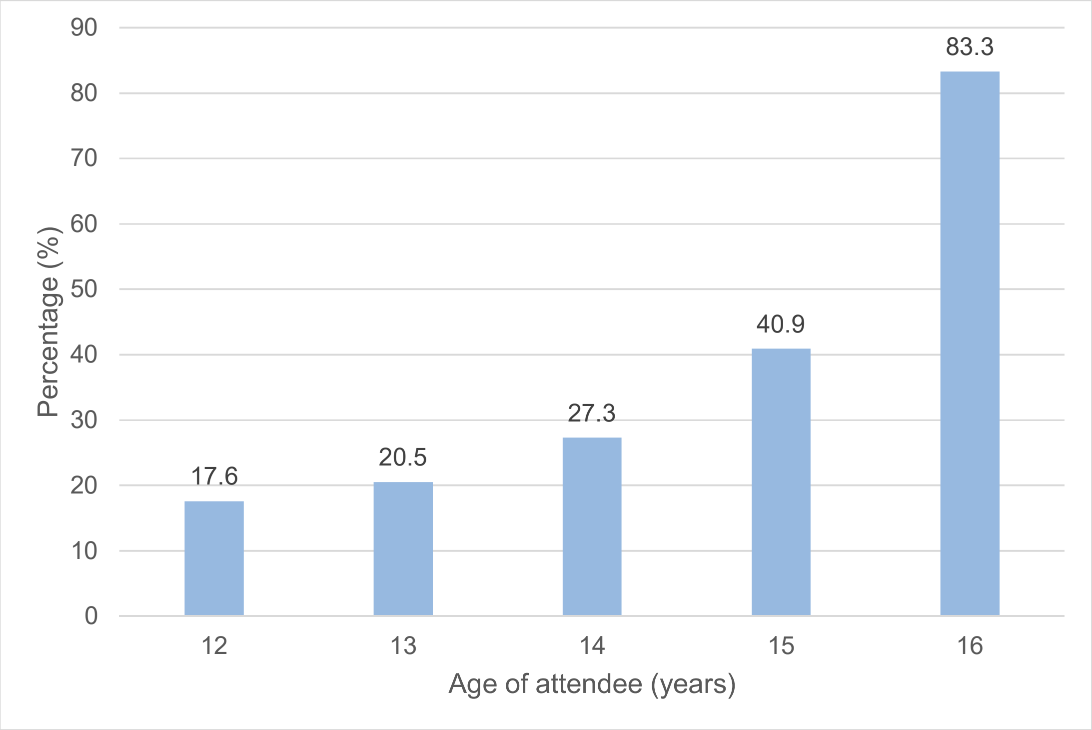
		Frequency (%)		
Factor	**n**	**Likert scale 4**	**Likert scale 5**	**Total, (scoring 4 or 5)**
Cleanliness	249	14.46	80.32	94.78
Feeling comfortable	249	25.30	65.86	91.16
Clear explanation	250	24.80	66.00	90.80
Staff communication	250	34.00	56.40	90.40
Seen quickly	251	20.32	69.32	89.64
Privacy	249	30.12	55.82	85.94
Confidentiality	247	21.46	62.35	83.81
Choice in treatment	250	33.20	29.20	62.40
Treated by same doctor	249	28.11	22.09	50.20
Treated with same age	248	12.50	13.31	25.81
Entertainment	247	12.15	4.86	17.01

A&E: Accident and Emergency; n: number

Source: adapted from Bryans 2018

The second question reported in the paper asked for young people's preference for being seen in a paediatric or adult setting. Many young people attending A&E did not have a preference, with 46.2% selecting the option 'Don't care'. Of the remaining respondents who did express a preference, there was a marked increase in the number who preferred to be seen in an adult setting with increasing age: 17.6% of 12 year olds attending A&E would prefer to be treated with adults, compared to 83.3% of 16 year olds. The trend (of those who expressed a preference) by age bands is shown in Figure 1.

Figure 1: Percentage of young people attending A&E who would prefer to be treated with the adult population

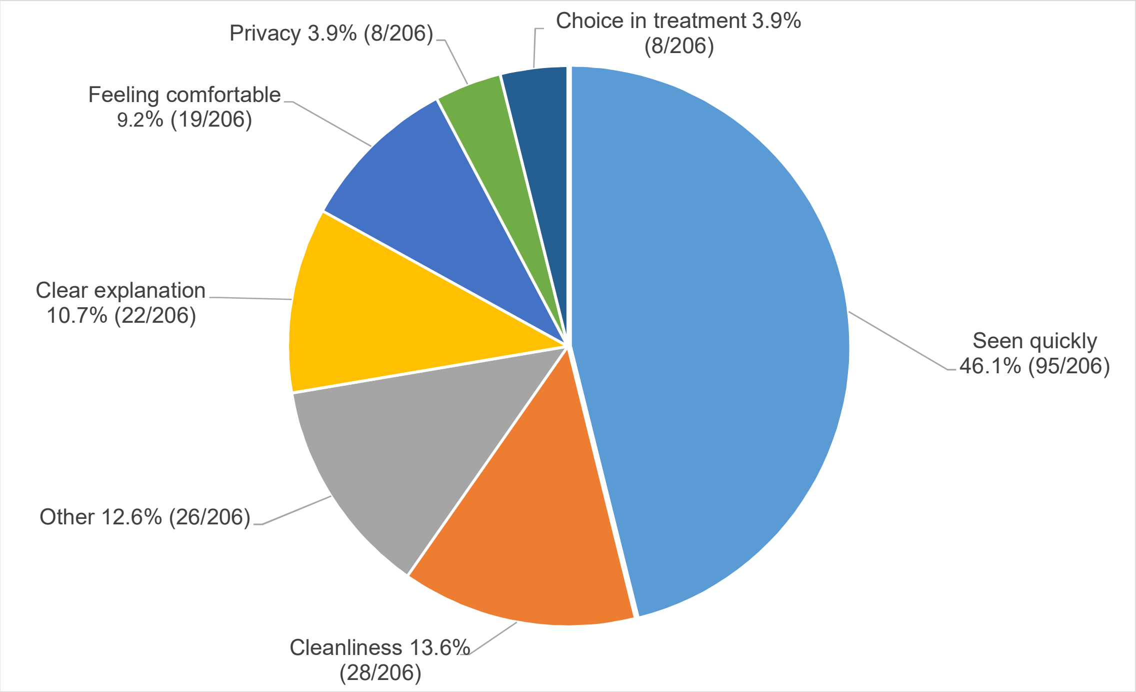


A&E: Accident and Emergency

Source: adapted from Bryans 2018

The third question reported in the paper asked young people 'What is the most important factor?' Young people could select only 1 factor that they deemed the most important to their healthcare experience when attending A&E. Of the 206 young people who answered this question, 46.1% of young people said that being seen quickly was the most important factor, followed by cleanliness (13.6%) and receiving a clear explanation (10.7%). Feeling comfortable was prioritised by 9.2% of the young people, and choice in treatment and privacy were the most important factors for 3.9% of young people. These results are shown in Figure 2. All other remaining factors selected by the young people were grouped together in the 'other' category but the paper does not report what factors contributed to the 'other' category.

Figure 2: Top 6 responses when young people attending A&E were asked to identify the single most important factor to their healthcare experience



A&E: Accident and Emergency

Source: adapted from Bryans 2018

The second study, Hopwood 2011 reported the results of a national young people outpatient survey. Questionnaires were posted to 850 recent outpatients aged 17 years and younger, at each of 14 NHS acute trusts in England. Questionnaires were aimed at the parents or carers of children aged 7 years or below or aimed at the outpatients themselves if aged 8 years or over.

The paper reports the percentage of respondents who rated the overall outpatient experience as good, although the exact terminology used differing between the parents' questionnaire and the children and young people's questionnaire. Overall, 96% of young people stated that they had been 'Looked after well or fairly well' and 95% of parents rating the care provided to their children as 'Excellent, very good or good'. See Table 8 for an overview of respondents who rated overall healthcare experience as good.

Table 8: Percentage of respondents to a posted outpatient questionnaire who rated overall healthcare experience as good

	Respondents (%)	
Overall care experience	**Young people**	**Parents**
Looked after well or fairly well	96	-
Care excellent, very good or good	-	95

Source: adapted from Hopwood 2011

The paper also reported negative experiences during outpatient care. For some questions the proportion of respondents reporting that negative experience was broken down into responses from children or young people and responses from parents, for other negative experiences the responses were combined, or it wasn't clear who had responded. The most common reported negative experience was waiting more than 5 minutes without being informed of the wait (65%), followed by 63% of young people reporting that there were not enough age-related activities while waiting for their appointment. Lack of information was the next most common area of negative experience with 57% of young outpatients and 62% of their parents or carers reported receiving inadequate pre-appointment information. In total, 55% of parents/carers reported that they were given new medication for their child without receiving full information about possible side effects. The lack of convenient parking and suitable food and drink was reported by 38% of parents or carers of young outpatients, but not by young people themselves. Overall, 35% of children and young people reported that doctors did not communicate in an understandable way, and 35% also felt as though they were not fully involved in decisions about their care. A total of 24% of young people felt as though they were not afforded enough privacy during their appointment, compared to 12% of the parent or carers. As a whole, 8% of respondents reported that the toilets were unclean, with 3% reporting the department as a whole was unclean. See Table 9 for an overview of respondents to a posted outpatient questionnaire.

Table 9: Percentage of respondents to a posted outpatient questionnaire who agree with each reported experience

	Respondents (%)		
Reported experience	**Young people**	**Parents**	**Unclear**
Waiting more than 5 minutes without being informed of wait	-	-	65
Not enough age-related activities while waiting	63	35	-
Inadequate pre-appointment information	57	62	-
Parents given new medication for child without receiving full information about side effects	-	55	-
No convenient parking	-	38	-
No access to suitable food and drink	-	38	-
Doctors not communicating in a understandable way	35	-	-
Not fully involved in decisions about care	35	-	-
Not enough privacy during appointment	24	12	-
Toilets were unclean	-	-	8
Department was unclean	-	-	3

Source: adapted from Hopwood 2011

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

Quality assessment of studies included in the evidence review

See the quality assessment reported in the evidence table in appendix D.

Evidence from reference groups and focus groups

The children and young people's reference groups and focus groups provided additional evidence for this review. A summary of findings is presented in Table 10.

Table 10: Summary of the evidence from reference groups and focus groups

Age groups	• <7 years • 7-11 years • 11-14 years
Areas covered	• Most and least important factors of healthcare
Key findings	• The 5 most important factors for those < 7 were: ○ Friendly

	○ Uses games and pictures ○ Close to home ○ The place feels comfy and feels like home ○ Asks me how I've been feeling • The 5 most important factors for those 7 to 11 were: ○ Friendly ○ The place feels comfy and feels like home ○ Asks me how I've been feeling ○ Fast diagnosis and treatment ○ Explains things to my parent/carer • The 5 most important factors for those 11 to 14 were: ○ Friendly ○ Explains things to me ○ Fast diagnosis ○ Asks me how I've been feeling ○ See the same person every time • The 5 least important factors for those < 7 were: ○ Explains things to me ○ Explains things to my parents ○ I see the same people every time ○ Fast – I don't have to wait long ○ Adults use words I understand • The 5 least important factors for those 7 to 11 were: ○ I see the same people every time ○ Uses games and pictures ○ No jargon-uses words I understand ○ Close to home ○ Explain things to me • The 5 most important factors for those 11 to 14 were: ○ Have dogs to comfort you ○ Cost-free ○ Comforting ○ A lot of attention ○ Gives you light refreshments

See the full evidence summary in appendix M.

Evidence from national surveys

No evidence from the grey literature review of national surveys was identified for this review so there is no evidence summary in appendix N.

Economic evidence

Included studies

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

Excluded studies

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

Summary of studies included in the economic evidence review

No studies were identified which were applicable to this review question

Economic model

This review question was identified as an economic priority, however, no economic modelling was undertaken because there was no available effectiveness data.

The committee's discussion of the evidence

Interpreting the evidence

The outcomes that matter most

This review focused on quantitative studies in which children and young people were asked to identify what factors were important to them to improve their healthcare experience. No specific healthcare factors were pre-defined in the protocol to ensure that the review captured any factors that were deemed important to babies, children or young people. Therefore, there were no outcomes prioritised by the committee.

Factors that were identified by this review that are not specifically covered by other review questions in the guideline were addressing needs in a timely manner (including a fast diagnosis, a short waiting time, or communicating what the wait will be) and entertainment or activities while waiting.

The quality of the evidence

The risk of bias of the included studies was assessed using the Centre for Evidence Based Management critical appraisal tool for a survey. The quality of the included studies was very low. This was mainly due to the lack of information included in the published articles regarding questionnaire content, data analysis and selection of presented results. This leads to a high risk of reporting bias in both studies. Additionally, there were concerns over the generalizability of the included studies. The emergency department setting in Bryans 2018 was very specific, and while Hopwood 2011 surveyed recent outpatients aged 17 years and below, no demographic information was presented on questionnaire respondents, types of outpatient clinics or the NHS trusts that were included.

Benefits and harms

The committee considered the results of this review in combination with the results from the corresponding qualitative review. The committee noted that both reviews had identified a number of factors which children and young people considered were important to their healthcare experience, but which had not specifically been addressed by other review questions in the guideline. The committee therefore considered each of the factors in turn and discussed whether it reflected their own knowledge and experience of what children and young people see as important, whether it was necessary or possible to make recommendations, or whether the importance of the factor to children and young people could be addressed by making amendments to recommendations that had already been made.

The committee discussed the evidence from the systematic review and agreed that the data presented reflected the healthcare settings in which the surveys were conducted but they were not confident all responses would be generalizable across different settings. For example, time spent in waiting areas is likely to be important in the emergency department setting, but may be less relevant in other areas of healthcare.

The committee discussed all the factors that had been identified in the review as being important to children and young people and then discussed which of these had already been covered in other sections of the guideline. For example, cleanliness and feeling comfortable were identified as the top 2 factors in the survey of young people attending accident and emergency (Bryans 2018), but the committee had already made recommendations relating to both these factors in the environment section of the guideline. Likewise, clear explanations, good staff communication, privacy, confidentiality, choice, and being treated by the same doctor (all of which were important or very important to more than 50% of children and young people) had already been covered in the guideline recommendations relating specifically to these topics. The committee had a similar discussion about the findings of the outpatient survey of children and young people (Hopwood 2011) and noted that information, communication, cleanliness, privacy and involvement in decisions about care were already covered by recommendations in relevant sections of the guideline. The committee noted that some of the priorities such as lack of convenient parking had only been identified by parents and therefore did not necessarily represent the views of children and young people.

The committee identified 2 topics which were not explicitly covered in other sections of the guideline and these were: addressing needs in a timely manner (including a fast diagnosis, a short waiting time, or communicating what the wait will be) and entertainment or activities while waiting.

The review identified that children and young people wanted to be treated in a timely manner and be kept informed when there is a delay. The committee agreed this was generalizable across all areas of healthcare, and although delays may be unavoidable (for example to ensure an accurate diagnosis, or due to unforeseen reasons in clinic) the committee agreed that providing people with information in advance about likely timings could improve experience of healthcare. The committee noted that they had already made some recommendations on waiting times in their recommendations on information provision and they amended these to make it clear that this applied to both waiting times for treatment and waiting times for appointments.

The review had also identified that children like to be kept entertained while waiting, and the committee agreed that this not only relieved boredom but could also reduce anxiety while waiting for appointments or procedures. The committee noted that they had already made recommendations about the availability of toys and activities in the environment section of the guideline, and they amended these recommendations to make it clear that this applied to waiting for appointments, and not just in an inpatient setting.

In addition to the evidence from the systematic review, the committee considered evidence from the reference groups in which children and young people were asked to prioritise healthcare factors that were important to them. The evidence from the age 11 to 14 age group showed that friendliness, having things explained to them (as opposed to their parents), and a fast diagnosis were the top 3 priorities for this group overall, with ‘ask me how I’m feeling’ also scoring highly. The committee agreed that this reinforced the findings about timeliness from the systematic review, but decided that they could not make recommendations about a fast diagnosis, as this was based on clinical factors. The committee agreed that the other factors identified were already covered by recommendations made in other sections of the guideline. For example, the creation of a friendly relationship with healthcare professionals, and making sure that young people were the focus of the discussions and had things explained to them, were both already covered by the recommendations on communication and information.

The evidence from the 7 to 11 age group also prioritised friendliness, ‘ask me how I’ve been feeling’ and timeliness of diagnosis and treatment, but the top 4 priorities for this younger age group also included that the environment should be ‘comfortable and feel like home’. The committee noted that the recommendations about environment already included that it should be comfortable, and they amended these to include the fact that it should be homely.

The evidence from the 4-7 age groups also prioritised friendliness, ‘uses games and pictures’, ‘close to home’ and ‘the place feels comfy and feels like home’. The committee agreed these findings also reinforced recommendations that they had made in the environment, and access sections of the guideline.

The committee noted that the 11-14 reference group had prioritised ‘explains things to me’ above ‘explains things to my parents’ while the younger age group of 7-11 had prioritised ‘explains things to my parents’ above ‘explains things to me.’ The 4-7 year olds had prioritised ‘explains things to me’ and ‘explains things to my parents’ similarly, but the committee discussed that they were surprised that this age group were keen on having things explained to them, but they used this information to confirm their recommendations on communication and support from healthcare staff to indicate that explanation should be offered to children of all ages.

Due to the overall low quality and quantity of evidence included in this review, the committee agreed that high quality research on healthcare priorities in a range of healthcare settings is needed and therefore made a research recommendation.

Cost effectiveness and resource use

No new recommendations were made based on this review, and the amendments to the existing recommendations on information about waiting times and ensuring access to toys and activities while waiting will not have any additional resource implications.

Recommendations supported by this evidence review

This evidence review supports recommendations 1.6.1 to 1.6.5 and 1.9.9 and the research recommendation on the factors that are important to babies, children and young people to improve their experience of healthcare.

References

Bryans 2018

Bryans, A., Camilleri-Brennan, J., Hua, L., Patel, N., Price, R., Browning, J., What do adolescents want from their ED? An evaluation on the preferences and opinions of adolescents attending local EDs, Emergency Medicine Journal, 35(11), 675-679, 2018

Hopwood 2011

Hopwood, B., Tallett, A., Little voice: giving young patients a say, Nursing Times, 107(49-50), 18-20, 2011

Appendices

Appendix A – Review protocol

Review protocol for review question 4.1a What factors are important to babies, children and young people to improve their experience of healthcare services? (Qualitative)

Table 11: Review protocol

Field	Content
PROSPERO registration number	CRD42019159570
Review title	Factors important to babies, children and young people to improve their experience of healthcare services
Review question	What factors are important to babies, children and young people to improve their experience of healthcare services?
Objective	To investigate which factors are important to babies, children and young people to improve their experience of healthcare services
Searches	The following databases will be searched: • CCTR • CDSR • Embase • MEDLINE • MEDLINE IN-Process • PsycINFO 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, Canada Denmark, Finland, France, Germany, Greece, Iceland, Ireland, Italy, Liechtenstein, Luxembourg, Malta, Monaco, Netherlands, New Zealand, Norway, Portugal, Spain, Sweden, Switzerland, and USA. Searches will be restricted by: • Date: 2009 • Language of publication: English language only

Field	Content
	• Publication status: Conference abstracts will be excluded because these do not typically provide sufficient information to fully assess risk of bias • Standard exclusions filter (animal studies/low level publication types) will be applied • UK-filter on guideline-wide search and systematic review filter on the remaining citations will also be applied For each search (including economic searches), the principal database search strategy is quality assured by a second information specialist using an adaption of the PRESS 2015 Guideline Evidence-Based Checklist.
Condition or domain being studied	Factors important to babies, children and young people to improve their experience of healthcare services
Population	• 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 - 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. 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.
Phenomenon of interest	Experience of healthcare, in particular of factors important to babies, children and young people to improve their experience of healthcare services
Comparator/Reference standard/Confounding factors	Not applicable
Types of study to be included	• Systematic reviews of qualitative studies • Studies using qualitative methods: focus groups, semi-structured and structured interviews, observations • Surveys conducted using open ended questions and a qualitative analysis of response. • Surveys with a qualitative analysis of response identified from grey literature search • Thematic analysis of focussed group discussions of reference groups 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.
Other exclusion criteria	Not applicable

Field	Content
Context	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 children or young people 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.
Primary outcomes (critical outcomes)	Themes identified from the focus groups will form the primary outcome. Themes will also be identified from surveys with a qualitative analysis of response identified from grey literature. Additionally, following themes from the literature will be included. However additional themes may be identified: • Food provision at the healthcare facility (e.g. out of hours service provision, choice of suitable food and fluid, provision of substantial snacks etc.) • General ambience and security (e.g. children feeling safe in adult wards) • Pain-related themes (e.g. recognition, belief of pain, distress from pain) • Recognition of symptoms (e.g. nausea, discomfort, anxiety) • Quality of life in general We will attempt to draw out themes which indicate which factors children and young people consider the most important; however, this will require the evidence to explicitly state this in their findings. Themes related to this topic but that will not be covered by this review include: • Features of physical environment which are important to babies, children and young people to improve their experience of care (6.1) • Perspectives of children and young people to design healthcare services (5.1) • Facilitators of, and barriers to, accessing healthcare services faced by babies, children and young people (8.1) • Access to healthcare information (2.1)

Field	Content
	• How should issues about consent, privacy and confidentiality be addressed with babies, children and young people (1.3) • How should healthcare staff communicate with babies, children and young people, and the parents or carers of babies and young children? (1.2) • Access to care (8.1) • Effective communication with healthcare providers • Support from healthcare staff (3.2)
Secondary outcomes (important outcomes)	Not applicable
Data extraction (selection and coding)	All references identified by the searches and from other sources will be uploaded into STAR and de-duplicated. Titles and abstracts of the retrieved citations will be screened to identify studies that potentially meet the inclusion criteria outlined in the review protocol. Duplicate screening will not be undertaken for this question. Dual sifting will be performed on at least 10% of records; 90% agreement is required. Disagreements will be resolved via discussion between the two reviewers, and consultation with senior staff if necessary. 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	Risk of bias of individual qualitative studies will be assessed using the CASP 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.
Strategy for data synthesis	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 themes or sub-themes synthesized 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. 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

Field	Content		
	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 with respect to the characteristics of the study population, setting, place and time, healthcare system, intervention, and broader social, policy, or political issues.		
Analysis of sub-groups	If there is sufficient data, views and experiences will be analysed separately by the following age ranges: • <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) If there is sufficient data, views and experience of children and young people will be analysed separately by different settings and services. 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. 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.		
Type and method of review	☐ Intervention ☐ Diagnostic ☐ Prognostic ☒ Qualitative ☐ Epidemiologic ☐ Service Delivery ☐ Other (please specify)		
Language	English		
Country	England		
Anticipated or actual start date	1st June 2020		
Anticipated completion date	14th July 2020		
Stage of review at time of this submission	Review stage	Started	Completed
	Preliminary searches	☑	☑
	Piloting of the study selection process	☑	☑

Field	Content		
	Formal screening of search results against eligibility criteria	☑	☑
	Data extraction	☑	☑
	Risk of bias (quality) assessment	☑	☑
	Data analysis	☑	☑
Named contact	5a. Named contact National Guideline Alliance 5b. Named contact e-mail Infant&younghealth@nice.org.uk 5c. Organisational affiliation of the review National Institute for Health and Care Excellence (NICE) and National Guideline Alliance		
Review team members	NGA Technical Team		
Funding sources/sponsor	This systematic review is being completed by the National Guideline Alliance, which receives funding from NICE.		
Conflicts of interest	All guideline committee members and anyone who has direct input into NICE guidelines (including the evidence review team and expert witnesses) must declare any potential conflicts of interest in line with NICE's code of practice for declaring and dealing with conflicts of interest. Any relevant interests, or changes to interests, will also be declared publicly at the start of each guideline committee meeting. Before each meeting, any potential conflicts of interest will be considered by the guideline committee Chair and a senior member of the development team. Any decisions to exclude a person from all or part of a meeting will be documented. Any changes to a member's declaration of interests will be recorded in the minutes of the meeting. Declarations of interests will be published with the final guideline.		
Collaborators	Development of this systematic review will be overseen by an advisory committee who will use the review to inform the development of evidence-based recommendations in line with section 3 of 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?RecordID=159570		
Dissemination plans	NICE may use a range of different methods to raise awareness of the guideline. These include standard approaches such as: notifying registered stakeholders of publication publicising the guideline through NICE's newsletter and alerts		

Field	Content	
	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	Babies; Children; Experience; Healthcare; Infants; Views	
Details of existing review of same topic by same authors	Not applicable	
Current review status	☒	Ongoing
	☐	Completed but not published
	☐	Completed and published
	☐	Completed, published and being updated
	☐	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	

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

Review protocol for review question 4.1b What factors are important to babies, children and young people to improve their experience of healthcare? (Quantitative)

Table 12: Review protocol

Field	Content
PROSPERO registration number	CRD42019159575
Review title	Improving experience of healthcare for babies, children and young people.
Review question	What factors are important to babies, children and young people to improve their experience of healthcare?
Objective	To determine the important factors to improve healthcare experiences for babies, children and young people.
Searches	The following databases will be searched: • CENTRAL • CDSR • Embase • MEDLINE • MEDLINE IN-Process • PsycINFO These database searches will be supplemented by a grey literature search to ensure more recent national and regional healthcare surveys are included in the data. Searches will be restricted by: • 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, Canada Denmark, Finland, France, Germany, Greece, Iceland, Ireland, Italy, Liechtenstein, Luxembourg, Malta, Monaco, Netherlands, New Zealand, Norway, Portugal, Spain, Sweden, Switzerland, and USA • Date: 2009 • Language of publication: English language only • Publication status: Conference abstracts will be excluded because these do not typically provide sufficient information to fully assess risk of bias • Standard exclusions filter (animal studies/low level publication types) will be applied • For each search (including economic searches), the principal database search strategy is quality assured by a second information specialist using an adaption of the PRESS 2015 Guideline Evidence-Based Checklist
Condition or domain being studied	• Babies, children's and young people's experience of healthcare

Field	Content
Population	• People <18 years-old who have experience of healthcare • Studies that use the responses of parents or carers as proxies for their child will be included only if they are responding on behalf of their child or charge, and o The baby or child of the parent or carer is under-5 years-old, or o There is a clear rationale provided as to why the study is using parents' or carers' views on healthcare as proxies for their child. 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 at least 66% of the sample is less than 18 years-old. Results will be stratified according to the following age groups: • <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)
Intervention/Exposure/Test	Any regional or UK-wide survey or closed-question questionnaire that measures or rates which factors babies, children and young people judge to be important for improving their experience of healthcare
Comparator/Reference standard/Confounding factors	Not applicable
Types of study to be included	• Cross-sectional studies • Longitudinal studies • National UK surveys using quantitative analysis of responses e.g. Likert scores or closed questions • Non-comparative studies • Regional surveys using quantitative analysis of responses e.g. Likert scores or closed questions • Systematic reviews of quantitative studies We will only include regional surveys if no national surveys are identified. Note: Mixed methods studies will be included but only quantitative data will be extracted and risk of bias assessed.
Other exclusion criteria	STUDY DESIGN • RCTs • Systematic reviews of RCTs • Case control studies • Case series and case reports

Field	Content
	• Cohort studies • Epidemiological reviews or reviews on associations • Non-RCTs • Studies using qualitative methods TOPIC OF STUDY Studies on the following topics will also be excluded: • Non-NHS commissioned health promotion interventions • Views and experiences of babies, children and young people on aspects of their healthcare that cannot be generalised to the wider population of babies, children and young people • Views and experiences of healthcare professionals and service managers • Views and experiences of babies, children and young people reporting only on social care planning 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: • Child abuse and maltreatment: o Child abuse and neglect (NG76) o Child maltreatment: when to suspect maltreatment in under 18s (CG89) • Community engagement (NG44) • Drug misuse in children and young people: o Alcohol: school-based interventions (PH7) o Alcohol-use disorders: diagnosis, assessment and management of harmful drinking and alcohol dependence (CG115) o Alcohol-use disorders: prevention (PH24) o 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: o Maternal and child nutrition (PH11) o Obesity prevention (CG43) o Physical activity for children and young people (PH17)

Field	Content
	○ Weight management: lifestyle services for overweight or obese children and young people (PH47) • Pregnancy, including routine antenatal, intrapartum or postnatal care: ○ 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: ○ 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: ○ 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: ○ Smoking: preventing uptake in children and young people (PH14) ○ Smoking prevention in schools (PH23) ○ Stop smoking interventions and services (NG92) • Transition from children's to adults services for young people using health or social care services (NG43)
Context	UK studies from 2009 onwards will be prioritised for decision making by the committee as those conducted in other countries may not be representative of current expectations about either services or current attitudes and behaviours of healthcare professionals. The committee presumes that due to their development, particular circumstances and/or condition, there are some topics that babies, children and young people may not be in a position to pronounce on, and that in these circumstances, it may be necessary to treat the 'indirect' views of their parents or carers as proxies for their own views on and experiences of healthcare in order to make recommendations. The guideline committee will be consulted on whether a study should be included if it is unclear why parents' or carer's views are being reported instead of their child or charge, and reasons for exclusion if appropriate will be documented. The topic about which the babies, children and young people are talking 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-

Field	Content
	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.
Primary outcomes (critical outcomes)	Factors important to babies, children and young people's experience of healthcare
Secondary outcomes (important outcomes)	Not applicable
Data extraction (selection and coding)	• All references identified by the searches and from other sources will be uploaded into STAR and de-duplicated. Titles and abstracts of the retrieved citations will be screened to identify studies that potentially meet the inclusion criteria outlined in the review protocol. • Dual sifting will be performed on at least 10% of records; 90% agreement is required. • Disagreements will be resolved via discussion between the two reviewers, and consultation with senior staff if necessary. • 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	Risk of bias of systematic reviews of quantitative studies will be assessed using the ROBIS checklist, whilst risk of bias of individual quantitative studies will be assessed using the Cochrane RoB tool, v.2, ROBINS-I or the CEBMa checklist as described in Developing NICE guidelines: the manual. The quality assessment will be performed by one reviewer and this will be quality assessed by a senior reviewer.
Strategy for data synthesis	• Depending on the availability of the evidence, the findings will be summarised narratively or quantitatively. The identified factors will be described narratively, and compared across included studies. Where possible rankings across studies will be combined using weighted means, or presented visually to aid decision making. • Heterogeneity in the effect estimates of the individual studies will be assessed using the I^2 statistic. I^2 values of greater than 50% and 80% will be considered as serious and very serious heterogeneity, respectively. Heterogeneity will be explored as appropriate using sensitivity analyses and pre-specified subgroup analyses. If heterogeneity cannot be explained through subgroup analysis then a random effects model will be used for meta-analysis, or the data will not be pooled. • Where meta-analysis is conducted, the confidence in the findings across available evidence will be evaluated for each outcome using an adaptation of the 'Grading of Recommendations Assessment, Development and Evaluation (GRADE) toolbox' developed by the international GRADE working group: http://www.gradeworkinggroup.org/
Analysis of sub-groups	If there is sufficient data, views and experiences will be analysed separately by the following age ranges: • <1 year-old (i.e. 364 days-old or less)

<table>
<tr><th>Field</th><th colspan="3">Content</th></tr>
<tr><td></td><td colspan="3">• ≥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)

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. 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.</td></tr>
<tr><td rowspan="7">Type and method of review</td><td>☐</td><td colspan="2">Intervention</td></tr>
<tr><td>☐</td><td colspan="2">Diagnostic</td></tr>
<tr><td>☐</td><td colspan="2">Prognostic</td></tr>
<tr><td>☐</td><td colspan="2">Qualitative</td></tr>
<tr><td>☒</td><td colspan="2">Epidemiologic</td></tr>
<tr><td>☐</td><td colspan="2">Service Delivery</td></tr>
<tr><td>☐</td><td colspan="2">Other (please specify)</td></tr>
<tr><td>Language</td><td colspan="3">English</td></tr>
<tr><td>Country</td><td colspan="3">England</td></tr>
<tr><td>Anticipated or actual start date</td><td colspan="3">27/11/2019</td></tr>
<tr><td>Anticipated completion date</td><td colspan="3">07/04/2021</td></tr>
<tr><td rowspan="7">Stage of review at time of this submission</td><td>Review stage</td><td>Started</td><td>Completed</td></tr>
<tr><td>Preliminary searches</td><td></td><td>☑</td></tr>
<tr><td>Piloting of the study selection process</td><td></td><td>☑</td></tr>
<tr><td>Formal screening of search results against eligibility criteria</td><td></td><td>☑</td></tr>
<tr><td>Data extraction</td><td></td><td>☑</td></tr>
<tr><td>Risk of bias (quality) assessment</td><td></td><td>☑</td></tr>
<tr><td>Data analysis</td><td></td><td>☑</td></tr>
</table>

Field	Content	
Named contact	**5a. Named contact** National Guideline Alliance **5b. Named contact e-mail** infant&younghealth@nice.org.uk **5c. Organisational affiliation of the review** National Institute for Health and Care Excellence (NICE) and National Guideline Alliance	
Review team members	NGA Technical Team	
Funding sources/sponsor	This systematic review is being completed by the National Guideline Alliance, which receives funding from NICE.	
Conflicts of interest	All guideline committee members and anyone who has direct input into NICE guidelines (including the evidence review team and expert witnesses) must declare any potential conflicts of interest in line with NICE's code of practice for declaring and dealing with conflicts of interest. Any relevant interests, or changes to interests, will also be declared publicly at the start of each guideline committee meeting. Before each meeting, any potential conflicts of interest will be considered by the guideline committee Chair and a senior member of the development team. Any decisions to exclude a person from all or part of a meeting will be documented. Any changes to a member's declaration of interests will be recorded in the minutes of the meeting. Declarations of interests will be published with the final guideline.	
Collaborators	Development of this systematic review will be overseen by an advisory committee who will use the review to inform the development of evidence-based recommendations in line with section 3 of 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?RecordID=159575	
Dissemination plans	NICE may use a range of different methods to raise awareness of the guideline. These include standard approaches such as: • notifying registered stakeholders of publication • publicising the guideline through NICE's newsletter and alerts • issuing a press release or briefing as appropriate, posting news articles on the NICE website, using social media channels, and publicising the guideline within NICE.	
Keywords	Babies; children; experience; healthcare; young people; improvement;	
Details of existing review of same topic by same authors	Not applicable	
Current review status	☒	Ongoing

Field	Content	
	☐	Completed but not published
	☐	Completed and published
	☐	Completed, published and being updated
	☐	Discontinued
Additional information		
Details of final publication	www.nice.org.uk	

CDSR: Cochrane Database of Systematic Reviews; CEBMa: Center for Evidence-Based Management; CENTRAL: Cochrane Central Register of Controlled Trials (also known as CCTR); GRADE: Grading of Recommendations Assessment, Development and Evaluation; NGA: National Guideline Alliance; NHS: National Health Service; NICE: National Institute for Health and Care Excellence; PRESS: Peer Review of Electronic Search Strategies; PROSPERO: International prospective register of systematic reviews; RCT: randomised controlled trial; RoB: risk of bias; ROBINS-I: Risk of bias in non-randomised studies of interventions.

Appendix B – Literature search strategies

Literature search strategies for review question 4.1a What factors are important to babies, children and young people to improve their experience of healthcare services? (Qualitative)

Databases: Embase/Medline/PsycINFO

Date searched: 29/07/2020

#	Searches
1	(ADOLESCENT/ or MINORS/) use ppez
2	exp ADOLESCENT/ use emez
3	(adolescen$ or teen$ or youth$ or young or juvenile? or minors or highschool$).ti,ab,jw,nw.
4	exp CHILD/
5	(child$ or schoolchild$ or "school age" or "school aged" or preschool$ or toddler$ or kid? or kindergar$ or boy? or girl?).ti,ab,jw,nw.
6	exp INFANT/
7	(infan$ or neonat$ or newborn$ or baby or babies).ti,ab,jw,nw.
8	exp PEDIATRICS/ or exp PUBERTY/
9	(p?ediatric$ or pubert$ or prepubert$ or pubescen$ or prepubescen$).ti,ab,jx,ec.
10	or/1-9
11	(Ambulance/ or Ambulance Transportation/ or Child Health Care/ or Community Care/ or Day Care/ or Dentist/ or Dental Facility/ or Pediatric Dentist/ or Dietitian/ or Emergency Care/ or Emergency Health Service/ or Emergency Ward/ or General Practice/ or Health Care/ or Health Care Delivery/ or Health Care Facility/ or Health Service/ or exp Home Care/ or Home Mental Health Care/ or Hospice/ or Hospice Care/ or exp Hospital/ or Hospital Care/ or Intensive Care Unit/ or Mental Health Care/ or Mental Health Service/ or Nursing Care/ or Newborn Care/ or Newborn Intensive Care/ or Neonatal Intensive Care Unit/ or Occupational Therapy/ or Ophthalmology/ or Orthodontics/ or Pediatric Intensive Care Unit/ or Pharmacy/ or exp Primary Health Care/ or Physiotherapy/ or Respite Care/ or School Health Nursing/ or exp School Health Service/ or Secondary Care Center/ or Secondary Health Care/ or "Speech and Language Rehabilitation"/ or Telemedicine/ or Tertiary Care Center/ or Tertiary Health Care/) use emez
12	(Ambulances/ or Adolescent Health Services/ or exp Child Health Services/ or Community Health Services/ or Community Pharmacy Services/ or Community Health Centers/ or Community Mental Health Centers/ or "Delivery of Health Care"/ or Dental Care for Children/ or exp Dental Health Services/ or Dentists/ or Dental Facilities/ or Emergency Medical Services/ or Emergency Service, Hospital/ or General Practice/ or Health Facilities/ or Health Services/ or Home Care Services/ or Home Care Services, Hospital-Based/ or Home Nursing/ or Hospice Care/ or Hospices/ or exp Hospitals/ or Intensive Care Units/ or Intensive Care Units, Pediatric/ or Intensive Care Units, Neonatal/ or exp Mental Health Services/ or Nutritionists/ or Occupational Therapy/ or Orthodontists/ or Pediatric Nursing/ or Pharmacies/ or Primary Health Care/ or Respite Care/ or exp School Health Services/ or School Nursing/ or Secondary Care/ or Telemedicine/ or Tertiary Healthcare/ or "Transportation of Patients"/) use ppez
13	(Adolescent Psychiatry/ or Community Health/ or Community Services/ or Dentists/ or Dental Health/ or Educational Psychology/ or Health Care Delivery/ or Health Care Services/ or Home Care/ or Home Visiting Programes/ or Hospice/ or exp Hospitals/ or Intensive Care/ or Language Therapy/ or exp Mental Health Services/ or Neonatal Intensive Care/ or Occupational Therapy/ or Outreach Programs/ or Pharmacy/ or Physical Therapy/ or Primary Health Care/ or Psychiatric Clinics/ or Psychiatric Units/ or Respite Care/ or Speech Therapy/ or Telemedicine/ or Telepsychiatry/ or Telepsychology/ or Walk In Clinics/) use psyh
14	(hospital patient/ or hospitalized adolescent/ or hospitalized child/ or hospitalized infant/ or hospitalization/ or hospital patient/ or outpatient/) use emez
15	(adolescent, hospitalized/ or child, hospitalized/ or Hospitalization/ or inpatients/ or outpatients/) use ppez
16	(hospitalized patients/ or exp hospitalization/ or outpatients/) use psyh
17	(hospital* or inpatient* or outpatient*).tw.
18	(health* adj3 (care or center* or centre* or clinic* or facility or facilities or service* or setting* or specialist*)).tw.
19	((dental or communit* or emergency or hospital* or home or intensive or high-dependen* or mental* or primary or secondary or tertiary) adj3 (care or health*)).tw.
20	(emergency adj2 room*).tw.
21	(ambulance* or CAMHS or dentist* or dietics or dieti?ian or hospice* or NICU or nutritionist* or orthodont* or ophthalmolog* or (outreach adj2 team*) or pharmacy or pharmacies or physio* or SCBU or SENCO or telemedicine*).tw.
22	((virtual* or online) adj2 (physician* or clinician* or doctor*)).tw.
23	(communit* adj3 (p?ediatric* or nurs*)).tw.
24	(home adj3 visit*).tw.

#	Searches
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
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

#	Searches
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 "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))).ti,ab,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 psyh
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 psyh
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

#	Searches
107	cohort analysis/ use emez
108	cohort analysis/ use psyh
109	case-control studies/ use ppez
110	case control study/ use emez
111	or/103-110
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 psyh
122	exp Models, Animal/ use ppez
123	animal model/ use emez
124	animal models/ use psyh
125	exp Rodentia/ use ppez
126	exp Rodent/ use emez
127	rodents/ use psyh
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 psyh
153	150 or 151 or 152
154	73 and 153
155	154 not 130
156	155 not 129

Database: Cochrane Library

Date searched: 29/07/2020

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

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

#	Search
96	(theme* or thematic):ti,ab,kw
97	(qualitative):ti,ab,kw
98	(questionnaire*):ti,ab,kw
99	(ethnological research):ti,ab,kw
100	(ethnograph*):ti,ab,kw
101	(ethnonursing):ti,ab,kw
102	(phenomenol*):ti,ab,kw
103	(life stor* or women* stor*):ti,ab,kw
104	(grounded near (theor* or study or studies or research or analys*s)):ti,ab,kw
105	((data near/1 saturat*) or participant observ*):ti,ab,kw
106	(field near (study or studies or research)):ti,ab,kw
107	(biographical method):ti,ab,kw
108	(theoretical sampl*):ti,ab,kw
109	((purpos* near/4 samp**) or (focus near group*)):ti,ab,kw
110	(account or accounts or unstructured or openended or open ended or text* or narrative*):ti,ab,kw
111	(life world or life-world or conversation analys*s or personal experience* or theoretical saturation):ti,ab,kw
112	((lived or life) near experience*):ti,ab,kw
113	(narrative analys*s):ti,ab,kw
114	#93 OR #94 OR #95 OR #96 OR #97 OR #98 OR #99 OR #100 OR #101 OR #102 OR #103 OR #104 OR #105 OR #106 OR #107 OR #108 OR #109 OR #110 OR #111 OR #112 OR #113
115	#11 AND #71 AND #92 AND #114 with Cochrane Library publication date Between Jan 2009 and Aug 20202
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 (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))):ti,ab,kw
122	(bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's"):ti,ab,kw
123	(aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's"):ti,ab,kw
124	armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's":ti,ab,kw
125	#116 OR #117 OR #118 OR #119 OR #120 OR #121 OR #122 OR #123 OR #124
126	MeSH descriptor: [Africa] explode all trees
127	MeSH descriptor: [Americas] explode all trees
128	MeSH descriptor: [Antarctic Regions] explode all trees
129	MeSH descriptor: [Arctic Regions] explode all trees
130	MeSH descriptor: [Asia] explode all trees

#	Search
131	MeSH descriptor: [Oceania] explode all trees
132	#126 OR #127 OR #128 OR #129 OR #130 OR #131
133	MeSH descriptor: [United Kingdom] explode all trees
134	MeSH descriptor: [Europe] this term only
135	#133 OR #134
136	#132 not #135
137	#125 not #136
138	#115 AND #137 with Cochrane Library publication date Between Jan 2009 and Aug 2020

Literature search strategies for review question 4.1b What factors are important to babies, children and young people to improve their experience of healthcare? (Quantitative)

Databases: Embase/Medline/PsycInfo

Date searched: 03/08/2020

#	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
14	(hospital patient/ or hospitalized adolescent/ or hospitalized child/ or hospitalized infant/ or hospitalization/ or hospital patient/ or outpatient/) use emez
15	(adolescent, hospitalized/ or child, hospitalized/ or Hospitalization/ or inpatients/ or outpatients/) use ppez
16	(hospitalized patients/ or exp hospitalization/ or outpatients/) use psyh
17	(hospital* or inpatient* or outpatient*).tw.
18	(health* adj3 (care or center* or centre* or clinic* or facility or facilities or service* or setting* or specialist*)).tw.
19	((dental or communit* or emergency or hospital* or home or intensive or high-dependen* or mental* or primary or secondary or tertiary) adj3 (care or health*)).tw.
20	(emergency adj2 room*).tw.
21	(ambulance* or CAMHS or dentist* or dietics or dieti?ian or hospice* or NICU or nutritionist* or orthodont* or ophthalmolog* or (outreach adj2 team*) or pharmacy or pharmacies or physio* or SCBU or SENCO or telemedicine*).tw.
22	((virtual* or online) adj2 (physician* or clinician* or doctor*)).tw.
23	(communit* adj3 (p?ediatric* or nurs*)).tw.
24	(home adj3 visit*).tw.
25	((walk-in or "urgent care") adj2 (centre* or center* or clinic* or service*)).tw.
26	"speech and language therap*".tw.
27	general practice*.tw.

#	Searches
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 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
46	(Health care survey/ or *health survey/ or Structured questionnaire/) use emez
47	(*"surveys and questionnaires"/ or *health care surveys/) use ppez
48	(Surveys/ or questionnaires/ or mail surveys/ or telephone surveys/) use psyh
49	(Close* adj2 question*).tw.
50	(structure* adj (survey* or interview* or question*)).tw.
51	((Quantitative or quantify or quantified) adj2 (result* or analys?s)).tw.
52	likert.tw.
53	or/46-52
54	45 and 53
55	exp United Kingdom/
56	(national health service* or nhs*).ti,ab,in,ad,cq.
57	(english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab.
58	(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.
59	(bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))).ti,ab,in,ad,cq.

#	Searches
60	(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.
61	(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.
62	(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.
63	or/55-62
64	((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
65	((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
66	64 or 65
67	63 not 66
68	meta-analysis/
69	meta-analysis as topic/
70	systematic review/
71	meta-analysis/
72	(meta analy* or metanaly* or metaanaly*).ti,ab.
73	((systematic or evidence) adj2 (review* or overview*)).ti,ab.
74	((systematic* or evidence*) adj2 (review* or overview*)).ti,ab.
75	(reference list* or bibliograph* or hand search* or manual search* or relevant journals).ab.
76	(search strategy or search criteria or systematic search or study selection or data extraction).ab.
77	(search* adj4 literature).ab.
78	(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.
79	cochrane.jw.
80	((pool* or combined) adj2 (data or trials or studies or results)).ab.
81	((comprehensive* or integrative or systematic*) adj3 (bibliographic* or review* or literature)).ti,ab,id.
82	(meta-analy* or metaanaly* or "research synthesis").ti,ab,id.
83	(((information or data) adj3 synthesis) or (data adj2 extract*)).ti,ab,id.
84	(review adj5 (rationale or evidence)).ti,ab,id. and "Literature Review".md.
85	(cinahl or (cochrane adj3 trial*) or embase or medline or psyclit or pubmed or scopus or "sociological abstracts" or "web of science").ab.
86	("systematic review" or "meta analysis").md.
87	(or/68-69,72,74-79) use ppez
88	(or/70-73,75-80) use emez
89	(or/81-86) use psyh
90	87 or 88 or 89
91	54 and 67
92	54 and 90
93	limit 91 to (yr="2009 - current" and english language)
94	limit 92 to (yr="2009 - current" and english language)
95	Letter/ use ppez
96	letter.pt. or letter/ use emez
97	note.pt.
98	editorial.pt.
99	Editorial/ use ppez
100	News/ use ppez
101	news media/ use psyh
102	exp Historical Article/ use ppez
103	Anecdotes as Topic/ use ppez
104	Comment/ use ppez
105	Case Report/ use ppez
106	case report/ or case study/ use emez
107	Case report/ use psyh

#	Searches
108	(letter or comment*).ti.
109	or/95-108
110	randomized controlled trial/ use ppez
111	randomized controlled trial/ use emez
112	random*.ti,ab.
113	cohort studies/ use ppez
114	cohort analysis/ use emez
115	cohort analysis/ use psyh
116	case-control studies/ use ppez
117	case control study/ use emez
118	or/110-117
119	109 not 118
120	animals/ not humans/ use ppez
121	animal/ not human/ use emez
122	nonhuman/ use emez
123	"primates (nonhuman)"/
124	exp Animals, Laboratory/ use ppez
125	exp Animal Experimentation/ use ppez
126	exp Animal Experiment/ use emez
127	exp Experimental Animal/ use emez
128	animal research/ use psyh
129	exp Models, Animal/ use ppez
130	animal model/ use emez
131	animal models/ use psyh
132	exp Rodentia/ use ppez
133	exp Rodent/ use emez
134	rodents/ use psyh
135	(rat or rats or mouse or mice).ti.
136	or/119-135
137	93 not 136
138	94 not 136
139	remove duplicates from 137
140	remove duplicates from 138

Database: Cochrane Library

Date searched: 03/08/2020

#	Searches
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
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
6	MeSH descriptor: [Infant] explode all trees
7	(infan* or neonat* or newborn* or baby or babies):ti,ab
8	MeSH descriptor: [Pediatrics] explode all trees
9	MeSH descriptor: [Puberty] explode all trees
10	(p*ediatric* or pubert* or prepubert* or pubescen* or prepubescen*):ti,ab
11	{OR #1-#10}
12	MeSH descriptor: [Ambulances] this term only
13	MeSH descriptor: [Adolescent Health Services] this term only
14	MeSH descriptor: [Child Health Services] this term only
15	MeSH descriptor: [Community Health Services] this term only

#	Searches
16	MeSH descriptor: [Community Pharmacy Services] this term only
17	MeSH descriptor: [Community Health Centers] this term only
18	MeSH descriptor: [Community Mental Health Centers] this term only
19	MeSH descriptor: [Delivery of Health Care] this term only
20	MeSH descriptor: [Dental Care for Children] this term only
21	MeSH descriptor: [Dental Health Services] explode all trees
22	MeSH descriptor: [Dentists] this term only
23	MeSH descriptor: [Dental Facilities] this term only
24	MeSH descriptor: [Emergency Medical Services] this term only
25	MeSH descriptor: [Emergency Service, Hospital] this term only
26	MeSH descriptor: [General Practice] this term only
27	MeSH descriptor: [Health Facilities] this term only
28	MeSH descriptor: [Health Services] this term only
29	MeSH descriptor: [Home Care Services] this term only
30	MeSH descriptor: [Home Care Services, Hospital-Based] this term only
31	MeSH descriptor: [Home Nursing] this term only
32	MeSH descriptor: [Hospice Care] this term only
33	MeSH descriptor: [Hospices] this term only
34	MeSH descriptor: [Hospitals] explode all trees
35	MeSH descriptor: [Intensive Care Units] this term only
36	MeSH descriptor: [Intensive Care Units, Pediatric] this term only
37	MeSH descriptor: [Intensive Care Units, Neonatal] this term only
38	MeSH descriptor: [Mental Health Services] explode all trees
39	MeSH descriptor: [Nutritionists] this term only
40	MeSH descriptor: [Occupational Therapy] this term only
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
58	(health* near/3 (care or center* or centre* or clinic* or facility or facilities or service* or setting* or specialist*)):ti,ab
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
60	(emergency near/2 room*):ti,ab
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
62	((virtual* or online) near/2 (physician* or clinician* or doctor*)):ti,ab
63	(communit* near/3 (p*ediatric* or nurs*)):ti,ab
64	(home near/3 visit*):ti,ab
65	((walk-in or "urgent care") near/2 (centre* or center* or clinic* or service*)):ti,ab
66	(speech and language therap*):ti,ab

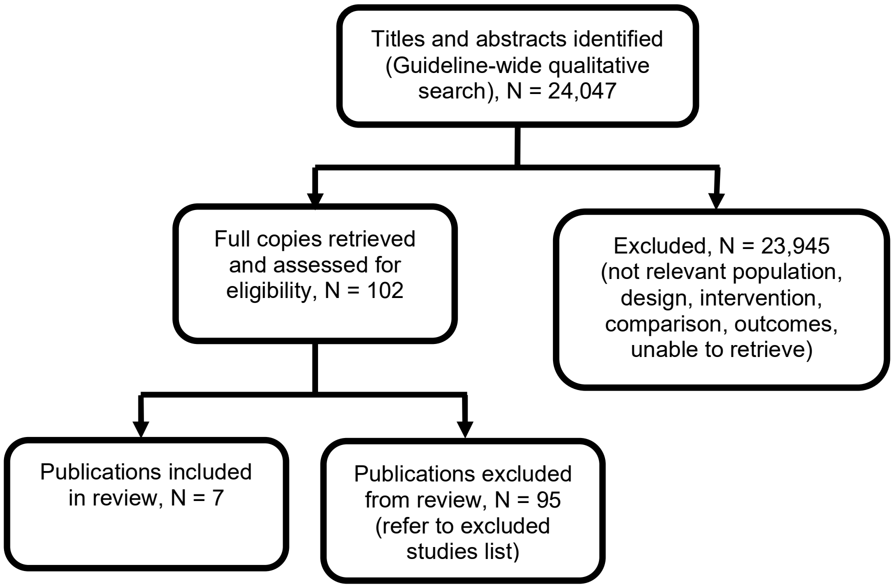
#	Searches
67	(general practice*):ti,ab
68	(health* and (nursery or nurseries or school*)):ti,ab
69	(respite near/2 care):ti,ab
70	(foster care or looked after children or children in care):ti,ab
71	{OR #12-#70}
72	MeSH descriptor: [Adverse Childhood Experiences] this term only
73	MeSH descriptor: [Attitude to Health] explode all trees
74	MeSH descriptor: [Patient Satisfaction] explode all trees
75	MeSH descriptor: [Community Participation] explode all trees
76	MeSH descriptor: [Patient Acceptance of Health Care] this term only
77	MeSH descriptor: [Consumer Behavior] explode all trees
78	MeSH descriptor: [Patient Preference] this term only
79	MeSH descriptor: [Attitude to Death] this term only
80	MeSH descriptor: [Health Knowledge, Attitudes, Practice] this term only
81	(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
82	((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
83	{OR #72-#82}
84	MeSH descriptor: [Surveys and Questionnaires] this term only
85	MeSH descriptor: [Health Care Surveys] this term only
86	(Close* near/2 question*):ti,ab
87	(structure* near (survey* or interview* or question*)):ti,ab
88	((Quantitative or quantify or quantified) near/2 (result* or analys?s)):ti,ab
89	likert:ti,ab
90	{OR #84-#89}
91	#11 AND #71 AND #83 AND #90 with Cochrane Library publication date Between Jan 2009 and Sept 2020
92	MeSH descriptor: [United Kingdom] explode all trees
93	(national health service* or nhs*):ti,ab,kw
94	(english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) near/5 english)):ti,ab,kw
95	(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
96	(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
97	(bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))):ti,ab,kw
98	(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
99	(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
100	(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
101	{OR #92-#100}

#	Searches
102	MeSH descriptor: [Africa] explode all trees
103	MeSH descriptor: [Americas] explode all trees
104	MeSH descriptor: [Antarctic Regions] explode all trees
105	MeSH descriptor: [Arctic Regions] explode all trees
106	MeSH descriptor: [Asia] explode all trees
107	MeSH descriptor: [Oceania] explode all trees
108	#102 OR #103 OR #104 OR #105 OR #106 OR #107
109	MeSH descriptor: [United Kingdom] explode all trees
110	MeSH descriptor: [Europe] this term only
111	#109 OR #110
112	#108 not #111
113	#101 not #112
114	#91 AND #113

Appendix C – Clinical evidence study selection

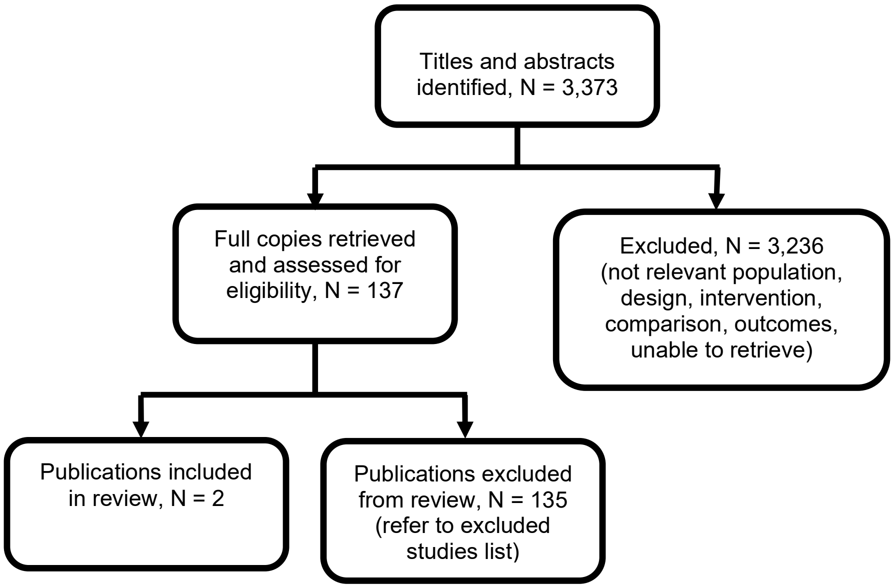
Study selection for 4.1a What factors are important to babies, children and young people to improve their experience of healthcare services? (Qualitative)

Figure 3: Study selection flow chart



Study selection for 4.1b What factors are important to babies, children and young people to improve their experience of healthcare? (Quantitative)

Figure 4: Study selection flow chart



Appendix D – Clinical evidence tables

Evidence tables for review question 4.1a What factors are important to babies, children and young people to improve their experience of healthcare services? (Qualitative)

Table 13: Evidence tables

Study details	Participants	Methods	Themes and findings	Limitations
Full citation Ali, Nasreen, McLachlan, Niel, Kanwar, Shama, Randhawa, Gurch, Pakistani young people's views on barriers to accessing mental health services, International Journal of Culture and Mental Health, 10, 33-43, 2017 **Ref Id** 1052663 **Aim of the study** To explore UK Pakistani young people's views of barriers and facilitators to accessing mental health services in Peterborough, as well designing	**Sample size** N=33 young people **Characteristics** • Age (range): 11-19 years ○ It was not possible to establish how many participants were ≥18 years old. ○ Themes have been downgraded for relevance where applicable. • Gender (M/F): 17/16 **Inclusion criteria** Participants had to: • Be aged 11-19 • Be of Pakistani origin (held or were descended from those who held Pakistani passport) • Resident in Peterborough **Exclusion criteria** Not reported.	**Setting** School, religious institutions or youth group. **Sample selection** Participants recruited from local schools, madrasas (Islamic religious education institutions) or youth groups. Done by personal communication with one of the researchers. **Data collection** 4 single-sex focus groups (lasting 60-90 mins) were held, facilitated by a discussion guide. This was developed from a variety of literature and included semi-structured questions on religion, knowledge about mental health, awareness of local mental health services and suggestions for changes. **Data analysis**	**Results summarised under the following themes:** • Religion as a source of support • Community connections **Findings** Religion can be a good resource to help with mental health issues. Young people felt that counsellors who share their culture are more relatable and can understand the cultural implications. It would be helpful to have more community events about mental health and discussion of it in Asian TV dramas.	**Limitations (assessed using the <u>CASP checklist for qualitative studies).</u>** *Q1 Was there a clear statement of the aims of the research?* Yes. *Q2 Was a qualitative methodology appropriate?* Yes. *Q3 Was the research design appropriate to address the aims of the research?* Yes. Qualitative design and focus groups both justified. *Q4 Was the recruitment strategy appropriate to the aims of the research?* No - Personal communication used for recruitment. This was justified by the researcher having good links to Peterborough Pakistani community but introduces potential for bias which cannot be overlooked *Q5: Were the data collected in a way that addressed the research issue?* Yes - Focus groups conducted in community settings for ease and

Study details	Participants	Methods	Themes and findings	Limitations
actions to improve access to these services. **Country/ies where the study was carried out** Peterborough, UK **Study type** Qualitative study **Study dates** 2012-2013 **Source of funding** This study received support from Cambridgeshire and Peterborough NHS Foundation Trust.		Thematic framework analysis. Discussions were audio-recorded and transcribed. Researchers met regularly to discuss and develop themes via group consensus.		privacy. Single sex focus groups used in order to be more culturally sensitive. Discussion guide used during focus groups, which was informed by existing policy, current literature and study aim as well as designed via consensus with 4 researchers. *Q6: Has the relationship between researcher and participants been adequately considered?* No - No description of potential bias/influence between researcher and participants (particularly an issue with recruitment method). An incentive (£20 voucher and light refreshments were given to the participants at the end of the focus group. No discussion regarding how that may impact findings. *Q7: Have ethical issues been taken into consideration?* Yes - Ethical approval received from University of Bedfordshire ethics board. Consent (parental for under 16s and individual for over 16s) process described and obtained from all participants. *Q8: Was the data analysis sufficiently rigorous?* Can't tell. Reports that a framework approach was used, and that the research team met regularly to discuss emerging patterns and themes. Themes were finalised via consensus. Multiple quotes to support and contradictory data is presented and taken into account. However, no mention of how many researchers

Study details	Participants	Methods	Themes and findings	Limitations
				were involved in analysis (at any of the time points), or how raw data quotes were chosen for reporting. No examination of bias in the study. *Q9: Is there a clear statement of findings?* Yes. Findings are well described, with discussion of multiple views and experiences that were captured in the focus groups. Related to both original research question and current literature. Credibility not discussed. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* Yes - Nature of review question in highlighting other areas important to babies, children and young people experience not previous identified means all are important. *Overall judgement of quality* Serious concerns **Other information** None.
Full citation Brady, Hospitalized Children's Views of the Good Nurse, 2009 **Ref Id** 1271880	**Sample size** N=22 children **Characteristics** • Age (years) (n): ○ 7: 2 ○ 8: 4	**Setting** Inpatient paediatric wards in urban hospital **Sample selection** Staff in the hospital paediatric department were informed of the study before it began. The	**Results summarised under the following themes:** • Physical appearance of healthcare staff • Healthcare workers' uniforms **Findings**	**Limitations (assessed using the <u>CASP checklist for qualitative studies</u>).** *Q1 Was there a clear statement of the aims of the research?* Yes. *Q2 Was a qualitative methodology appropriate?* Yes.

Study details	Participants	Methods	Themes and findings	Limitations
Country/ies where the study was carried out Southeast England, UK **Study type** Qualitative **Aim of the study** To explore inpatient children's views of what characteristics make good nurses and bad nurses, in order to inform nursing practice. **Study dates** Winter between 2006-2007 **Source of funding** Not reported.	○ 9: 2 ○ 10: 4 ○ 11: 6 ○ 12: 4 • Gender (M/F): 11/11 • Ethnicity (n): ○ African: 1 ○ African-Chinese: 1 ○ Afro-Caribbean: 4 ○ Asian: 1 ○ Mixed race Afro-Caribbean: 2 ○ South America: 1 ○ White: 12 **Inclusion criteria** Participants had to: • Be able to communicate with researcher • Be able to provide informed consent **Exclusion criteria** Not reported.	author visited study wards several times per week to ask staff if they recommended any children to approach for recruitment. If so, the researcher met with the children and their parents to give them details of the study and answer any questions. A 2nd meeting was arranged for when they had time to consider participation, when consent was obtained. **Data collection** Children were asked by the researcher to draw a good and bad nurse. Drawings themselves were not analysed extensively, but used as a discussion tool by the researcher. A mixture of closed and open questions were asked to explore the drawings and reasoning behind them. **Data analysis** Constant comparative approach with the assistance of an 'experienced researcher'. Interviews were recorded and transcribed. Field notes were used to capture researcher's own thoughts and non-verbal cues. No further details reported.	Name and ID badges for hospital staff are an important safety feature. Children and young people highlighted the need for healthcare staff to be clean and hygienic in order to prevent spread of infection. The physical appearance of nurses was important to children and young people, who thought they should appear healthy, clean and 'graceful'. Hairstyles should be neat and professional, kept tied back for safety reasons. Good nurses should have a uniform that is well-kept, neat and clean, with sensible shoes.	*Q3 Was the research design appropriate to address the aims of the research?* Yes - Modified draw/write and tell method justified *Q4 Was the recruitment strategy appropriate to the aims of the research?* No - Ward staff identified children for the research to interview. Although the strict 4-month time frame justifies this, the selection bias that it introduces cannot be overlooked. Time given after explanation of the study for families to decide whether to participate. *Q5: Were the data collected in a way that addressed the research issue?* Yes - Adequate description of data collection methods, with justification given. First interview was used as a pilot of the questions, with no subsequent changes being made. 5 children did not want to participate in the drawing, which was noted along with reasons. No mention of a topic guide, although a few sample phrases were included in write up. Interviews were audio-recorded and transcribed. Saturation not reached due to 4-month time frame. *Q6: Has the relationship between researcher and participants been adequately considered?* Can't tell - Small section commenting on the

Study details	Participants	Methods	Themes and findings	Limitations
				need to address researcher preconceptions (although no information on how this was achieved) and the use of field notes to record researcher's own interpretations and non-verbal cues from participants. Not enough information to make a judgement. *Q7: Have ethical issues been taken into consideration?* Yes - Approval from local research ethics committee and the study hospital's Research and Development Committee. Informed consent and assent received. *Q8: Was the data analysis sufficiently rigorous?* Can't tell - Poor description of the analysis process and no explanation of how themes were derived. Analysis was carried out with 'experienced researcher' but no mention of independent coding. Mentions that researcher was unable to validate interview transcripts with children to ensure that they are accurate. Adequate presentation of data to support findings. Contradictory data discussed. *Q9: Is there a clear statement of findings?* Can't tell - Findings are not explicit, with concepts and quotes presented multiple times throughout the study. Good discussion of evidence for/against the findings. Only a brief discussion on the credibility of findings.

Study details	Participants	Methods	Themes and findings	Limitations
				Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability) Yes - Nature of review question in highlighting other areas important to babies, children and young people experience not previous identified means all are important. *Overall judgement of quality* Serious concerns **Other information** None.
Full citation Carlton, J., Identifying potential themes for the Child Amblyopia Treatment Questionnaire, Optometry and vision science: official publication of the American Academy of Optometry, 90, 867-873, 2013 **Ref Id** 1054073 **Aim of the study** Overall, to develop a paediatric disease specific	**Sample size** N=59 children **Characteristics** • Age (mean [range]): 6 years 3 months (3 years 9 months - 9 years 11 months) • Gender (M/F): 36/23 • Ethnicity (n): ○ Asian-Pakistani: 1 ○ Black: (African) 1 ○ Chinese: 1 ○ Mixed (white and Asian): 1 ○ White: 54 ○ Other: 1	**Setting** Eye clinics in Sheffield **Sample selection** Opportunistic recruitment of potential participants, identified after scheduled appointment at participating eye clinics. No further details reported. **Data collection** Average 6 min 15 sec semi-structured interviews using open ended questions, focusing on how amblyopia and its treatment affects children's lives. Although researchers did not wish to influence answers, answers were prompted to find out details that might not have otherwise been talked about. 7	**Results summarised under the following themes:** • Side-effects of treatment **Findings** The physical sensation of certain treatments (in this case, patches or glasses) can affect babies, children and young people quality of life, by causing pain or being uncomfortable.	**Limitations (assessed using the CASP checklist for qualitative studies).** *Q1 Was there a clear statement of the aims of the research?* Yes. *Q2 Was a qualitative methodology appropriate?* Yes. *Q3 Was the research design appropriate to address the aims of the research?* Yes - Semi-structured interviews justified. *Q4 Was the recruitment strategy appropriate to the aims of the research?* Yes - Opportunistic sampling used as it was not possible to identify participants before clinical examination (not explained but assuming so as not to limit participants as some diagnoses may occur at this

Study details	Participants	Methods	Themes and findings	Limitations
health related quality of life questionnaire for amblyopia (commonly known as lazy eye). This paper reports on the identification of potential items for inclusion in the CAT-QOL (Child Amblyopia Treatment Questionnaire). **Country/ies where the study was carried out** Sheffield, UK **Study type** Qualitative **Study dates** June 2009 - May 2010 **Source of funding** This study received support from National Institute for Health Research, via a Personal Development	• Sociodemographic group (measured using LSOA scores where higher scores = less deprivation) (n): ○ 0-6500: 21 ○ 6501-13,000: 7 ○ 13,001-19,500: 14 ○ 19,501-26,000: 12 ○ 26,001-32,500: 5 • Severity of amblyopia (at time of interview) (n): ○ Mild: 41 ○ Moderate: 11 ○ Severe: 7 **Inclusion criteria** Participants had to: • Be over 4 years old • Have a clinical diagnosis of amblyopia (previously or currently) **Exclusion criteria** Not reported.	interviews were conducted with only child present, the rest had parents in attendance. **Data analysis** Thematic framework analysis. Interviews were audio-recorded and transcribed verbatim. Initial codes and themes were developed by the 1st author, before arranging results into a draft instrument. 3 independent researchers who were experienced in qualitative research validated the appropriateness and accuracy of analysis before the draft instrument was designed.		appointment) and they didn't want to limit participant pool). Resulting sample was balanced for age, social class, and type of amblyopia treatment. No information on children who declined to participate. *Q5: Were the data collected in a way that addressed the research issue?* Yes - Adequate description of interview process, with justification of methods. Topic guide was used, which was formed from a literature review and previous focus groups with clinicians. The topic guide only included themes to be discussed, to prevent biasing the children's opinions on what should be included in the draft instrument. Slight modifications made to the interview process, with familiarisation techniques (beyond conversational, e.g. colouring) being stopped after initial few interviews due to being distracting. Interviews were audio-recorded and transcribed. 5 interviews terminated due to unresponsiveness but noted that data saturation reached. *Q6: Has the relationship between researcher and participants been adequately considered?* Can't tell - Lack of information presented on researcher's bias. *Q7: Have ethical issues been taken into consideration?* Yes - Ethical approval from NHS Research Ethics

Study details	Participants	Methods	Themes and findings	Limitations
Award research training fellowship.				Committee and study adhered to Declaration of Helsinki. Informed consent received before interviews. *Q8: Was the data analysis sufficiently rigorous?* Yes - Good description of analysis process and how themes were derived. Initial coding of transcripts and development of themes was done by 1st author. However, results were validated by 3 experienced qualitative researchers who evaluated the conceptual framework and checked transcripts for consistency. Good amount of data presented to support findings. No discussion of contradictory findings. *Q9: Is there a clear statement of findings?* Yes - Good discussion on the findings, with relation back to the original question. Adequate discussion concerning evidence surrounding the findings (both for and against) and the credibility of findings. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* Yes - Nature of review question in highlighting other areas important to babies, children and young people experience not previous identified means all are important.

Study details	Participants	Methods	Themes and findings	Limitations
				Overall judgement of quality No/minor concerns **Other information** None.
Full citation Fletcher, T., Glasper, A., Prudhoe, G., Battrick, C., Coles, L., Weaver, K., Ireland, L., Building the future: Children's views on nurses and hospital care, British Journal of Nursing, 20, 39-45, 2011 **Ref Id** 470328 **Country/ies where the study was carried out** South of England, UK **Study type** Qualitative **Aim of the study** To reflect children and young people's involvement in the development of a	**Sample size** N=69 children and young people • Arm 1: n=61 • Arm 2: n=8 **Characteristics** *Arm 1* • Age (n): ○ Pre-school: 8 ○ School age <11 years old: 28 ○ Young people >11 years old: 25 • Gender (M/F): 25/36 *Arm 2* Unclear age of young people at Connexions but the service is designed for age 13-19 years, or up to 25 years for those with learning difficulties and/or disabilities. **Inclusion criteria** Not reported. **Exclusion criteria**	**Setting** • Arm 1: Inpatient children's wards • Arm 2: Young people attending youth parliament at Connexions **Sample selection** Arm 1: Families were contacted during an appropriately safe part of hospital admission by designated play specialist who had been briefed on the project. Arm 2: Youth Parliament members were from one of the cities involved in the study, and were contacted through Connexions Headquarters (free information and advice service for young people). Before recruitment, they had a full visit to children's inpatient ward areas and were had the project explained to them. **Data collection** 'Draw and write/draw and tell technique. Arm 1: Specialised 'Draw and write' sheet created,	**Results summarised under the following themes:** • Pain management **Findings** Children wanted nurses to be able to provide distraction (e.g. play therapy and distraction therapy) during small procedures. Children wanted nurses to be able to keep them free from pain.	**Limitations (assessed using the <u>CASP checklist for qualitative studies</u>).** *Q1 Was there a clear statement of the aims of the research?* Yes. *Q2 Was a qualitative methodology appropriate?* Yes. *Q3 Was the research design appropriate to address the aims of the research?* Yes - Single interviews and focus groups justified. *Q4 Was the recruitment strategy appropriate to the aims of the research?* Can't tell - Recruitment appropriate for arm 1 of the study. No one approached refused to participate but target sample of 50 families per hospital was not achieved. There is a lack of information on how the special youth parliament was recruited and how many didn't want to participate. *Q5: Were the data collected in a way that addressed the research issue?* Can't tell - Draw and write/tell method was adequately described, with very good justification given. Settings well

Study details	Participants	Methods	Themes and findings	Limitations
new undergraduate nursing curriculum and in service developments in 2 children's hospitals. **Study dates** Summer 2010 **Source of funding** Not reported.	Not reported.	showing a fictional character called Sam in a hospital bed and space for drawings. Play specialists interviewed the children (using a full script), the results of which were used to draw a picture of Sam's nurse. Occasionally, parents or play specialists of pre-literate children were used a proxy to embellish certain aspects of the drawing. The reverse of the sheet was used to record child's age and any nurse characteristics they wanted to note specifically. Arm 2: Focus groups. Specialised 'Draw and write/tell' sheet created, showing a fictional character called Sam in 2 different settings. 1 was a neutral environment, symbolising Sam before hospital admission. Participants were asked to complete an annotated drawing about what babies, children and young people might think about before being admitted as an inpatient. The 2nd showed Sam in hospital, with children annotating it with what babies, children and young people might think about as an inpatient. **Data analysis** Data was coded using coloured highlighter pens		described, and the script given to play specialists for arm 1 is reported in full (although no mention of how it was developed). However, it is unclear if discussions with the children were recorded (e.g. audio, field notes) to ensure all discussion points were captured. No mention of data saturation. *Q6: Has the relationship between researcher and participants been adequately considered?* No - Good discussion on researcher bias, referencing other qualitative publications, but no information on how they considered it in their study. This is important considering the use of parental/play therapist proxies in arm 1 and focus groups in arm 2. *Q7: Have ethical issues been taken into consideration?* Can't tell - Briefly mentions that assent/consent was received from all participants, and that the play specialists were given instructions on how to gain consent. No mention of approval from ethics board. *Q8: Was the data analysis sufficiently rigorous?* Can't tell - Thematic analysis using highlighters. No presentation of supporting quotes or a description of how much data supports the findings. No mention of contradictory data, potential biases etc.

Study details	Participants	Methods	Themes and findings	Limitations
		which were used to identify common themes. Written embellishments from each drawing were separately transcribed and delineated for each child.		*Q9: Is there a clear statement of findings?* Yes - Good discussion on the findings, with relation back to the original question. Adequate discussion concerning evidence surrounding the findings (both for and against) and the credibility of findings. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* Yes - Nature of review question in highlighting other areas important to babies, children and young people experience not previous identified means all are important. *Overall judgement of quality* Moderate concerns **Other information** None.
Full citation Gibson, F., Shipway, L., Barry, A., Taylor, R. M., What's it like when you find eating difficult: Children's and parents' experiences of food intake, Cancer Nursing, 35, 265-277, 2012	**Sample size** • N=13 children • N adults=13 ○ Mother: n=9 ○ Father: n=3 ○ Mother and close relative: n=1 • Only views of children were analysed and included in the review **Characteristics**	**Setting** Specialised cancer centre in London **Sample selection** Eligible participants were introduced to the research team over 6 months by healthcare staff. No further details reported. **Data collection**	**Results summarised under the following themes:** • Hospital food **Findings** The majority of children disliked hospital food, describing it as 'hard', 'dodgy' and tasting 'funny'. The smell was the worst aspect, with	**Limitations (assessed using the <u>CASP checklist for qualitative studies</u>).** *Q1 Was there a clear statement of the aims of the research?* Yes. *Q2 Was a qualitative methodology appropriate?* Yes. *Q3 Was the research design appropriate to address the aims of the research?* Yes - Scrapbooks, diaries and interviews all justified.

Study details	Participants	Methods	Themes and findings	Limitations
Ref Id 1056156 **Country/ies where the study was carried out** London, UK **Study type** Qualitative **Aim of the study** To explore the experience of children and their families regarding food intake and management of nutrition while receiving chemotherapy. **Study dates** Not reported. **Source of funding** This study received support from the Olivia Hodson Fellowship Fund.	• Age (n [%]): ○ 4-6 years: 5 (38) ○ 7-12: 8 (62) • Gender (M/F): 5/8 • Ethnicity (n [%]): ○ Asian Pakistani: 2 (15) ○ White British: 10 (77) ○ White other: 1 (8) • Stage of treatment (n [%]): ○ Beginning: 6 (46) ○ Middle: 5 (39) ○ End: 2 (15) **Inclusion criteria** Participants had to: • Be aged 4-12 years old • Had a cancer diagnosis for 1 month or longer • Be receiving chemotherapy and 1 other treatment **Exclusion criteria** Not reported	1 month prior to interviews, children were given a single use camera and asked to take pictures and record their experiences of eating and food. This was to be done during 1 hospital admission and 1 period at home. If 4-6 years old, children were given scrapbooking supplies to create pictures. If 7-12 years old, children were given a diary. 15-40 minute interviews were then scheduled, allowing children to talk through their diaries and scrapbooks with 2 of the researchers. 1 would interview the child, with another taking notes. **Data analysis** Inductive thematic analysis. Field notes from child interviews were transcribed and analysed by 3 researchers. 1st stage involved independent coding by researchers, reading the scrapbooks and diaries to remain immersed in the data. Child transcripts were analysed individually and together with their parental counterpart. The team went on to develop a coding framework and identifying emerging themes. Any discrepancies were resolved through discussion.	aesthetics also mentioned. Children often refused hospital food, preferring to get their own food from outside the hospital.	*Q4 Was the recruitment strategy appropriate to the aims of the research?* Can't tell - No information provided about which healthcare staff introduced eligible participants, type of sampling carried out or information on families who decided not to take part. Study aimed to recruit 24 participants, 4 for each of the 6 identified sample categories (stratified by stage of treatment (after 1st course of treatment, middle of treatment, end of treatment) and nutritional risk (low or high risk). Only 13 were recruited. *Q5: Were the data collected in a way that addressed the research issue?* Yes - Photo elicitation 'auto driven' interviews well described and justified. The instructions of how to complete scrapbooks/diaries were given in written form and contact was maintained throughout the month long process. Settings described, and all child interviews happened without parents in attendance. Topic guide not needed for this type of interview. Interviews were not audio-recorded, and only field notes were taken. An attempt to increase accuracy of data and decrease resulting bias this was made by ensuring a 2nd research completed this, who was not involved in the interviewing.

Study details	Participants	Methods	Themes and findings	Limitations
				Q6: Has the relationship between researcher and participants been adequately considered? No - Lack of information presented on researcher's bias. Possibility is decreased by using 2 researchers for data collection. However, study mentions that children received a gift voucher at the end of the interview with no details given about if they were made aware before the interview, or how much it was for. *Q7: Have ethical issues been taken into consideration?* Yes - Ethical approval from NHS trust and local research ethics committee. Children's understanding of and assent to the study was determined using age-appropriate techniques. No information on consent from parents/guardians. *Q8: Was the data analysis sufficiently rigorous?* Yes - Good description of the analysis process and how themes were derived. Analysis included 3 independent researchers, with overall themes being discussed by the team as a whole. Good amount of data presented to support findings. Contradictory data included. *Q9: Is there a clear statement of findings?* Yes - Good discussion on the findings, with relation back to the original question. Adequate discussion concerning evidence surrounding the

Study details	Participants	Methods	Themes and findings	Limitations
				findings (both for and against) and the credibility of findings. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* Yes - Nature of review question in highlighting other areas important to babies, children and young people experience not previous identified means all are important. *Overall judgement of quality* Minor concerns **Other information** Semi-structured interviews were carried out with parents as well. However, due to the age of participants, these are outside of our protocol and, where possible, data has not been extracted.
Full citation Heath, G., Greenfield, S., Redwood, S., The meaning of 'place' in families' lived experiences of paediatric outpatient care in different settings: A descriptive phenomenological study, Health and Place, 31, 46-53, 2015	**Sample size** • N=14 children and young people ○ Hospital outpatient: n = 8 ○ Community clinic outpatient: n = 6 • N=13 adults ○ Hospital outpatient: n = 7 ○ Community clinic outpatient: n = 6 • Only views of children and young people were analysed and included in the review	**Setting** Paediatric outpatient clinic **Sample selection** Purposive sampling. Families were approached in person while in the waiting area for general paediatric clinic, and via a letter for families who had received an appointment at general paediatric clinic. Participants were selected through their experience with attending appointments in 1 of	**Results summarised under the following themes:** • Boredom while waiting • Community connections **Findings** Older children felt frustrated and bored when waiting between appointments (multiple	**Limitations (assessed using the CASP checklist for qualitative studies).** *Q1 Was there a clear statement of the aims of the research?* Yes. *Q2 Was a qualitative methodology appropriate?* Yes. *Q3 Was the research design appropriate to address the aims of the research?* Yes - Semi-structured interviews justified.

Study details	Participants	Methods	Themes and findings	Limitations
Ref Id 989549 **Country/ies where the study was carried out** Birmingham/West Midlands, UK **Study type** Qualitative **Aim of the study** To explore paediatric outpatient care as experienced by patients and parents, focusing on the impact of healthcare setting. **Study dates** Not reported. **Source of funding** This study received support from National Institute for Health Research via Collaborations for Leadership in Applied Health Research and Care	**Characteristics** Not reported. **Inclusion criteria** Not reported. **Exclusion criteria** Not reported (although a lower age limit of 'approximately 8 years' was noted).	3 settings (hospital, health centre, children's centre). **Data collection** Semi-structured interviews. Each interview began with an overarching question about the decision to attend the clinic, followed by a description of their last visit. After this, responses were tailored to participant's stories and care experiences. No further details reported. **Data analysis** Descriptive phenomenology. Interviews were audio-recorded and transcribed. Researchers familiarised themselves with the data, dividing them into units of meaning before developing codes and themes. These themes were organised into experiences found in hospital settings and those found in community settings. Variations between these 2 settings were compared and highlighted.	appointments at the same healthcare provider). These feelings were increased if there was not enough communication on how long the wait would be. Community clinics should be involved in the community, not just located there, to facilitate relationships with babies, children and young people.	*Q4 Was the recruitment strategy appropriate to the aims of the research?* Can't tell - Purposive sampling used to ensure each setting was covered, with a range of demographic characteristics ensured (including age, sex, ethnicity and geographical distance from hospital). However, lack of reported demographics, inclusion criteria and exclusion criteria mean that it is not possible to see whether the final sample was representative. *Q5: Were the data collected in a way that addressed the research issue?* Can't tell - Interviews justified but poorly described. Interviews were driven by interviewee so no use of topic guides, and no mention of much the methods deviated between participants. Interviews were conducted at a time and place of participants choosing, with discussion on how place of interview might affect the answers. Interviews were audio-recorded and transcribed. No mention of data saturation. *Q6: Has the relationship between researcher and participants been adequately considered?* Can't tell - Researcher's reflected answers back to participants and asked to explain their use of descriptive words in order to confirm understanding of their experience. However, lack of

Study details	Participants	Methods	Themes and findings	Limitations
for Birmingham and Black Country programme.				information on other aspects of the interview limits certainty. *Q7: Have ethical issues been taken into consideration?* Yes - Ethical approval from West Midlands NHS Research Ethics Committee and informed consent received from all parents. Informed assent was received from young people. *Q8: Was the data analysis sufficiently rigorous?* Yes - Confusing description of analysis process and how themes were derived, but accurate. Good presentation of data to support findings. No mention of multiple or independent analysis. Discussion of contradictory data. Researcher bias was discussed and limited by acknowledging existing views and preventing attributing false importance to certain aspects by treating all areas of an experience as equally important. *Q9: Is there a clear statement of findings?* Yes - Good discussion on the findings, with relation back to the original question. Adequate discussion concerning evidence surrounding the findings (both for and against) and the credibility of findings. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* Yes - Nature of

Study details	Participants	Methods	Themes and findings	Limitations
				review question in highlighting other areas important to babies, children and young people experience not previous identified means all are important. *Overall judgement of quality* Moderate concerns **Other information** Parents were also interviewed during this study. However, as children participants were over 5 years old, data was not extracted for this population where possible.
Full citation Law, H., Gee, B., Dehmahdi, N., Carney, R., Jackson, C., Wheeler, R., Carroll, B., Tully, S., Clarke, T., What does recovery mean to young people with mental health difficulties?- "It's not this magical unspoken thing, it's just recovery", Journal of Mental Health, 2020 **Ref Id** 1280080	**Sample size** N=23 young people • n=15 under 18 years • n=8 > 18 years **Characteristics** • Age (years, n): ○ 14-17: 15 ○ 18-21: 5 ○ 22-25: 3 • Gender (M/F/non-binary): 4/18/1 • Ethnicity (n): ○ White British: 20 ○ Asian Pakistani: 1 ○ White Other: 1 ○ Other: 1	**Setting** In the community **Sample selection** Participants recruited using convenience sampling from Norfolk and Suffolk NHS Foundation Trust (n=11) and Greater Manchester Mental Health NHS Foundation Trust (n=12). Referrals received from participants themselves (self-referral) or via youth mental health service professionals. Consent forms obtained or when appropriate, consent forms from parents/guardians obtained where required and assent form from participant. **Data collection details**	**Results summarised under the following themes:** • Benefits and harms of a diagnosis **Findings** For young people, receiving a diagnosis can be a dual-edged sword. It can help to explain symptoms and reassure patients that they have a cause that can be treated. However, it can also be an unwelcome label, especially if not much is understood about their condition.	**Limitations (assessed using the <u>CASP checklist for qualitative studies</u>).** Q1: *Was there a clear statement of the aims of the research?* Yes. Q2: *Was a qualitative methodology appropriate?* Yes. Q3: *Was the research design appropriate to address the aims of the research?* Can't tell. No justification for use of interview provided. Q4: *Was the recruitment strategy appropriate to the aims of the research?* Yes. Q5: *Were the data collected in a way that addressed the research issue?* Yes.

Study details	Participants	Methods	Themes and findings	Limitations
Country/ies where the study was carried out East Anglia and Greater Manchester, UK **Study type** Qualitative **Aim of the study** To understand young people's concept of mental health recovery. **Study dates** Not reported **Source of funding** Not reported	• Duration of access to mental health services (years, n): ○ <1: 5 ○ 1-3: 10 ○ 4-7: 4 ○ >7: 4 **Inclusion criteria** Participants had to: • Be aged between 14 and 25-years old. • Speak English • Be currently receiving services from mental health trusts **Exclusion criteria** Not reported	Interview schedule developed with local Youth Council members. Semi-structured organic interviews conducted at location of participants' choice with individual interviews guided by participant's responses to questions. Topics in interview included background history of mental health difficulties and access of services, understanding of the word 'recovery' generally and what it means to them, and personal experience of recovery including what has helped or hindered recovery. Interviews recorded and transcribed verbatim. **Analysis details** Thematic analysis conducted to understand each participant's unique perspective. Analysis data-driven and coding using participant's own language conducted. Bottom-up approach followed beginning with familiarisation with dataset, then initial independent code generation (by 2 of the authors), search for themes, review of themes for internal and external homogeneity and to ensure coherence, and finally defining		Q6: *Has the relationship between researcher and participants been adequately considered?* Yes. Q7: *Have ethical issues been taken into consideration?* Yes. Ethical approval for study obtained from East of England - Cambridge Central Research Ethics Committee (Ref: 17/EE/0231). Q8: *Was the data analysis sufficiently rigorous?* Yes. Q9: *Is there a clear statement of findings?* Yes. Q10: *Is the research valuable for the UK?* Yes. 1. Yes, discusses in context of literature. 2. Possibly yes. Nature of topic (mental health recovery) and use of convenience sampling risking sample bias limits applicability of findings to young people generally; also includes 8 participants over-18 . *Overall judgement of quality:* Minor concerns. **Other information** Study also involved participants 18-25 years old. However, these participants are outside the protocol population and data was not extracted where possible.

Study details	Participants	Methods	Themes and findings	Limitations
		and naming of themes. Any discrepancies discussed by all authors. Process of reflexivity used to bracket researchers own beliefs/preconceptions.		

F: Female; M: Male; N: Number; NHS: National Health Service; LSOA: Lower Layer Super Output Area

Evidence tables for review question 4.1b What factors are important to babies, children and young people to improve their experience of healthcare? (Quantitative)

Table 14: Evidence tables

Study details	Participants	Survey	Methods	Results	Comments
Full citation Bryans, A., Camilleri-Brennan, J., Hua, L., Patel, N., Price, R., Browning, J., What do adolescents want from their ED? An evaluation on the preferences and opinions of adolescents attending local EDs, Emergency medicine journal, 35, 675-679, 2018 **Ref Id** 987547 **Country/ies where the study was carried out** UK **Study type** Cross-sectional survey	**Sample size** N=2,904 A&E attendees **Characteristics** • Age: 12-16 years (mean 13.8) • Gender: 133 male:121 female • Site: Royal Hospital for Sick Children (42 responses) and Royal Infirmary Edinburgh (212 responses) **Inclusion criteria** • Age: 12-16 • Attending emergency departments at The Royal Hospital for Sick Children or The Royal Infirmary of Edinburgh. **Exclusion criteria** Adolescents who:	**Methodological details** Questionnaires distributed to adolescents attending the emergency departments of Royal Hospital for Sick Children (12 years old) and The Royal Infirmary Edinburgh (13-16 years old). Questionnaires were given upon entrance to A&E by reception staff and nurses, and completed in the waiting room. Interviews were conducted with a convenience sample to obtain quotes from adolescents and were taken by medical students using an interview template to ensure consistency with the written questionnaire. Interviewers were available between 9:00-18:00, Monday-Friday. **Questionnaire details** A new adolescent-specific questionnaire developed guided by existing	**Recruitment details** An estimated 10% representative figure and previous analysis of adolescent attendees in a 6 month period equalled a target sample size of 300 attendees. Consecutive sampling of adolescents attending either The Royal Hospital for Sick Children or The Royal Infirmary of Edinburgh. Interviews were conducted with a convenience sample of 38 attendees. **Data analysis details** An estimated 10% representative figure and previous analysis of adolescent attendees in a 6 month period equalled a 300 attendee sample size. Quantitative data was entered into Microsoft Excel. Likert scale responses were treated as ordinal data without the assumption of interval-level measurement.	**Results** Respondents: 254 (216 questionnaires, 38 interviews) Response rate: 8.8% Reports data on healthcare factors rated by importance, single most important factor and preference for treatment on adult or children's A&E. Please see table 3, figure 1 and figure 2 for a comprehensive list of experiences.	**Limitations** **Risk of bias assessed using <u>CEBMa critical appraisal tool for a survey</u>** Q1 *Did the study address a clearly focused question/issue?* Yes. Q2 *Is the research method (study design) appropriate for answering the research question?* Yes. Q3 *Is the method of selection of the subjects clearly described?* Yes. Q4 *Could the way the sample was obtained introduce (selection) bias?* Yes. Researchers only on-site 9:00-18:00, Monday to Friday. At other times, questionnaires were distributed by nurses and staff upon adolescent presenting at A&E, and completed in the waiting room. Given the waiting times associated with peak times at A&E, this may not have occurred (or occurred sporadically) during busy periods. Additionally,

Study details	Participants	Survey	Methods	Results	Comments
Aim of the study To determine the factors of emergency healthcare that are important to young people, and use these to inform future A&E services. **Study dates** Feb 2015 - Aug 2015 **Source of funding** None declared in the public, commercial or not-for-profit sectors.	• Required emergency treatment • Were not able to speak English • Had previously completed the survey during a previous A&E visit	literature on patient satisfaction. In comparison to existing questionnaires, it was designed to be short and simple to complete, maximising adolescent involvement. It was reviewed by emergency department professionals before implementation, and amended based on their suggestions prior to the study period. Questionnaires were presented in a 5-point Likert scale (1 = low importance, 5 = high importance) and qualitative questions. An interview template was designed at the same time to ensure consistency with the written questionnaire.	Missing data and questions with more than 1 answer selected were excluded from analysis.		parents/carer were in attendance and may have affected desire to complete survey or answers. Q5 *Was the sample of subjects representative with regard to the population to which the findings will be referred?* Unsure. Edinburgh has 8% ethnic minority population. Additionally, inability to speak English was an exclusion criterion for the survey. Q6 *Was the sample size based on pre-study considerations of statistical power?* Unsure. Noted that the study aimed for 10% sample representation of the estimated 3,000 adolescent attendees in a 6 month period. However, not information given on why 10% was the target. Q7 *Was a satisfactory response rate achieved?* Probably not. Response rate was 8.8% (256), which was under the estimated 10%. Some discrepancy in the report as the discussion section states that they were unable to calculate the response rate due to issues identifying non-eligible adolescents.

Study details	Participants	Survey	Methods	Results	Comments
					Q8 *Are the measurements (questionnaires) likely to be valid and reliable?* Unsure. No piloting process described with adolescents, and they were not consulted in the development process. No mention of inter-rater reliability or test-retest reliability. Q9 *Was the statistical significance assessed?* No. Q10 *Are confidence intervals given for the main results?* No. Q11 *Could there be confounding factors that haven't been accounted for?* Survey was completed while adolescents were sitting in the waiting room. During periods with a long wait-time, this may have affected the importance attributed to temporal factors. Q12 *Can the results be applied to your population?* Probably. However, it should be noted that this is a very specific population. **Overall judgement of quality** Very low quality

Study details	Participants	Survey	Methods	Results	Comments
					Other information The verbal interview had an additional 4 open-ended questions and 1 closed question, designed to gain qualitative data. However, no qualitative analysis was performed, and no data extraction of qualitative responses has occurred.
Full citation Hopwood, B., Tallett, A., Little voice: giving young patients a say, Nursing times, 107, 18-20, 2011 **Ref Id** 817938 **Country/ies where the study was carried out** UK **Study type** Cross-sectional survey **Aim of the study** To design a paediatric questionnaire to obtain reliable	**Sample size** N=11,900 outpatients (n=850 from each of 14 NHS trusts) **Characteristics** Not reported. **Inclusion criteria** • Aged 17 years old and under • Attending one of the 14 sampled acute NHS trusts in a specified month (not reported) **Exclusion criteria** Not reported.	**Methodological details** The questionnaires were piloted with 1,200 recent young outpatients in Sheffield before being rolled out. Surveys were posted out to recent outpatients of 14 acute NHS trusts in England. Questionnaire was aimed at parents for patients aged 7 and under, and at young people themselves if aged 8 and over. **Questionnaire details** 2 questionnaires developed to measure the experience of young outpatients, using existing adult and paediatric experience questionnaires. 1 questionnaire was aimed at the parents/carers of outpatients aged 7 and under, the other was	**Recruitment** Random sample of 850 patients from each of 14 acute NHS trusts in England during a specific month. **Data analysis** Not reported. Only percentages presented in article.	**Results** Respondents: 3,783 questionnaires Response rate: 33% • Young people questionnaire: 32% • Parental questionnaire: 34% Reports percentage scores for areas of experience such as overall care, cleanliness, communication and amenities. Please see table 4 and table 5 for a comprehensive list of experiences.	**Limitations** **Risk of bias assessed using CEBMa critical appraisal tool for a survey** Q1 *Did the study address a clearly focused question/issue?* Yes. Q2 *Is the research method (study design) appropriate for answering the research question?* Yes. Q3 *Is the method of selection of the subjects clearly described?* Yes. Q4 *Could the way the sample was obtained introduce (selection) bias?* Unsure. Large sample size over 14 acute NHS trust sites but no information reported on randomisation process, which month, location of acute trusts or which outpatient clinics participated.

Study details	Participants	Survey	Methods	Results	Comments
feedback from young people as hospital outpatients. **Study dates** 2009 - ? **Source of funding** Sheffield Children's Foundation Trust.		aimed at young outpatients over the age of 8. Parent questionnaire: 61 experience questions, 4 demographic questions, 4 free text questions. Young people's questionnaire (2 parts): Children had 34 experience questions, 3 demographic questions and 2 free text questions. Parents had 20 experience questions, 4 demographic questions and 1 free text question. Cognitive interviews informed the survey design, resulting in it being shortened, illustrations and colour being added, amended wording and some complex questions being removed. No further information provided on the method for cognitive testing.			Q5 *Was the sample of subjects representative with regard to the population to which the findings will be referred?* Unsure. No demographic data reported. Q6 *Was the sample size based on pre-study considerations of statistical power?* Unsure. No information reported. Q7 *Was a satisfactory response rate achieved?* Probably. 33% (3,783 completed surveys) Q8 *Are the measurements (questionnaires) likely to be valid and reliable?* Unsure. Article mentions cognitive testing used in the development of the questionnaire, but no further details after that. No mention of inter-rater reliability or test-retest reliability. Q9 *Was the statistical significance assessed?* No. Q10 *Are confidence intervals given for the main results?* No. Q11 *Could there be confounding factors that haven't been accounted for?* No information presented regarding data

Study details	Participants	Survey	Methods	Results	Comments
					analysis or on the format of questions e.g. Likert scale, smiley faces etc. Reported that 25% of the children's questionnaires were completed along with a parent and 9% by parents only. Strong reporting bias in the article regarding why certain results were selected for publication. Q12 *Can the results be applied to your population?* Probably. However, it should be noted that there is no demographic data presented. **Overall judgement of quality** Very low quality **Other information** None.

A&E: accident and emergency; CEBMa; Center for Evidence-Based Management; N: number; NHS: National Health Service

Appendix E – Forest plots

Forest plots for review question 4.1a What factors are important to babies, children and young people to improve their experience of healthcare services? (Qualitative)

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

Forest plots for review question 4.1b What factors are important to babies, children and young people to improve their experience of healthcare? (Quantitative)

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

Appendix F – GRADE tables

GRADE-CERQual tables for review question 4.1a What factors are important to babies, children and young people to improve their experience of healthcare services? (Qualitative)

Table 15: Evidence summary for theme 1: Benefits and harms of a diagnosis

Study information		**Description of theme or finding**	**CERQUAL Quality assessment**				
No of studies	**Design**		**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
1 (Law 2020)	Semi-structured interview	Evidence from 1 study shows that young people view receiving a diagnosis as a good and a bad thing. Benefits include a sense of relief from understanding that there is an explanation for their symptoms and that there are treatment options available. These could be medications, or coping strategies that young people can learn to employ. However, if the diagnosis is vague or under researched, the opposite might occur. Young people feel frustrated with the lack of knowledge and definite answers which might lead young people to become disengaged with their healthcare. *'Diagnoses themselves they are a double edge sword. They are very useful for clearing up potential issues trying to think about what may be the cause for something and especially if you have a definite answer. They can be very helpful but to an extent they can also be less helpful maybe even harmful if say there is that lack of any*	Minor concerns[1]	No/very minor concerns	Minor concerns[2]	Serious concerns[3]	VERY LOW

Study information		Description of theme or finding	CERQUAL Quality assessment				
No of studies	Design		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
		sort of knowledge or education around it' (Law 2020, page 470)					

1 Evidence was downgraded due to minor concerns about methodological limitations as per CASP qualitative checklist
2 Evidence was downgraded due to minor concerns over the relevance of the evidence, as the study included participants above 18 years old
3 Evidence was downgraded for adequacy because studies together did not offer rich data

Table 16: Evidence summary (GRADE-CERQual) for theme 2: Community connections

Study information		Description of theme or finding	CERQUAL Quality assessment				
No of studies	Design		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
2 (Ali 2017, Heath 2015)	Focus group, semi-structured interview	Evidence from 2 studies suggest that healthcare services should make connections with the local community, not just be located there. Sharing cultures and experiences helps to facilitate building relationships with children and young people. *'someone with a similar viewpoint…like you are a Pakistani as well and you kind of understand so if it was a White person they wouldn't understand our issues' (Ali 2017, page 30)*	Moderate concerns[1]	No/very minor concerns	Minor concerns[2]	Serious concerns[3]	VERY LOW

1 Evidence was downgraded due to moderate concerns about methodological limitations as per CASP qualitative checklist
2 Evidence was downgraded due to minor concerns about the relevance of evidence as it contains 1 study which includes participants up to the age of 19 years.
3 Evidence was downgraded for adequacy because studies together did not offer rich data

Table 17: Evidence summary (GRADE-CERQual) for theme 3: Hospital food

Study information		Description of theme or finding	CERQUAL Quality assessment				
No of studies	**Design**		**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
1 (Gibson 2012)	Scrapbook/ diaries and interview	Evidence from 1 study showed that hospital food is unappealing, with many children reporting it smells and looks bad. They often refused hospital food, preferring to get their own food from outside the hospital. *'I don't like hospital food, I don't like the taste of it, so I wait for dad. He's a chef so I wait for him.' (Gibson 2012, page 270)*	Minor concerns[1]	No/very minor concerns	No/very minor concerns	Serious concerns[2]	VERY LOW

1 Evidence was downgraded due to minor concerns about methodological limitations as per CASP qualitative checklist
2 Evidence was downgraded for adequacy because study did not offer rich data

Table 18: Evidence summary (GRADE-CERQual) for theme 4: Pain management

Study information		Description of theme or finding	CERQUAL Quality assessment				
No of studies	**Design**		**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
1 (Fletcher 2011)	Participatory-based activities, focus group, individual interview or focus group	Evidence from 1 study showed that children and young people wanted healthcare professionals to provide adequate pain management and to be able to distract them during small procedures. No quotes presented for this theme.	Moderate concerns[1]	Minor concerns[2]	Minor concerns[3]	Serious concerns[4]	VERY LOW

1 Evidence was downgraded due to moderate concerns about methodological limitations as per CASP qualitative checklist
2 Evidence was downgraded due to minor concerns about the coherence of the findings, as distraction management was not explicitly related to pain management
3 Evidence was downgraded due to minor concerns over the relevance of the evidence, as the study was only exploring children's attitudes to nurses rather than healthcare professionals in general
4 Evidence was downgraded for adequacy because study did not offer rich data

Table 19: Evidence summary (GRADE-CERQual) for theme 5: Physical appearance of healthcare staff

Study information		Description of theme or finding	CERQUAL Quality assessment				
No of studies	**Design**		**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
1 (Brady 2009)	Participatory-based activities and semi-structured interview	Evidence from 1 study showed that the physical appearance of healthcare staff was important to children who thought they should appear healthy, clean and 'graceful'. This was linked to hygiene and preventing the spread of infection. No quotes presented for this theme.	Serious concerns[1]	No/very minor concerns	Minor concerns[2]	Serious concerns[3]	VERY LOW

1 Evidence was downgraded due to serious concerns about methodological limitations as per CASP qualitative checklist
2 Evidence was downgraded due to minor concerns over the relevance of the evidence, as the study was only exploring children's attitudes to nurses rather than healthcare professionals in general
3 Evidence was downgraded for adequacy because study did not offer rich data

Table 20: Evidence summary (GRADE-CERQual) for theme 6: Religion as a source of support

Study information		Description of theme or finding	CERQUAL Quality assessment				
No of studies	**Design**		**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
1 (Ali 2017)	Focus group	Evidence from 1 study found that religion is an important resource to young people when dealing with health problems, particularly mental health issues. This appears to stem from the belief that mental health is not purely a medical problem, but had a spiritual component. Religious texts can be used to provide guidance, as well as possibly providing treatment for mental health issues. '*Yeah because in the Quran there are certain verses that you can read to help you.' (Participant 1)'…and*	Serious concerns[1]	No/very minor concerns	Minor concerns[2]	Serious concerns[3]	VERY LOW

Study information		Description of theme or finding	CERQUAL Quality assessment				
No of studies	Design		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
		cure the illness' (Participant 2) (Ali 2017, page 38)					

1 Evidence was downgraded due to serious concerns about methodological limitations as per CASP qualitative checklist
2 Evidence was downgraded due to minor concerns about the relevance of evidence as it contains 1 study which includes participants up to the age of 19 years.
3 Evidence was downgraded for adequacy because study did not offer rich data

Table 21: Evidence summary (GRADE-CERQual) for theme 7: Side-effects of treatment

Study information		Description of theme or finding	CERQUAL Quality assessment				
No of studies	Design		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
1 (Carlton 2013)	Semi-structured interview	Evidence from 1 study showed that treatment of a condition or disease can also cause pain and discomfort for children. In turn, this affects quality of life for children (for example, preventing them from taking part in activities with peers), particularly with treatments that have to be worn or applied regularly throughout the day. *'it feeled that when I took it off it hurted, and when I weared it, it tickled' (Carlton 2013, page 870)*	No/minor concerns	No/very minor concerns	No/very minor concerns	Serious concerns[1]	VERY LOW

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

Table 22: Evidence summary (GRADE-CERQual) for theme 8: Healthcare workers' uniforms

Study information		Description of theme or finding	CERQUAL Quality assessment				
No of studies	Design		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
1 (Brady 2009)	Participatory-based activities and semi-	Evidence from 1 study showed that children believed that healthcare workers should wear a uniform that is well-kept, neat and clean, with	Serious concerns[1]	Minor concerns[2]	Minor concerns[3]	Serious concerns[4]	VERY LOW

Study information		Description of theme or finding	CERQUAL Quality assessment				
No of studies	**Design**		**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
	structured interview	sensible shoes. A tidy, neat appearance was associated with professionalism and efficiency of healthcare professionals. If a healthcare professional was unkempt or appeared visibly unhealthy, children believed that they would not be able to provide good, safe healthcare. Additionally, a uniform should include a visible name or identification badge. This was highlighted by some children as an important safety measure, and a way of validating their carers. *'Cos like, I don't know them ... I would say show me your pass and stuff.' (Brady 2009, page 552)*					

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

2 Evidence was downgraded due to minor concerns over coherence as the contributing study identified the uniform theme in 2 separate contexts (1 was to do with confidence in healthcare staff and the other was to do with safety in the hospital)

3 Evidence was downgraded due to minor concerns over the relevance of the evidence, as the study was only exploring children's attitudes to nurses rather than healthcare professionals in general

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

Table 23: Evidence summary (GRADE-CERQual) for theme 9: Boredom while waiting

Study information		Description of theme or finding	CERQUAL Quality assessment				
No of studies	**Design**		**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
1 (Heath 2015)	Semi-structured interview	Evidence from 1 study showed that waiting for or between appointments was a factor that affected young people's healthcare experiences.	Moderate concerns[1]	No/very minor concerns	Minor concerns[2]	Serious concerns[3]	VERY LOW

Study information		Description of theme or finding	CERQUAL Quality assessment				
No of studies	**Design**		**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
		Young people felt frustrated and bored when waiting between multiple appointments at the same healthcare setting. These feelings were increased if there was not enough communication on how long the wait would be. *'I was sitting there thinking how bored and what a waste of time it was just sitting there for ages but, like, I didn't really have anything to do so I just sat there and waited.' (page 49, Heath 2015)*					

1 Evidence was downgraded due to moderate concerns about methodological limitations as per CASP qualitative checklist
2 Evidence was downgraded due to minor concerns about the relevance of evidence, as this theme was only highlighted in the older children participating in the study
3 Evidence was downgraded for adequacy because study did not offer rich data

GRADE tables for review question 4.1b What factors are important to babies, children and young people to improve their experience of healthcare? (Quantitative)

No GRADE analysis was conducted for this review and so there are no GRADE tables.

Appendix G – Economic evidence study selection

Economic evidence study selection for review question 4.1a What factors are important to babies, children and young people to improve their experience of healthcare services? (Qualitative)

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

Economic evidence study selection for review question 4.1b What factors are important to babies, children and young people to improve their experience of healthcare? (Quantitative)

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

Appendix H – Economic evidence tables

Economic evidence tables for review question 4.1a What factors are important to babies, children and young people to improve their experience of healthcare services? (Qualitative)

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

Economic evidence tables for review question 4.1b What factors are important to babies, children and young people to improve their experience of healthcare? (Quantitative)

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

Appendix I – Economic evidence profiles

Economic evidence profiles for review question 4.1a What factors are important to babies, children and young people to improve their experience of healthcare services? (Qualitative)

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

Economic evidence profiles for review question 4.1b What factors are important to babies, children and young people to improve their experience of healthcare? (Quantitative)

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

Appendix J – Economic analysis

Economic evidence analysis for review question 4.1a What factors are important to babies, children and young people to improve their experience of healthcare services? (Qualitative)

No economic analysis was conducted for this review question.

Economic evidence analysis for review question 4.1b What factors are important to babies, children and young people to improve their experience of healthcare? (Quantitative)

No economic analysis was conducted for this review question.

Appendix K – Excluded studies

Excluded studies for review question 4.1a What factors are important to babies, children and young people to improve their experience of healthcare services? (Qualitative)

Clinical studies

Table 24: Excluded studies and reasons for their exclusion

Study	Reason for exclusion
Abbas, F., Luhar, A., Terry, D., Swallowing medicines: A study of paediatric patients, Archives of disease in childhood, 99 (8), e3, 2014	Conference abstract
Abid, S., Greenshields, N., Lowe, J., Survey of stakeholders of a paediatric anaesthetic room, Archives of disease in childhood, 103 (Supplement 1), A163-A164, 2018	Conference abstract
Abrines Jaume, N., Hoffman, J., Wolpert, M., Law, D., Wright, E., Shared decision making in child and adolescent mental health services, Neuropsychiatrie de l'Enfance et de l'Adolescence, 1), S294, 2012	Conference abstract
Ahmed, A., Chu, D., Wang, S., Current Caregiver Perspectives and Effects of Demographics on Family-Centered Rounds, Clinical Pediatrics, 57, 694-699, 2018	Country not included in protocol - USA
Ahmed, S., Ihe, C., Findings from a pre-clinic questionnaire given prior consultation at an NHS paediatric diabetes outpatient service in England-the patient's perspective: A survey of patient/carer experience of a paediatric diabetes outpatient service, Pediatric Diabetes, 17 (Supplement 24), 127-128, 2016	Conference abstract
Ahuja, Alka S., Williams, Richard, Telling stories: Learning from patients' and families' experiences of specialist child and adolescent mental health services, International Journal of Consumer Studies, 34, 603-609, 2010	Population not included in protocol – Included 15 families of CAMHS attenders but babies, children and young people only participated in 2/15 interviews.
Ainsworth, S., Raiising awareness of invisible illnesses in schools and education, Annals of the rheumatic diseases, 77 (Supplement 2), 10, 2018	Conference abstract
Ainsworth, S., Ainsworth, J., Preston, J., Stones, S., Challinor, R., Rowe, M., Introducing RAiISE-raising awareness of invisible illnesses in schools and education, Pediatric Rheumatology, 15 (Supplement 2), 67-68, 2017	Conference abstract
Akhtar, M. A., Honeyman, C., Aziz, F., Greenough, C., Kalyan, R., Hekal, W., The sky's the limit: Raising the quality and scope of communication for children with scoliosis and their families using digital and social media, British journal of neurosurgery, 30 (2), 177, 2016	Conference abstract
Akhter, K., Dockray, S., Simmons, D., Exploring factors influencing non-attendance at the diabetes clinic and service improvement strategies from patients' perspectives, Practical Diabetes, 29, 113-116, 2012	Population not included in protocol - Adults over 25 years old
Albutt, A. K., O'Hara, J. K., Conner, M. T., Fletcher, S. J., Lawton, R. J., Is there a role for patients and their relatives in escalating clinical deterioration in hospital? A systematic review, Health ExpectationsHealth Expect, 20, 818-825, 2017	Population of included studies not in protocol. Included studies checked for inclusion.

Study	Reason for exclusion
Alexander, S., Bath, L., McDonald, M., Adolescent diabetic outpatient clinics-more than just an HbA1c, Archives of disease in childhood, 101 (Supplement 1), A275-A277, 2016	Conference abstract
Allsop, M. J., Holt, R. J., Evaluating methods for engaging children in healthcare technology design, Health and Technology, 3, 295-307, 2013	Phenomenon of interest not included in protocol - Description of engagement in different data collection methods but no qualitative data from babies, children and young people included
AlQuraini, N., Shah, R., Cunningham, S. J., Perceptions of outcomes of orthodontic treatment in adolescent patients: a qualitative study, European journal of orthodontics, 25, 25, 2019	Phenomenon of interest not included in protocol - No factors identified that are important babies, children and young people to improve their healthcare experience that haven't been covered in previous reviews
Amin, A., Oragui, E., Khan, W., Puri, A., Psychosocial considerations of perioperative care in children, with a focus on effective management strategies, Journal of perioperative practice, 20, 198-202, 2010	Review article
Anonymous,, The development and analysis of feedback from a pilot chronic pain group at the Royal Manchester Children's Hospital, Rheumatology (united kingdom), 56 (Supplement 7), vii30, 2017	Conference abstract
Arain, M., Nicholl, J., Campbell, M., Patients' experience and satisfaction with GP led walk-in centres in the UK; a cross sectional study, BMC health services research, 13, 142, 2013	Study design includes qualitative interviews but results not presented in this article. Checked for published qualitative findings and none identified.
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, Journal of Clinical Nursing, 27, 375-385, 2018	Phenomenon of interest not included in protocol - No factors identified that are important babies, children and young people to improve their healthcare experience that haven't been covered in previous reviews
Armitage, S., Swallow, V., Kolehmainen, N., Ingredients and change processes in occupational therapy for children: a grounded theory study, Scandinavian journal of occupational therapy, 24, 208-213, 2017	Phenomenon of interest not included in protocol - No factors identified that are important babies, children and young people to improve their healthcare experience
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, Patient, 12, 199-212, 2019	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Aston, Hermione J., Lambert, Nathan, Young people's views about their involvement in decision-making, Educational Psychology in Practice, 26, 41-51, 2010	Setting not included in protocol - Shared decision making in education only
Aston, J., Wilson, K., Terry, D., Starting a new medicine study, Archives of disease in childhood, 101 (9), A28, 2016	Conference abstract
Balaguer, I., Duda, J. L., Castillo, I., Motivational Antecedents of Well-Being and Health Related Behaviors in Adolescents, Journal of Human Kinetics, 59, 121-130, 2017	Study design not included in protocol - Quantitative methods only
Bali, A., Robinson, K., Lakhanpaul, M., Cross, J. H., Involving children and young people in identifying ways to improve epilepsy care, Archives of disease in childhood, 103 (Supplement 2), A4, 2018	Conference abstract

Study	Reason for exclusion
Batt, N. M., Ahmetaga, A., Blackstock, S. J., Using a patient led 'comms chart' as a bedside information sharing tool to improve communication, Archives of disease in childhood, 101 (Supplement 1), A325-A326, 2016	Conference abstract
Baxter, S., Enderby, P., Evans, P., Judge, S., Barriers and facilitators to the use of high-technology augmentative and alternative communication devices: a systematic review and qualitative synthesis, International Journal of Language & Communication Disorders, 47, 115-29, 2012	Population of included studies not in protocol. Included studies checked for inclusion.
Becker, E. M., Wilson, B., Jr., Chen-Lim, M. L., Ely, E., The Experience of Pain and Pain Tool Preferences of Hospitalized Youth, Pain Management Nursing, 10, 10, 2019	Conference abstract
Beisbier, S., Laverdure, P., Occupation- and Activity-Based Interventions to Improve Performance of Instrumental Activities of Daily Living and Rest and Sleep for Children and Youth Ages 5-21: A Systematic Review, The American journal of occupational therapy : official publication of the American Occupational Therapy Association, 74, 2020	Systematic review; only quantitate studies were included
Bell, J., Finlay, F., Baverstock, A., Mobile phone use on a young person's unit, Paediatric Nursing, 21, 14-18, 2009	Study design not included in protocol - Quantitative data only
Bellis, J., Medicines in schools-A survey of stakeholders, Archives of Disease in Childhood. Conference: 22nd Annual Conference of the Neonatal and Paediatric Pharmacists Group. United Kingdom, 103, 2018	Conference abstract
Bellis, J. R., Arnott, J., Barker, C., Prescott, R., Dray, O., Peak, M., Bracken, L., Medicines in schools: A cross-sectional survey of children, parents, teachers and health professionals, BMJ paediatrics open, 1 (1) (no pagination), 2017	Outcomes not included in protocol - Only quantitative data presented for babies, children and young people
Bensted, R., Hargreaves, D. S., Lombard, J., Kilkelly, U., Viner, R. M., Comparison of healthcare priorities in childhood and early/late adolescence: analysis of cross-sectional data from eight countries in the Council of Europe Child-friendly Healthcare Survey, 2011, Child: care, health and development, 41, 160-165, 2015	Study countries of included studies not in protocol. Included studies checked for inclusion.
Best, Paul, Gil-Rodriguez, Elena, Manktelow, Roger, Taylor, Brian J., Seeking help from everyone and no-one: Conceptualizing the online help-seeking process among adolescent males, Qualitative health research, 26, 1067-1077, 2016	Phenomenon of interest not included in protocol - No factors identified that are important babies, children and young people to improve their healthcare experience that haven't been covered in previous reviews
Bharadwaj Padhye, S., Bilal, S., Jampala, C. S., Improving allergy services using patient feedback, Archives of Disease in Childhood, 99, A166, 2014	Conference abstract
Bice, A. A., Hall, J., Devereaux, M. J., Exploring Holistic Comfort in Children Who Experience a Clinical Venipuncture Procedure, Journal of Holistic Nursing, 36, 108-122, 2018	Country not included in protocol - USA
Blackstock, S., Solomon, S., Watson, M., Kumar, P., The use of a WhatsAppTM broadcast group to improve knowledge and engagement of adolescents with type 1 diabetes, Archives of disease in childhood, 101 (Supplement 1), A315-A316, 2016	Conference abstract
Boyden, P., Muniz, M., Laxton-Kane, M., Listening to the views of children with learning disabilities: An evaluation of	Phenomenon of interest not included in protocol - No factors identified that

Study	Reason for exclusion
a learning disability CAMHS service, Journal of Intellectual Disabilities, 17, 51-63, 2013	are important babies, children and young people to improve their healthcare experience that haven't been covered in previous reviews
Brady, Hospitalized Children' ™s Views of the Good Nurse, 2009	Duplicate
Bryson, S. P., Patient-centred, administration friendly medicines for children - An evaluation of children's preferences and how they impact medication adherence, International Journal of Pharmaceutics, 469, 257-259, 2014	Study design not included in protocol - Quantitative data only
Butt, M. L., McGrath, J. M., Samra, H. A., Gupta, R., An integrative review of parent satisfaction with care provided in the neonatal intensive care unit, 42, 105-20, 2013	Study design of included studies not in protocol. Included studies checked for inclusion.
Cai, R. A., Beste, D., Chaplin, H., Varakliotis, S., Suffield, L., Josephs, F., Sen, D., Wedderburn, L. R., Ioannou, Y., Hailes, S., Eleftheriou, D., Developing and Evaluating JIApp: Acceptability and Usability of a Smartphone App System to Improve Self-Management in Young People With Juvenile Idiopathic Arthritis, JMIR MHealth and UHealth, 5, e121, 2017	Population not included in protocol - babies, children and young people aged 10-23, with no way of determining which ages contributed to which themes
Camelo Castillo, W., Ross, M. M., Fitz-Randolph, M., Dos Reis, S., Eliciting patient treatment preferences: Development of a methodological framework for attribute identification and validation for discrete choice experiments, Value in Health, 18 (3), A27, 2015	Conference abstract
Chakravorty, S., Tallett, A., Hay, H., Chisholm, A., Warner, J., Sathyamoorthy, G., James, J., Assessing the care experiences of people living with sickle cell disease to inform the development of a patient reported experience measure (PREM), British Journal of Haematology, 1), 25-26, 2015	Conference abstract
Chambers, M., McAndrew, S., Nolan, F., Thomas, B., Watts, P., Kantaris, X., Service user involvement in the coproduction of a mental health nursing metric: The Therapeutic Engagement Questionnaire, Health expectations : an international journal of public participation in health care and health policy, 20, 871-877, 2017	Population not included in protocol - People aged 18 years and over
Chaney, D., Coates, V., Shevlin, M., Carson, D., McDougall, A., Long, A., Diabetes education: What do adolescents want?, Journal of clinical nursing, 21, 216-223, 2012	Phenomenon of interest not included in protocol - No factors identified that are important babies, children and young people to improve their healthcare experience that haven't been covered in previous reviews
Collins, Rebecca, Notley, Caitlin, Clarke, Tim, Wilson, Jon, Fowler, David, Participation in developing youth mental health services: "Cinderella service" to service re-design, Journal of Public Mental Health, 16, 159-168, 2017	Unsure of population - Mixture of current CAMHS users, previous CAMHS user and healthcare professionals, with demographics and proportions not reported
Cottrell, E., Chandwani, M., Hanson, F., Wong, J., Gaining from patient experience on a local level: The introduction of annual questionnaires for children and teenagers with diabetes, Hormone Research in Paediatrics, 1), 179, 2015	Conference abstract
Crane, L., Adams, F., Harper, G., Welch, J., Pellicano, E., 'Something needs to change': Mental health experiences of young autistic adults in England, Autism, 23, 477-493, 2019	Population not included in protocol - Age range 16-26 years old with no way of separating data and results
Criddle, J., Hall, D., Jones, M., Mitchell, R., Taking the 'ouch!' out of emergency: Using illustrative and digital arts to	Conference abstract

Study	Reason for exclusion
guide, reassure and role model behaviours at the children's emergency department, evelina london children's hospital, Archives of disease in childhood, 103 (Supplement 1), A135, 2018	
Crossley, E., Yusuf, Z., Robinson, S., Turley, G., Woods, M., Grose, C., Kaushik, A., Hindley, P., Hedderly, T., Parental and child experiences from a service evaluation of the TANDeM MDT clinic, Developmental medicine and child neurology, 1), 63, 2015	Conference abstract
Curtis-Tyler, K., Arai, L., Stephenson, T., Roberts, H., What makes for a 'good' or 'bad' paediatric diabetes service from the viewpoint of children, young people, carers and clinicians? A synthesis of qualitative findings, Archives of Disease in ChildhoodArch Dis Child, 100, 826-33, 2015	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Datt, C., Travers, M., Odell, C., Improving the hospital experience for young people (YP) with autism, Archives of disease in childhood, 102 (Supplement 1), A20, 2017	Conference abstract
Davies, Adam, Randall, Duncan, Perceptions of children's participation in their healthcare: A critical review, Issues in comprehensive pediatric nursing, 38, 202-221, 2015	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Davison, Jo, Zamperoni, Victoria, Stain, Helen J., Vulnerable young people's experiences of child and adolescent mental health services, Mental Health Review Journal, 22, 95-110, 2017	Phenomenon of interest not included in protocol - No factors identified that are important babies, children and young people to improve their healthcare experience that haven't been covered in previous reviews
Dow, B. L., Kenardy, J. A., Long, D. A., Le Brocque, R. M., Cognitive/affective factors are associated with children's acute posttraumatic stress following pediatric intensive care, Psychological trauma : theory, research, practice and policy, 11, 55-63, 2019	Country not included in protocol - Australia
Dunne, A., Carolan, R., Swords, L., Fortune, G., Patient and family perspectives of paediatric psychogenic non-epileptic seizures: A systematic review, Seizure, 71, 279-285, 2019	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Duran, C., Curtis-Tyler, K., Exploring children's healthcare experiences of haematopoietic stem cell transplantation (HSCT)-a small scale study for service improvement, Bone Marrow Transplantation, 1), S257, 2016	Conference abstract
Eisen, Isabel, Cunningham, Barbara Jane, Campbell, Wenonah, Al-Busaidi, Batorowicz Bell Bergold Boxall Bruce Burles Capewell Carlsson Carnahan Carter Cheak-Zamora Cheak-Zamora Clark-Ibanez Cluley Coad Collier Connelly Cussen Danker Dassah Dockrell Faircloth Fereday Galloway Germain Gibson Gibson Gillam Goldbart Goodwin Ha Harper Harrington Holliday Jones King Kirk Lal Lamb Lariviere-Bastien Lindsay Lloyd Mahon Molloy Nguyen Obrusnikova Owen Phelan Pinborough-Zimmerman Prins Ripat Savin-Baden Singhal Smith Sunderland Teti Wang Wang Ware Whitney Wiart, Conducting participatory photography with children with disabilities: A literature review, Disability and Rehabilitation: An International, Multidisciplinary Journal, 41, 1943-1954, 2019	Narrative review. Included studies checked for inclusion.
Ely, B., Chen Lim, M., Becker, E., Wilson Jr, B., The pain experience of hospitalized youth: Assessment and management preferences, Journal of Pain, 1), S3, 2016	Conference abstract
Ely, E., Chen-Lim, M. L., Carpenter, K. M., Wallhauser, E., Friedlaender, E., Pain Assessment of Children with Autism	Country not included in protocol - USA

Study	Reason for exclusion
Spectrum Disorders, Journal of developmental and behavioral pediatrics : JDBP, 37, 53-61, 2016	
Entwistle, V. A., McCaughan, D., Watt, I. S., Birks, Y., Hall, J., Peat, M., Williams, B., Wright, J., Patient Involvement in Patient Safety, Group, Speaking up about safety concerns: multi-setting qualitative study of patients' views and experiences, Quality & Safety in Health Care, 19, e33, 2010	Population not included in protocol - 5 healthcare domains investigated, only 1 involving babies, children and young people (childhood asthma). Data collected from parents with no record of age of babies, children and young people.
Espinel, A. G., Shah, R. K., McCormick, M. E., Krakovitz, P. R., Boss, E. F., Patient satisfaction in pediatric surgical care: A systematic review, Otolaryngology - Head and Neck Surgery (United States), 150, 739-749, 2014	Study design of included studies not in protocol. Included studies checked for inclusion.
Fagerstad, A., Windahl, J., Arnrup, K., Understanding avoidance and non-attendance among adolescents in dental care - an integrative review, Community dental health, 33, 195-207, 2016	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Fern, L. A., Taylor, R. M., Whelan, J., Pearce, S., Grew, T., Brooman, K., Starkey, C., Millington, H., Ashton, J., Gibson, F., The art of age-appropriate care: Reflecting on a conceptual model of the cancer experience for teenagers and young adults, Cancer Nursing, 36, E27-E38, 2013	Population not included in protocol - Young people aged 13-25 at diagnosis (27% currently 16-19 years) with no way to identify ages of people contributing to themes
Foster, M. J., Whitehead, L., Maybee, P., Cullens, V., The parents', hospitalized child's, and health care providers' perceptions and experiences of family centered care within a pediatric critical care setting: a metasynthesis of qualitative research, Journal of Family Nursing, 19, 431-468, 2013	Population and phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Franck, L. S., Ferguson, D., Fryda, S., Rubin, N., The child and family hospital experience: Is it influenced by family accommodation?, Medical Care Research and Review, 72, 419-437, 2015	Country not included in protocol - USA
Gabbie, S., Dublon, V., Levi, R., Runnacles, J., An innovative method of gathering feedback as part of the 'What matters to you?' movement, Archives of Disease in Childhood, 103 (Supplement 1), A155, 2018	Conference abstract
Gondek, D., Edbrooke-Childs, J., Velikonja, T., Chapman, L., Saunders, F., Hayes, D., Wolpert, M., Facilitators and Barriers to Person-centred Care in Child and Young People Mental Health Services: A Systematic Review, Clinical Psychology & Psychotherapy, 24, 870-886, 2017	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Hope, G., Haake, A., Hilliard, C., The bare necessities of life: An evaluation of a live-music programme in a children's hospital, Psycho-Oncology, 25 (Supplement 3), 72, 2016	Conference abstract
James, J., Children as service users of a children's centre, Community practitioner : the journal of the Community Practitioners' & Health Visitors' Association, 89, 42-45, 2016	Setting not included in protocol - Education setting not healthcare setting
Jobbins, A., Baily, C., Wilkinson, G., Menzies, J., Mildner, R., Adolescents in PICU: Are we meeting their needs?, Pediatric critical care medicine, 1), A37-A38, 2011	Conference abstract
Kerri, O., Byron, P., Improving strategies to better support adolescents with cancer: The creation of an "adolescent-friendly oncology ward", Pediatric Blood and Cancer, 53 (5), 751-752, 2009	Conference abstract
Liossi, C., Noble, G., Franck, L. S., How parents make sense of their young children’s expressions of everyday	Phenomenon of interest not included in protocol - Concerning parents

Study	Reason for exclusion
pain: A qualitative analysis , European journal of pain (united kingdom), 16, p.1166-1175, 2012	interpretation and communication of their child's pain rather than pain experiences within healthcare
Loyland, B., Angelhoff, C., Kristjansdottir, G., Sjolie, H., A systematic integrative review of parents' experience and perception of sleep when they stay overnight in the hospital together with their sick children, Journal of Clinical Nursing, 29, 706-719, 2020	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Masoumi, M., Shahhosseini, Z., Self-care challenges in adolescents: A comprehensive literature review, International Journal of Adolescent Medicine and Health, 31, 0152, 2019	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
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, International journal of behavioral medicine, 27, 444-454, 2020	Phenomenon of interest not included in protocol - No factors identified that are important babies, children and young people to improve their healthcare experience that haven't been covered in previous reviews
McCormack, A., Norrish, S., Parker, L., Frampton, I., Consulting with young people about healthcare. Part 2: Experience of long-term health conditions, Pediatric Health, 4, 167-175, 2010	Phenomenon of interest not included in protocol - No factors identified that are important babies, children and young people to improve their healthcare experience that haven't been covered in previous reviews
McNair, C., Chinian, N., Shah, V., McAllister, M., Franck, L. S., Stevens, B., Burry, L., Taddio, A., Metasynthesis of Factors That Influence Parents' Participation in Pain Management for Their Infants in the NICU, Journal of obstetric, gynecologic, and neonatal nursing : JOGNN, 49, 263-271, 2020	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Moran, P., Kelesidi, K., Guglani, S., Davidson, S., Ford, T., What do parents and carers think about routine outcome measures and their use? A focus group study of CAMHS attenders, Clinical Child Psychology and Psychiatry, 17, 65-79, 2012	Population not included in protocol - babies, children and young people were included in original sample but data was not included in this article due to paucity of evidence. Other participants included healthcare professionals and parents of children >5 years old
Moss, K. M., Healy, K. L., Ziviani, J., Newcombe, P., Cobham, V. E., McCutcheon, H., Montague, G., Kenardy, J., Trauma-informed care in practice: Observed use of psychosocial care practices with children and families in a large pediatric hospital, Psychological services, 16, 16-28, 2019	Country not included in protocol - Australia
Murphy, M., Hollinghurst, S., Turner, K., Salisbury, C., Patient and practitioners' views on the most important outcomes arising from primary care consultations: a qualitative study, BMC family practice, 16, 108, 2015	Population not included in protocol - People aged 18 years and above
Neill, S. J., Jones, C. H., Lakhanpaul, M., Roland, D. T., Thompson, M. J., Parent's information seeking in acute childhood illness: what helps and what hinders decision making?, Health expectations : an international journal of public participation in health care and health policy, 18, 3044-3056, 2015	Phenomenon of interest not included in protocol - No factors identified that are important babies, children and young people to improve their healthcare experience that haven't been covered in previous reviews
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	Phenomenon of interest not included in protocol - No factors identified that are important babies, children and

Study	Reason for exclusion
and Young People With Long-Term, Chronic Conditions: A Qualitative Exploration, Journal of medical Internet research, 19, e235, 2017	young people to improve their healthcare experience that haven't been covered in previous reviews
Petrie, K., McArdle, A., Cookson, J., Powell, E., Poblete, X., 'Let us speak'-children's opinions of doctors, Archives of Disease in Childhood, 102 (Supplement 1), A200-A201, 2017	Conference abstract
Richardson, C., Paslakis, G., Men's experiences of eating disorder treatment: A qualitative systematic review of men-only studies, Journal of psychiatric and mental health nursing, 2020	Population of included studies not in protocol. Included studies checked for inclusion.
Robards, F., Kang, M., Usherwood, T., Sanci, L., How Marginalized Young People Access, Engage With, and Navigate Health-Care Systems in the Digital Age: Systematic Review, Journal of Adolescent Health, 365-381, 2018	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Ronzoni, P., Dogra, N., Children, adolescents and their carers' expectations of child and adolescent mental health services (CAMHS), The International journal of social psychiatry, 58, 328-336, 2012	Study design not included in protocol - Qualitative data obtained through free-text answers but were then categorised to obtain percentages so no qualitative data analysis.
Sexton, K., Heinz, P., Lothian, K., Young people get active! focus group involvement to improve the experience of adolescent paediatric patients in emergency departments, Archives of Disease in Childhood: Education and Practice Edition, 1), A109, 2013	Conference abstract
Shields, L., Zhou, H., Pratt, J., Taylor, M., Hunter, J., Pascoe, E., Familyâ centred care for hospitalised children aged 0â 12 years, Cochrane Database of Systematic Reviews, 2012	Study design of included studies not in protocol. Included studies checked for inclusion.
Shilling, V., Edwards, V., Rogers, M., Morris, C., The experience of disabled children as inpatients: a structured review and synthesis of qualitative studies reporting the views of children, parents and professionals, Child: care, health and development, 38, 778-88, 2012	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Svirydzenka, N., Ronzoni, P., Dogra, N., Meaning and barriers to quality care service provision in Child and Adolescent Mental Health Services: Qualitative study of stakeholder perspectives, BMC health services research, 17, 151, 2017	Phenomenon of interest not in protocol - No factors identified that are important babies, children and young people to improve their healthcare experience that haven't been covered in previous reviews
van, C., McInerney, P., Cooke, R., Patients' involvement in improvement initiatives: a qualitative systematic review, JBI Database of Systematic Reviews and Implementation Reports, 13, 232-90, 2015	Population of included studies not in protocol. Included studies checked for inclusion.
Waite-Jones, J. M., Majeed-Ariss, R., Smith, J., Stones, S. R., Van Rooyen, V., Swallow, V., Young People's, Parents', and Professionals' Views on Required Components of Mobile Apps to Support Self-Management of Juvenile Arthritis: Qualitative Study, JMIR MHealth and UHealth, 6, e25, 2018	Phenomenon of interest not included in protocol - No factors identified that are important babies, children and young people to improve their healthcare experience that haven't been covered in previous reviews
Waite-Jones, J., Swallow, V., Smith, J., Stones, S., Majeed-Ariss, R., Van Rooyen, V., Developing a mobile-app to aid young people's self-management of chronic rheumatic disease: A qualitative study, Rheumatology (United Kingdom), 56 (Supplement 6), vi8, 2017	Conference abstract

Study	Reason for exclusion
Wood, D., Geoghegan, S., Ramnarayan, P., Davis, P. J., Pappachan, J. V., Goodwin, S., Wray, J., Eliciting the experiences of the adolescent-parent dyad following critical care admission: a pilot study, European Journal of Pediatrics, 177, 747-752, 2018	Phenomenon of interest not included in protocol - No factors identified that are important babies, children and young people to improve their healthcare experience that haven't been covered in previous reviews

Economic studies

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

Excluded studies for review question 4.1b What factors are important to babies, children and young people to improve their experience of healthcare? (Quantitative)

Clinical studies

Table 25: Excluded studies and reasons for their exclusion

Study	Reason for Exclusion
Abualfaraj, R. J., McDonald, F., Daly, B., Scambler, S., Patients with cleft: Experiences, understanding and information provision during treatment, Orthodontics & craniofacial research, 22, 289-295, 2019	Outcomes not in PICO - No relevant quantitative data presented.
Agarwal, H. S., Wolfram, K. B., Slayton, J. M., Saville, B. R., Cutrer, W. B., Bichell, D. P., Harris, Z. L., Barr, F. E., Deshpande, J. K., Template of patient-specific summaries facilitates education and outcomes in paediatric cardiac surgery units, Interactive Cardiovascular and Thoracic Surgery, 17, 704-709, 2013	Outcomes not in PICO - Patient experiences of template of patient-specific summaries
Aghdasi, B., Bachmann, K. R., Clark, D., Koldenhoven, R., Sultan, M., George, J., Singla, A., Abel, M. F., Patient-reported Outcomes Following Surgical Intervention for Adolescent Idiopathic Scoliosis: A Systematic Review and Meta-Analysis, Clinical spine surgery, 2019	Outcomes of included studies not in PICO. Included studies checked for inclusion.
Aghdasi, B., Bachmann, K. R., Clark, D., Koldenhoven, R., Sultan, M., George, J., Singla, A., Abel, M. F., Patient-reported Outcomes Following Surgical Intervention for Adolescent Idiopathic Scoliosis: A Systematic Review and Meta-Analysis, Clinical Spine Surgery, 33, 24-34, 2020	Duplicate paper
Aldiss, S., Fern, L. A., Phillips, R. S., Callaghan, A., Dyker, K., Gravestock, H., Groszmann, M., Hamrang, L., Hough, R., McGeachy, D., Morgan, S., Smith, S., Upadhyaya, S., Veitch, H., Veitch, L., Williamson, M., Whelan, J. S., Gibson, F., Research priorities for young people with cancer: A UK priority setting partnership with the James Lind Alliance, BMJ open, 9, e028119, 2019	Outcomes not in PICO - Prioritisation of healthcare research questions in young people with cancer
Alexakis, C., Nash, A., Lloyd, M., Brooks, F., Lindsay, J. O., Poullis, A., Inflammatory bowel disease in young patients: challenges faced by black and minority ethnic communities in the UK, Health & Social Care in the Community, 23, 665-672, 2015	Study design not in PICO - Qualitative paper
Al-Shimari, F., Parker, E., McCarty, C., O. Connor M, Richardson, L., Factors Associated With Teens Having Time Alone With Their Primary Care Providers, Journal of adolescent health, 64, S60, 2019	Conference abstract

Study	Reason for Exclusion
Ames, C. S., Richardson, J., Payne, S., Smith, P., Leigh, E., Mindfulness-based cognitive therapy for depression in adolescents, Child and Adolescent Mental Health, 19, 74-78, 2014	Outcomes not in PICO - No relevant quantitative data presented
Anderson, Joanna K., Howarth, Emma, Vainre, Maris, Jones, Peter B., Humphrey, Ayla, Aisbett, Allison Arksey Armbruster Asarnow Atkins Aupont Barwick Bear Bitar Boyd Boyd Boyd Boydell Boydell Bringewatt Brown Brown Cavaleri Cawthorpe Clark Clarke Clemente Cohen Cohen Davis DeRigne Diamond Dixon Draucker Eapen Fatimilehin Flisher Ford Fuggle Gallucci Golding Gondek Gould Green Gulliver Hagell Hernan Honigfeld Iskra Jones Kaukonen Kim-Cohen Levac Macdonald Maguire McCann Meltzer Muir Naughton O'Brien Oke Oruche Parker Pfefferle Polanczyk Popay Pullmann Radovic Reardon Reid Reid Richardson Robotham Robotham Rowe Sakai Samargia Saxena Schraeder Sherman Smith Snell Stern Stiffman Vohra Walders Walker Westin Williams Wilson Wisdom Woodhouse Woodward Wye York, A scoping literature review of service-level barriers for access and engagement with mental health services for children and young people, Children and Youth Services Review, 77, 164-176, 2017	Scoping review. Included studies checked for inclusion.
Anonymous,, Development of more focused questionnaires improves results, Nursing children and young people, 28, 13, 2016	Article unavailable
Aston, J., Wilson, K. A., Sinclair, A., Terry, D., A telephone survey to determine the experiences of children and their parents/carers, following the initiation of a new medicine, European Journal of Hospital Pharmacy, 24, 266-271, 2017	Outcomes not in PICO - No relevant quantitative data presented
Aston, J., Wilson, K., Terry, D., Starting a new medicine study, Archives of disease in childhood, 101 (9), A28, 2016	Conference abstract
Athalye, S., Archbold, S., Mulla, I., Lutman, M., Nikolopoulous, T., Exploring views on current and future cochlear implant service delivery: the perspectives of users, parents and professionals at cochlear implant centres and in the community, Cochlear Implants International, 16, 241-253, 2015	Population not in PICO - Mixed population of carers/ parents and children with data not presented separately for target population.
Bagnall, A. M., South, J., Forshaw, M. J., Spoor, C., Marchant, P., Witty, K., White, A. K., Self-care in primary care: findings from a longitudinal comparison study, Primary health care research & development, 14, 29-39, 2013	Outcomes not in PICO - No relevant quantitative data presented
Barr, Paul J., Brady, Shauna C., Hughes, Carmel M., McElnay, James C., Public knowledge and perceptions of connected health, Journal of evaluation in clinical practice, 20, 246-54, 2014	Population not in PICO - Participants >18 years.
Bensted, R., Hargreaves, D. S., Lombard, J., Kilkelly, U., Viner, R. M., Comparison of healthcare priorities in childhood and early/late adolescence: analysis of cross-sectional data from eight countries in the Council of Europe Child-friendly Healthcare Survey, 2011, Child: care, health and development, 41, 160-165, 2015	Country not in PICO - Answers from 8 countries presented together with data not presented separately for UK
Bichard, E., Wray, J., Cooper, J., Aitken, L., Discharged from paediatric intensive care unit (PICU): A mixed - methods study of young people's (YP) anxiety levels and experiences after picu discharge, Archives of disease in childhood, 103 (Supplement 2), A34, 2018	Conference abstract
Brodermann, M., Cross, D., Harden, P., Innovative approach to engage and manage teenage and young adult transplant recipients: User views of a community based young adult service, Transplant International, 30 (Supplement 2), 329, 2017	Conference abstract
Bull, L., Survey of complementary and alternative therapies used by children with specific learning difficulties (dyslexia), International journal of language & communication disorders /	Population and interventions not in PICO - Views on the usage of alternative therapies

Study	Reason for Exclusion
Royal College of Speech & Language Therapists, 44, 224-235, 2009	in parents of children with dyslexia
Bundock, H., Tudor-Williams, G., Fidler, S., McDonald, S., Foster, C., Crossing the divide: Transitional care for young adults with HIV - Their views, HIV Medicine, 1), 12-13, 2009	Conference abstract
Callery, P., Kyle, R. G., Banks, M., Ewing, C., Kirk, S., Enhancing parents' confidence to care in acute childhood illness: Triangulation of findings from a mixed methods study of Community Children's Nursing, Journal of advanced nursing, 69, 2538-2548, 2013	Outcomes not in PICO - No relevant quantitative data presented
Cheak-Zamora, N. C., Yang, X., Farmer, J. E., Clark, M., Disparities in transition planning for youth with autism spectrum disorder, Pediatrics, 131, 447-54, 2013	Outcomes not in PICO - No relevant quantitative data presented
Chow, Maria Yui Kwan, Morrow, Angela M., Robbins, Spring Chenoa Cooper, Leask, Julie, Abidin, Arafa Bachmann Barnard Basra Basra Berdeaux Bode Boland Boling Bowden Breau Brisson Busch Byles Camfield Camfield Caples Cappelleri Chamlin Chamlin Chien Cohen Coons Davis Davis de Civita Donohue Dube Duguid Edmonds-Myles Farnik Faulkner Forns Gorsuch Hatt Hoffman Hunt Juniper Knock Kondo-Endo Kuhlthau Kunz Landgraf Landgraf Lawson Locker Lohr Lv Matsumoto Mazer McCubbin McKenna McKenna Morrow Myaskovsky Patjanasoontorn Pawankar Pearlin Perkins Pike Polinder Punpanich Riley Schulz Solans Sparacino Spielberger Stein Streiner Streisand Terwee Van Vandagriff Von Essen Walters Ware Weitzner Weitzner Werner Wiebe, Condition-specific quality of life questionnaires for caregivers of children with pediatric conditions: A systematic review, Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care & Rehabilitation, 22, 2183-2200, 2013	Outcomes of included studies not in PICO. Included studies checked for inclusion.
Clucas, C., Cancer patients' respect experiences in relation to perceived communication behaviours from hospital staff: analysis of the 2012-2013 National Cancer Patient Experience Survey, Supportive Care in Cancer, 24, 1719-1728, 2016	Population not in PICO - Adults >18 years
Cohen, Wendy, Wynne, David McGregor, Parent and Child Responses to the Pediatric Voice-Related Quality-of-Life Questionnaire, Journal of voice : official journal of the Voice Foundation, 29, 299-303, 2015	Outcomes not in PICO - Level of agreement between child and parent questionnaires
Comer, Christine, Glover, Jennie, Richardson, Jennifer, Yaseen, Rachel, Foster, Steven, Wolfenden, Neil M., Hughes, Gareth J., Stratification of Treatment in a Community-Based Musculoskeletal Service: A Mixed-Methods Study to Assess Predictors of Requiring Complex Care, Archives of physical medicine and rehabilitation, 97, 900-911.e10, 2016	Population not in PICO - >16 years old with data not presented separately for target population
Darzi, Andrea J., Officer, Alana, Abualghaib, Ola, Akl, Elie A., Stakeholders' perceptions of rehabilitation services for individuals living with disability: a survey study, Health and quality of life outcomes, 14, 2, 2016	Population not in PICO - Adults >18 years old
Day, Crispin, Michelson, Daniel, Hassan, Imren, Child and adolescent service experience (ChASE): measuring service quality and therapeutic process, The british journal of clinical psychology, 50, 452-64, 2011	Outcomes not in PICO - Internal consistency and test-retest reliability of new quality measure
Dewlett, S., Polychronakis, T., Ng, G. Y. T., Look who's talking: How well are we communicating with parents in the neonatal unit? A patient survey, Intensive Care Medicine, 37, S419-S420, 2011	Conference abstract

Study	Reason for Exclusion
Donaldson, L., Subramanian, A., Conway, M. L., Eye care in young children: a parent survey exploring access and barriers, Clinical & experimental optometry, 101, 521-526, 2018	Population not in PICO - Barriers and attitudes to eye healthcare for parents of children
Dotson, J. L., Bricker, J., Crandall, W., Chisolm, D., Mackner, L., Social and Community Support Associated with Barriers to Care and Disease Severity in Pediatric Inflammatory Bowel Disease at Diagnosis, Gastroenterology, 156 (3 Supplement), S13, 2019	Conference abstract
Dotson, J., Bricker, J., Crandall, W., Chisolm, D., Mackner, L., Barriers to pediatric inflammatory bowel disease care at time of diagnosis: Results from a prospective cohort, Journal of Pediatric Gastroenterology and Nutrition, 67 (Supplement 1), S184-S185, 2018	Conference abstract
Doyle, C., Reed, J., Woodcock, T., Bell, D., Understanding what matters to patients - identifying key patients' perceptions of quality, JRSM Short Reports, 1, 1-6, 2014	Population not in PICO - >16 years old with answers presented together with no way of differentiating data
El Turabi, A., Abel, G. A., Roland, M., Lyratzopoulos, G., Variation in reported experience of involvement in cancer treatment decision making: evidence from the National Cancer Patient Experience Survey, British Journal of Cancer, 109, 780-787, 2013	Population not in PICO - >16 years with data not presented separately for target population
Fazel, M., Garcia, J., Stein, A., The right location? Experiences of refugee adolescents seen by school-based mental health services, Clinical Child Psychology and Psychiatry, 21, 368-380, 2016	Outcomes not in PICO - No relevant quantitative data presented
Fenton, Brenda, Thankappan, Kavumpurathu Raman, Champagne, Beatriz, Lv, Jun, Anthony, Denis, Akhtar, Akhtar Akhtar Alwan Hammond Haw Jones Kish Mills Mittal Murukutla O'Connor Duffany Oberg Phillips Pradeepkumar Raute Roberts-Thomson Robinson Robinson Robinson Sharma Siddiqi Sims Turk Wilson Zhang, Increased knowledge of the effects of smoking and second-hand smoke encourages smoke-free homes, Journal of Research in Nursing, 19, 373-387, 2014	Outcomes not in PICO - No relevant quantitative data presented
Fletcher-Watson, S., Larsen, K., Salomone, E., What do parents of children with autism expect from participation in research? A community survey about early autism studies, Autism, 23, 175-186, 2019	Population not in PICO - Answers from 11 countries the data not presented separately for UK
Foster, Theresa, Maillardet, Victoria, Surveying young patients, Emergency medicine journal : EMJ, 27, 221-3, 2010	Outcomes not in PICO - Response rate of survey of children and young people
Gabbie, S., Dublon, V., Levi, R., Runnacles, J., An innovative method of gathering feedback as part of the 'What matters to you?' movement, Archives of Disease in Childhood, 103 (Supplement 1), A155, 2018	Conference abstract
Geoghegan, S., Oulton, K., Bull, C., Peters, M., Brierley, J., Wray, J., The experience of long-stay parents in the PICU: Perspectives of parents and staff, Archives of disease in childhood, 101 (Supplement 1), A296, 2016	Conference abstract
Ghosh, R., Gandhi, V., MacKinnon, L., Paediatric epilepsy and core evaluation service (PEACES): A quality improvement initiative, Archives of disease in childhood, 104, A76-A77, 2019	Conference abstract
Gilbert, C., Bush, A., Cunningham, S., A questionnaire survey of parent experiences and perspectives in children diagnosed with interstitial lung disease (ILD), Thorax, 2), A120, 2014	Conference abstract
Girling, I., Colville, S., Borrelli, M., Bowman, N., Christie, D., From referral to discharge: Young people and parents' experience of a	Study design not in PICO - Not regional or national survey

Study	Reason for Exclusion
systemic paediatric psychology service, Clinical Child Psychology and Psychiatry, 21, 297-307, 2016	
Gulliver, A., Griffiths, K. M., Christensen, H., Perceived barriers and facilitators to mental health help-seeking in young people: A systematic review, BMC psychiatry, 10, 113, 2010	Outcomes of included studies not in PICO. Included studies checked for inclusion.
Hamm, M. P., Shulhan, J., Williams, G., Milne, A., Scott, S. D., Hartling, L., A systematic review of the use and effectiveness of social media in child health, BMC Pediatrics, 14, 138, 2014	Interventions of included studies not in PICO. Included studies checked for inclusion.
Harijan, P. D., Brown, A., Dunkley, C., Jones, A., Martin, K., Moran, M., Picton, C., Thomas, D., Williams, J., Whitehouse, W. P., Service evaluation of a teenage epilepsy clinic: Preliminary results, Developmental medicine and child neurology, 59 (Supplement 4), 118, 2017	Conference abstract
Harley, Clare, Adams, Jacqui, Booth, Laura, Selby, Peter, Brown, Julia, Velikova, Galina, Patient experiences of continuity of cancer care: development of a new medical care questionnaire (MCQ) for oncology outpatients, Value in health : the journal of the International Society for Pharmacoeconomics and Outcomes Research, 12, 1180-6, 2009	Outcomes not in PICO - No relevant quantitative data presented
Hartley, S., Stockley, R., It's more than just physical therapy: reported utilization of physiotherapy services for adults with neuromuscular disorders attending a specialist centre, Disability and Rehabilitation, 35, 282-290, 2013	Population not in PICO - Adults >18 years
Hawley, C., Forsyth, R., Morris, K., Tasker, R., Parslow, R., Outcomes following admission to UK Paediatric intensive care after traumatic brain injury, Brain Injury, 24 (3), 437, 2010	Conference abstract
Heidi, M., Emily, K., Benjamin, H., Michael, C., Robert, K., Mitch, B., Chris, G., Mando, W., Andrew, B., Patient reported outcomes for preschool children with recurrent wheeze, NPJ primary care respiratory medicine, 29 (1) (no pagination), 2019	Outcomes not in PICO - No relevant quantitative data presented
Herbert, S., Rowbotham, N. J., Smith, S. J., Smyth, A. R., Exploring the challenges of accessing medications for patients with cystic fibrosis, Pediatric Pulmonology, 54, 379, 2019	Conference abstract
Hewitson, P., Skew, A., Graham, C., Jenkinson, C., Coulter, A., People with limiting long-term conditions report poorer experiences and more problems with hospital care, BMC health services research, 14, 33, 2014	Population not in PICO - >16 years with data not presented separately for target population
Hill, C., Knafl, K. A., Santacroce, S. J., Family-Centered Care From the Perspective of Parents of Children Cared for in a Pediatric Intensive Care Unit: An Integrative Review, Journal of pediatric nursing., 16, 2017	Outcomes of included studies not in PICO. Included studies checked for inclusion.
Hodgekins, J., Clarke, T., Cole, H., Markides, C., Ugochukwu, U., Cairns, P., Lower, R., Fowler, D., Wilson, J., Pathways to care of young people accessing a pilot specialist youth mental health service in Norfolk, United Kingdom, Early intervention in psychiatry, 11, 436-443, 2017	Outcomes not in PICO - No relevant quantitative data presented
Hoffman, J. M., Keeling, N. J., Forrest, C. B., Tubbs-Cooley, H. L., Moore, E., Oehler, E., Wilson, S., Schainker, E., Walsh, K. E., Priorities for pediatric patient safety research, Pediatrics, 143 (2) (no pagination), 2019	Country not in PICO - USA
Houx, L., Saudreau, H., Galien, P., Pons, C., Roquet, M., Garlantezec, R., Brochard, S., Perceived effectiveness, tolerance of cares in children and adults with cerebral palsy, Annals of Physical and Rehabilitation Medicine, 59 (Supplement), e5-e6, 2016	Conference abstract

Study	Reason for Exclusion
Howard, R. F., Jay, M. A., Peters, J., Lilley, S., McNicholas, J., Bayliss, R., Trotman, L., Williams, G., Long-term outcomes in children with complex regional pain syndrome: A cross-sectional study, British Journal of Pain, 12 (2 Supplement 1), 46-47, 2018	Conference abstract
Iles,N., Lowton,K., What is the perceived nature of parental care and support for young people with cystic fibrosis as they enter adult health services?, Health and Social Care in the Community, 18, 21-29, 2010	Study design not in PICO - Qualitative paper
Iloabachie, C., Wells, C., Goodwin, B., Baldwin, M., Vanderplough-Booth, K., Gladstone, T., Murray, M., Fogel, J., Van Voorhees, B. W., Adolescent and parent experiences with a primary care/Internet-based depression prevention intervention (CATCH-IT), General Hospital Psychiatry, 33, 543-555, 2011	Country not in PICO - USA
Jenkins, M., Parylo, C., Evaluation of health services received by homeless families in Leicester, Community practitioner : the journal of the Community Practitioners' & Health Visitors' Association, 84, 21-24, 2011	Study design not in PICO - Qualitative paper
John, M., Jeffries, F. W., Acuna-Rivera, M., Warren, F., Simonds, L. M., Development of Measures to Assess Personal Recovery in Young People Treated in Specialist Mental Health Services, Clinical Psychology & Psychotherapy, 22, 513-524, 2015	Development of questionnaire to assess recovery after discharge from mental health services
Johnson, S., Lloyd-Evans, B., Morant, N., Gilburt, H., Shepherd, G., Slade, M., Jagielska, D., Leese, M., Byford, S., Osborn, D. P. J., Alternatives to standard acute in-patient care in England: roles and populations served, The British journal of psychiatry. Supplement, 53, s6-s13, 2010	Population not in PICO - Adults >18 years
Jones, L. J. W., Pini, S. A., Morgan, S. J., Birk, G. K., Stark, D. P., How Do Teenagers and Young Adults with Cancer Experience Their Care? A European Survey, Journal of Adolescent and Young Adult Oncology, 6, 102-110, 2017	Article unavailable
Kapur, P., Hayes, D., Waddingham, R., Hillman, S., Deighton, J., Midgley, N., The experience of engaging with mental health services among young people who hear voices and their families: a mixed methods exploratory study, BMC health services research, 14, 527, 2014	Study country not in PICO - Answers from variety of countries with data not presented separately for UK
Kenny, L. J., Bostock, N. J., Parkhurst, A., Exploring young people's attitudes towards routine health screening in a UK secondary school, Archives of disease in childhood, 101 (Supplement 1), A73, 2016	Conference abstract
Kinderman, P., Schwannauer, M., Pontin, E., Tai, S., The development and validation of a general measure of well-being: the BBC well-being scale, Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation, 20, 1035-1042, 2011	Population not in PICO - Mean age 29.9 years with data not presented separately for target population
Kirk, S., Fallon, D., Fraser, C., Robinson, G., Vassallo, G., Supporting parents following childhood traumatic brain injury: a qualitative study to examine information and emotional support needs across key care transitions, Child: care, health and development, 41, 303-313, 2015	Study design not in PICO - Qualitative paper
Knightsmith, P., Sharpe, H., Breen, O., Treasure, J., Schmidt, U., 'My teacher saved my life' versus 'Teachers don't have a clue': An online survey of pupils' experiences of eating disorders, Child and Adolescent Mental Health, 19, 131-137, 2014	Outcomes not in PICO - No relevant quantitative data presented
Kontopantelis, E., Roland, M., Reeves, D., Patient experience of access to primary care: identification of predictors in a national patient survey, BMC family practice, 11, 61, 2010	Population not in PICO - Adults >18 years

Study	Reason for Exclusion
Lambert, V., Coad, J., Hicks, P., Glacken, M., Aldiss, Battles Birch Bishop Bishop Braun Brokstein Bush Carney Clark Clift Coad Coiera Corlett Coyne Curtis Fletcher Gibson Haiat Holden Holden Horstman Humber Hutton Hutton Kazak LeVieux-Anglin Lewis Nicholas Nicholas Norton-Westwood Pelander Pelander Plowman Sartain Schneider Wilson, Social spaces for young children in hospital, Child: care, health and development, 40, 195-204, 2014	Outcomes not in PICO - No relevant quantitative data presented
Larkins, A. S., Windsor, A. V. C., Trebble, T. M., An evaluation of patient attitudes to the gastroenterology outpatient experience, European Journal of Gastroenterology and Hepatology, 25, 44-55, 2013	Population not in PICO - >17 years with data not presented separately for target population
Lebwohl, Mark G., Bachelez, Herve, Barker, Jonathan, Girolomoni, Giampiero, Kavanaugh, Arthur, Langley, Richard G., Paul, Carle F., Puig, Lluis, Reich, Kristian, van de Kerkhof, Peter C. M., Patient perspectives in the management of psoriasis: results from the population-based Multinational Assessment of Psoriasis and Psoriatic Arthritis Survey, Journal of the American Academy of Dermatology, 70, 871-30, 2014	Population not in PICO - Adults >18 years
Lereya, Suzet Tanya, Humphrey, Neil, Patalay, Praveetha, Wolpert, Miranda, Bohnke, Jan R., Macdougall, Amy, Deighton, Jessica, Bai, Bank Becker-Weidman Benn Benzies Bukowski Cronbach Deighton Duncan Fergus Formoso Garmezy Hu Huston Ladd Liu Lohman Luthar Luthar Masten McDonald Mellor Mouw Muthen Muthen O'Connor Patalay Penfield Penfield Penfield Penfield Rabaglietti Rae-Grant Ravens-Sieberer Raykov Rogers Schultze-Lutter Shiner Sowislo Stochl Sun Tanaka Trizano-Hermosilla Viner Walker Werner Wetzel Wetzel Williams Windle Zahn-Waxler, The student resilience survey: Psychometric validation and associations with mental health, Child and Adolescent Psychiatry and Mental Health, 10, 2016	Outcomes not in PICO - No relevant quantitative data presented
Levesque, D., Baird, R., A mixed methodology analysis of caregiver satisfaction towards the multidisciplinary care of children with esophageal atresia-the importance of caregiver interactions, Journal of Surgical Research. Conference: 8th Annual Academic Surgical Congress of the Association for Academic Surgery, AAS and the Society of University Surgeons, SUS New Orleans, LA United States. Conference Start, 179, 2013	Conference abstract
Levy, S., Wynd, A. H., Carachi, R., Transition into adult healthcare services in scotland: Findings from a study concerning service users at the scottish spina bifida association, Scottish Medical Journal, 59, 209-213, 2014	Outcomes of included studies not in PICO - Transition from child to adult health services
Llewellyn, Alison M., Skevington, Suzanne M., Evaluating a new methodology for providing individualized feedback in healthcare on quality of life and its importance, using the WHOQOL-BREF in a community population, Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation, 25, 605-14, 2016	Population not in PICO - Adults >18 years
Lopez, C., Hanson, C. C., Yorke, D., Johnson, J. K., Mill, M. R., Brown, K. J., Barach, P., Improving communication with families of patients undergoing pediatric cardiac surgery, Progress in Pediatric Cardiology, 45, 83-90, 2017	Outcomes not in PICO - No relevant quantitative data presented
Lotto, A. A., Peens-Hough, H., Guerrero, R., Dhannapuneni, R., Lotto, R. R., Risk perception of mothers and fathers of children undergoing heart surgery: A quantitative longitudinal analysis, World Journal for Pediatric and Congenital Heart Surgery, 9, NP11, 2018	Conference abstract

Study	Reason for Exclusion
Lotto, R., Jones, I., Seaton, S. E., Dhannapuneni, R., Guerrero, R., Lotto, A., Congenital Cardiac Surgery and Parental Perception of Risk: A Quantitative Analysis, World Journal for Pediatric and Congenital Hearth Surgery, 10, 669-677, 2019	Outcomes not in PICO - No relevant quantitative data presented
MacDonald, K., Mathews, A., Exploring experiences of the in-patient ward round with young people with CF, Journal of Cystic Fibrosis, 16 (Supplement 1), S163, 2017	Conference abstract
MacLure, K., Craig, G., MacLure, A., Boyter, A., Power, A., Osprey, A., McGregor, A., Stewart, D., When would the general public view community pharmacy as their 'first port of call'?, International journal of pharmacy practice, 27, 21-22, 2019	Conference abstract
Marriage, D., Kanchanatheera, M., Thursby-Pelham, A., Thomas, H., Parental satisfaction in the nurse-led pediatric allergy clinic, Allergy: European Journal of Allergy and Clinical Immunology, 96), 512, 2012	Conference abstract
Martin, K. R., O'Neill, C., Bosworth, A. M. B. E., Who cares? an investigation of the health and perceived social care needs of people with rheumatoid arthritis living in Scotland, Rheumatology (United Kingdom), 56 (Supplement 2), ii114, 2017	Conference abstract
McEachan, Rosemary R. C., Lawton, Rebecca J., O'Hara, Jane K., Armitage, Gerry, Giles, Sally, Parveen, Sahdia, Watt, Ian S., Wright, John, Yorkshire, Quality, Safety Research, Group, Developing a reliable and valid patient measure of safety in hospitals (PMOS): a validation study, BMJ quality & safety, 23, 565-73, 2014	Study design not in PICO - Not regional/national survey
McKenzie Smith, M., Shafran, R., Kouzoupi, N., Bryon, M., Families matter: Connecting the quality of life in families living with cystic fibrosis with their experiences, Pediatric Pulmonology, 54, 390, 2019	Conference abstract
McKenzie, A., Saxena, R., Slee-Wijffels, F., Developing a parent-centred website for the paediatric intensive care unit-time for a change!, Pediatric Critical Care Medicine, 19 (6 Supplement 1), 92-93, 2018	Conference abstract
McMurray, Josephine, McNeil, Heather, Lafortune, Claire, Black, Samantha, Prorok, Jeanette, Stolee, Paul, Measuring Patients' Experience of Rehabilitation Services Across the Care Continuum. Part I: A Systematic Review of the Literature, Archives of physical medicine and rehabilitation, 97, 104-20, 2016	Population of included studies not in PICO. Included studies checked for inclusion.
McNeilly, P., Macdonald, G., Kelly, B., The participation of parents of disabled children and young people in health and social care decisions, Child: care, health and development, 43, 839-846, 2017	Population not in PICO - Parental views and experiences only
Mitchell, T., Knighting, K., O'Brien, M., Jack, B., Sutherland-Oakes, J., "No other choice" when children's hospice care is unavailable: an emergency care impact assessment for claire house children's hospice, Palliative medicine. Conference: 11th palliative care congress. United kingdom, 30, S50, 2016	Conference abstract
Mitchell, Wendy, Abberley, Almack Barnes Bercow Bianco Brody Cannella Chambers Commendador Coyne Edwards Entwistle Government Grigal Guess Harris Henderson Jackson Jenkinson Jenkinson Kearney Kirchler Lancioni Lease Lindstrom Mack Maddison Mitchell Mitchell Mitchell Murphy Oliver Peterson-Badali Pilnick Pilnick Pyke-Grimm Ritchie Rueda Sloper Small Smyth Snethen Thomson Trujillo Varma Ware Willink Wolfensberger, Parents' accounts: Factors considered when deciding how far to involve their son/daughter with learning disabilities in choice-making, Children and Youth Services Review, 34, 1560-1569, 2012	Outcomes not in PICO - No relevant quantitative data presented

Study	Reason for Exclusion
Morell, G. C., An orthodontic patient expects?, Evidence-based dentistry, 17, 103-104, 2016	Study design not in PICO - summary review
Murphy, M., Hollinghurst, S., Turner, K., Salisbury, C., Patient and practitioners' views on the most important outcomes arising from primary care consultations: a qualitative study, BMC family practice, 16, 108, 2015	Population not in PICO - >18 years old
Naranjo, D., Suttiratana, S. C., Iturralde, E., Barnard, K. D., Weissberg-Benchell, J., Laffel, L., Hood, K. K., What end users and stakeholders want from automated insulin delivery systems, Diabetes Care, 40, 1453-1461, 2017	Outcomes not in PICO - No relevant quantitative data presented
Nash, P., Darby, K., Nash, S., Understanding the spiritual and religious needs of young people with cancer and their families to enhance holistic care, Archives of disease in childhood, 3), A100-A101, 2015	Conference abstract
O'Cathain, Alicia, Knowles, Emma, Nicholl, Jon, Measuring patients' experiences and views of the emergency and urgent care system: psychometric testing of the urgent care system questionnaire, BMJ quality & safety, 20, 134-40, 2011	Population not in PICO - Presented as >65 and <65 years old with data not presented separately for target population
O'Hara, J. K., Reynolds, C., Moore, S., Armitage, G., Sheard, L., Marsh, C., Watt, I., Wright, J., Lawton, R., What can patients tell us about the quality and safety of hospital care? Findings from a UK multicentre survey study, BMJ Quality and Safety, 27, 673-682, 2018	Population not in PICO - ≤16 years (mean age 60 years) with data not presented separately for target population
Parker, H., Ross, J. D., White, J. A., Wilson, J. D., British Association for Sexual, Health, Hiv,, How important is confidentiality in sexual health clinics? A survey of patients across 51 clinics in England, Sexually transmitted infections, 90, 354-5, 2014	Population not in PICO - Variety of ages with only 2.4% under 17 years old and results not presented separately for target population
Petrie, K., McArdle, A., Cookson, J., Powell, E., Poblete, X., 'Let us speak'-children's opinions of doctors, Archives of Disease in Childhood, 102 (Supplement 1), A200-A201, 2017	Conference abstract
Plomp, H. N., Ballast, N., Trust and vulnerability in doctor-patient relations in occupational health, Occupational medicine (oxford, england), 60, 261-269, 2010	Country not in PICO - The Netherlands
Rabiee, Parvaneh, Glendinning, Caroline, Arksey, Barnes Barnett Baxter Beresford Beresford Boeije Burchardt Campbell Clark Dowse Fine French Glendinning Grewel Hart Government Lent Lloyd Miles Morris Morris Morris Morris Parry Priestley Priestley Robertson Schwartz Shakespeare Vernon Williams, Choice: What, when and why? Exploring the importance of choice to disabled people, Disability & Society, 25, 827-839, 2010	Outcomes not in PICO - No relevant quantitative data presented
Read, N., Schofield, A., Autism: are mental health services failing children and parents?, The journal of family health care, 20, 120-124, 2010	Narrative description of study
Roueche, A., Menson, E., Callaghan, A., 22Q: What matters to you? improving care for children with 22q11.2 deletion syndrome, Archives of disease in childhood, 102 (Supplement 1), A14, 2017	Conference abstract
Ruseckaite, R., Ratnayake, I., Ahern, S., Measuring what matters: Health-related quality of life in patients with cystic fibrosis, Pediatric Pulmonology, 54, 241, 2019	Conference abstract
Scott, Judith, Wishart, Jennifer, Currie, Candace, Aitken, Bambas Nolen Bittles Buckley Chaplin Chapman Cooney Cuckle Cunningham Currie Currie Currie Currie D'Haem Deater-Deckard Deb Dykens Emerson Emerson Emerson Glenn Heath Holland Jansen Jarrold Jobling Jobling Kaptein Kerr Kinne Lakin Linehan	Study design not in PICO - Not regional/national survey

Study	Reason for Exclusion
Lunsky Masi Pennington Swanson Vallgarda Van Schrojenstein Lantman-de Valk Van Schrojenstein Lantman-de Valk Willis, Including children with intellectual disabilities/special educational needs into national child health surveys: A pilot study, Journal of Applied Research in Intellectual Disabilities, 24, 437-449, 2011	
Shah, Koonal Kirit, Mulhern, Brendan, Longworth, Louise, Janssen, M. F., Views of the UK General Public on Important Aspects of Health Not Captured by EQ-5D, The patient, 10, 701-709, 2017	Population not in PICO - >18 years old
Shearn, P., Ford, N. J., Murphy, R. G., An evaluation of an occupational health advice service, Health Education Journal, 69, 13-20, 2010	Population not in PICO - >16 years old with data not presented separately for target population
Shields, Linda, Zhou, Huaqiong, Taylor, Marjory, Hunter, Judith, Munns, Ailsa, Watts, Robin, Family-centred care for hospitalised children aged 0-12 Years: A systematic review of quasi-experimental studies, JBI Library of Systematic Reviews, 10, 2559-2592, 2012	Published protocol
Shilling, V., Bailey, S., Logan, S., Morris, C., Peer support for parents of disabled children part 1: perceived outcomes of a one-to-one service, a qualitative study, Child: care, health and development, 41, 524-36, 2015	Outcomes not in PICO - No relevant quantitative data presented
Siebelt, L., Jackson, C., McFadden, A., Dyson, L., Atkin, K., Use of UK health services by Gypsies, Roma, and Travellers: Triangulation of two mixed methods studies, The Lancet, 390 (SPEC.ISS 1), S81, 2017	Conference abstract
Sousa, Vanessa E. C., Dunn Lopez, Karen, Towards Usable E-Health. A Systematic Review of Usability Questionnaires, Applied clinical informatics, 8, 470-490, 2017	Interventions of included studies not in PICO. Included studies checked for inclusion.
Stalker, Kirsten, Taylor, Julie, Fry, Deborah, Stewart, Alasdair B. R., Biehal, Biehal Brandon Braun Burns Duan Elsley Franklin Gilbert Goffman Hershkowitz Jones Lemert Lerpiniere Lightfoot Manders Miller Murray Oliver Oliver Reeves Reiter Roulstone Schenkel Schutz Shannon Stalker Stalker Stuart Sullivan Sullivan Sylvester Taylor Thomas Thomas Young, A study of disabled children and child protection in Scotland-A hidden group?, Children and Youth Services Review, 56, 126-134, 2015	Population not in PICO - Healthcare professionals in child protection field
Stocks, Susan J., Donnelly, Ailsa, Esmail, Aneez, Beresford, Joanne, Gamble, Carolyn, Luty, Sarah, Deacon, Richard, Danczak, Avril, Mann, Nicola, Townsend, David, Ashley, James, Bowie, Paul, Campbell, Stephen M., Development and piloting of a survey to estimate the frequency and nature of potentially harmful preventable problems in primary care from a UK patient's perspective, BMJ open, 8, e017786, 2018	Population not in PICO - >16 years with data not presented separately for target population
Swallow, V., Smith, T., Carolan, I., Promoting personal and family management of long-term conditions: Children and young people's views on desirable components for an interactive health communication application (IHCA), European Journal of Paediatric Neurology, 1), S93, 2015	Conference abstract
Tanton, C., Jones, K. G., Macdowall, W., Clifton, S., Mitchell, K. R., Datta, J., Lewis, R., Field, N., Sonnenberg, P., Stevens, A., Wellings, K., Johnson, A. M., Mercer, C. H., Patterns and trends in sources of information about sex among young people in Britain: Evidence from three National Surveys of Sexual Attitudes and Lifestyles, BMJ open, 5 (3) (no pagination), 2015	Population not in PICO - 16-24 years with data not presented separately for target population
Taylor, R., Fern, L., Gibson, F., Whelan, J., Steps in the development of a patient-reported outcome measure for teenage	Conference abstract

Study	Reason for Exclusion
and young adults with cancer: The brightlight survey, Pediatric Blood and Cancer, 59 (6), 1009, 2012	
Tingle, J., The results of the NHS 2012 inpatients survey, British journal of nursing (Mark Allen Publishing), 22, 538-539, 2013	Population not in PICO - >16 years with data not presented separately for target population
Topal, K., Eser, E., Sanberk, I., Bayliss, E., Saatci, E., Challenges in access to health services and its impact on quality of life: a randomised population-based survey within Turkish speaking immigrants in London, Health and quality of life outcomes, 10, 11, 2012	Population not in PICO - >17 years with data not presented separately for target population
Usher-Smith, J. A., Thompson, M. J., Zhu, H., Sharp, S. J., Walter, F. M., The pathway to diagnosis of type 1 diabetes in children: a questionnaire study, BMJ Open, 5, e006470, 2015	Narrative description of clinical pathway in paediatric diabetes
van Velthoven, M. H., Atherton, H., Powell, J., A cross sectional survey of the UK public to understand use of online ratings and reviews of health services, Patient Education and Counseling, 101, 1690-1696, 2018	Population not in PICO - >16 years old with answers presented together with no way of differentiating data
Verstraete, Janine, Ramma, Lebogang, Jelsma, Jennifer, Item generation for a proxy health related quality of life measure in very young children, Health and quality of life outcomes, 18, 11, 2020	Population not in PICO - Caregivers of children with no information given about the ages of children and healthcare professionals
Vincent, S., Jopling, M., The health and well-being of children and young people who are looked after: Findings from a face-to-face survey in Glasgow, Health & social care in the community, 26, 182-190, 2018	Outcomes of interest not in PICO - No relevant quantitative data presented
Vowles, Kevin E., Jordan, Abbie, Eccleston, Christopher, Bursch, Clinch Crombez Dunn-Geier Eccleston Eccleston Eccleston Eccleston Eccleston Eccleston Everitt Gauntlett-Gilbert Hair Hermann Huguet Huguet Hunfeld Hunfeld Jordan Jordan Jordan Kashikar-Zuck Kashikar-Zuck Kerns Konijnenberg Kovacs Logan Malleson Mikkelsson Palermo Perquin Price Roth-Isigkeit Scharff Sherry Sleed Sullivan Tabachnick Turk Turk Varni Vetter Vowles Walker Walker Wicksell Zeltzer, Toward a taxonomy of adolescents with chronic pain: Exploratory cluster and discriminant analyses of the Bath adolescent pain questionnaire, European Journal of Pain, 14, 214-221, 2010	Study design not in PICO - Exploratory cluster analysis
Wagland, R., Bracher, M., Drosdowsky, A., Richardson, A., Symons, J., Mileshkin, L., Schofield, P., Differences in experiences of care between patients diagnosed with metastatic cancer of known and unknown primaries: Mixed-method findings from the 2013 cancer patient experience survey in England, BMJ open, 7 (9) (no pagination), 2017	Population not in PICO - >16 years with data not presented separately for target population
Warren, Fiona C., Abel, Gary, Lyratzopoulos, Georgios, Elliott, Marc N., Richards, Suzanne, Barry, Heather E., Roland, Martin, Campbell, John L., Characteristics of service users and provider organisations associated with experience of out of hours general practitioner care in England: population based cross sectional postal questionnaire survey, BMJ (Clinical research ed.), 350, h2040, 2015	Population not in PICO - Adults >18 years old
Watanabe, A., Shaw, K., Rankin, E., McDonagh, J., Young people's expectations of and satisfaction with transitional care from paediatric and adult care perspectives, Archives of disease in childhood, 1), A65, 2010	Conference abstract

Study	Reason for Exclusion
Watson, G., Parental liminality: A way of understanding the early experiences of parents who have a very preterm infant, J Clin NursJournal of clinical nursing, 20, 1462-1471, 2011	Outcomes not in PICO - No relevant quantitative data presented
Waxman, Michael J., Lozier, Kurt, Vasiljevic, Lana, Novakofski, Kira, Desemone, James, O'Kane, John, Dufort, Elizabeth M., Wood, David, Ata, Ashar, Filhour, Louis, Blinkhorn, Richard J., Jr., Hospitalized patients' and family members' preferences for real-time, transparent access to their hospital records, The American journal of managed care, 24, e17-e23, 2018	Population not in PICO - Adults >18 years old
Webb, C. M., Collin, S. M., Deave, T., Haig-Ferguson, A., Spatz, A., Crawley, E., What stops children with a chronic illness accessing health care: a mixed methods study in children with Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME), BMC health services research, 11, 308, 2011	Outcomes not in PICO - Correlation between time-to-assessment and patient characteristics
Westwood, Joanne, Howard, Louise M., Stanley, Nicky, Zimmerman, Cathy, Gerada, Clare, Oram, Sian, Access to, and experiences of, healthcare services by trafficked people: findings from a mixed-methods study in England, The British journal of general practice : the journal of the Royal College of General Practitioners, 66, e794-e801, 2016	Population not in PICO - >16 years with data not presented separately for target population
White, H., Gillgrass, L., Wood, A., Peckham, D. G., Requirements and access needs of patients with chronic disease to their hospital electronic health record: results of a cross-sectional questionnaire survey, BMJ open, 6, e012257, 2016	Population not in PICO - >17 years with data not presented separately for target population
Williams, G., Pattison, G., Mariathas, C., Lazar, J., Rashied, M., Improving parental satisfaction in pediatric orthopaedics, Journal of Pediatric Orthopaedics, 31, 610-615, 2011	Outcomes not in PICO - No relevant quantitative data presented
Worth, A., Regent, L., Levy, M., Ledford, C., East, M., Sheikh, A., Living with severe allergy: an Anaphylaxis Campaign national survey of young people, Clinical and translational allergy, 3, 1-7, 2013	Population not in PICO - 15-25 years (mean is 18.5 years, 43% 15-17 years) with data not presented separately for target population
Wright, C., Stark, D., Coad, J., Morgan, S., Fuller, S., Cable, M., An evaluation of a specialist service for teenagers/young adults with cancer in the United Kingdom, European Journal of Cancer, 49, S355, 2013	Conference abstract
Wright, Christine, Richards, Suzanne H., Hill, Jacqueline J., Roberts, Martin J., Norman, Geoff R., Greco, Michael, Taylor, Matthew R. S., Campbell, John L., Multisource feedback in evaluating the performance of doctors: the example of the UK General Medical Council patient and colleague questionnaires, Academic medicine : journal of the Association of American Medical Colleges, 87, 1668-78, 2012	Population not in PICO - All age ranges with data not presented separately for target population
Zuzak, T. J., Bonkova, J., Careddu, D., Garami, M., Hadjipanayis, A., Jazbec, J., Merrick, J., Miller, J., Ozturk, C., Persson, I. A. L., Petrova, G., Saz Peiro, P., Schraub, S., Simoes-Wust, A. P., Steinsbekk, A., Stockert, K., Stoimenova, A., Styczynski, J., Tzenova-Savova, A., Ventegodt, S., Vlieger, A. M., Langler, A., Use of complementary and alternative medicine by children in Europe: Published data and expert perspectives, Complementary Therapies in Medicine, 21, S34-S47, 2013	Narrative review.

Economic studies

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

Appendix L – Research recommendations

Research recommendations for review question 4.1a What factors are important to babies, children and young people to improve their experience of healthcare services? (Qualitative)

No research recommendations were made for this review question.

Research recommendations for review question 4.1b What factors are important to babies, children and young people to improve their experience of healthcare? (Quantitative)

Research question

What elements of healthcare matter most to babies, children and young people to create positive experiences of healthcare?

Why this is important

A number of factors can impact on the healthcare experiences of children and young people, but to improve experiences it would be useful to know which factors are most important to them. This may identify 'new' factors that have not been considered by the health service before, or may enable prioritisation of service improvement initiatives. The overall quality of evidence for this question was judged to be very low, and there was very little published evidence. It is therefore important to carry out research to identify what matters to children and young people.

Table 26: Research recommendation rationale

Research question	**What elements of healthcare matter most to babies, children and young people to create positive experiences of healthcare?**
Why is this needed	
Importance to 'patients' or the population	A number of factors are important to children and young people in terms of their experience of healthcare services and it is crucially important to engage them in discussions about the quality of their healthcare to improve their experience.
Relevance to NICE guidance	High: there is little direct evidence on what matters most to children and young people so this is directly relevant to NICE guidance on their experience.
Relevance to the NHS	High: improving healthcare experience has the potential to improve the quality of life of babies, children young people and their parents or carers. In addition, it is important in improving engagement and concordance with treatment, which in turn can improve outcomes.
National priorities	The National Service Framework for children, young people and maternity services aims for long-term and sustained improvement in children's health, and sets standards for health and social care services for children, young people and pregnant women.
Current evidence base	The guideline review has identified that there is a gap in the evidence base..

Research question	**What elements of healthcare matter most to babies, children and young people to create positive experiences of healthcare?**
Equality	Research on factors important to babies, children and young people should take into consideration their socioeconomic, cultural, religious and ethnic environment, and potential language barriers. Certain groups may be at greater risk of a poorer experience including those with learning-disabled parents or carers, asylum seekers, and looked-after children, who may find it more of a challenge to access services.
Feasibility	Access to children and their families would be needed at a sensitive time. This could be managed by using practitioners known to the families, or through a network of support groups.
Other comments	Parental support is recognised as important

Table 27: Research recommendation modified PICO table

Criterion	Explanation
Population	Babies, children and young people accessing health care services. The population of children considered should be from representative age groups (parents of babies and children up to 5 years, and 5-18 year olds), include both sexes and be as ethnically diverse as possible (so as to capture issues in the wider family context). Recruitment strategy should include patients in acute and community settings, and ideally be comprised of multiple centres within different regions nationally.
Phenomena of interest	Concerns, experiences and priorities (both in terms of outcomes and service delivery) of babies, children and young people in order to derive variables most important to this population.
Context	Babies, children and young people accessing healthcare services in all settings
Study design	Utilizing person centred methodology, this information can be used to construct a standardized checklist with high face validity that could be used by clinicians to optimize tailored support and intervention. The study aims to explore the factors that are important to babies, children and young people when accessing services. A semi-structured interview may have some closed and some open-ended questions. For example, closed questions could include: • Did you feel satisfied with the health care service? Qualitative open ended questions will be piloted to be developmental age-appropriate and will vary according to child or parent/carer. Examples of these could be: • Describe your experience • What options were you provided with?

Criterion	**Explanation**
	A multi-phase study using person centred methodology, commencing in Phase 1 with an open survey of views and experiences of babies, children and young people to determine desired outcomes of interventions and desired aspects of service delivery. Themes to be grouped and investigated in depth via focus groups and individual interview. Preliminary questionnaire based on the themes to be used in Phase 2 survey with emphasis on assessing salience across different age ranges and types of population (e.g. in terms of severity) as well as ensuring saturation of themes.
Timeframe	2-3 years
Additional information	If appropriate, age groups should be stratified to align with WHO and ONS bands: • (Parents or carers of) 0-4 years • 5-9 years • 10-14 years • 15-17 years

ONS: Office of National Statistics; WHO: World Health Organisation

Appendix M – Evidence from reference groups and focus groups

Evidence from reference groups and focus groups for the review question 4.1a What factors are important to babies, children and young people to improve their experience of healthcare services? (Qualitative)

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

Table 28: Evidence from focus groups and reference groups

Age < 7 years	Age 7-11 Years	Age 11-14 years	Overall quality of the evidence
• ‘I don’t like going to the doctors’ • ‘I love games’ • ‘I like it feeling comfy’ • ‘I don’t like the doctors because they have to do injections and vets have to do injections for your pets’ • ‘You’re not allowed to have food at your doctors and this means you get hungry’ • ‘I went to the doctors before going to school and had a jab and it really hurt but my mummy was there. It was good because she holded my hand while I did it’ • ‘I had to have a few injections and there were toys and they gave me a plaster’ • ‘I’ve been to a dentist to sort out my mouth. They opened my mouth wide in case I’ve been good and have clean teeth’ • ‘I don’t like going to the doctors because of injections’ • ‘They might make me feel a little bit better’ • ‘Everybody wants to feel better’	• ‘Food and water’ • ‘Change the hospital food, it’s dry’ • ‘Nice hospital food’ x 2 • ‘Food to suit my needs’ (pescatarian) • ‘Good chef (to cook the meals I like)’ • ‘Doctors who do their job properly’ • ‘Having someone who has done the job before, not someone who is new and inexperienced’ • ‘Experienced staff doing things right’ • ‘Doctors doing the procedures correctly’ • ‘Lots of caring and helpful doctors’ • ‘Getting the right diagnosis’ • ‘Helpful – solve the problem’ • ‘Getting better’ • ‘Only getting treatment you need’ • ‘Treatment not hurting’ x 2 • ‘Examination not hurting’ • ‘No needles’ • ‘Getting right prescription’	• ‘Having a service available’ (MH services) • ‘Good food’ x 2 • ‘Not being forced to eat food you don’t like’ • ‘Giving people the help they need’ (MH services) • ‘Whenever you need someone, they’re always there’ (MH services) • ‘Staff who are able to respond/help straight away – good service’ • ‘Giving support at home’ (MH services) • ‘Home/online visits in the comfort of the patient’s home’ (MH services) • ‘Whenever you need someone, they’re always there • ‘Not adults only there’ • ‘Tailored specifically to them (MH services) x2 • ‘Cost-free’ x2 • ‘Really fast’ • ‘Qualified staff’ • ‘Know what they are talking about’	• Low

Age < 7 years	Age 7-11 Years	Age 11-14 years	Overall quality of the evidence
• Appearance of healthcare professionals: o The children were shown pictures of a variety of healthcare professionals (in uniform, not in uniform, smiling, looking serious, male, female) and asked to pick the one that looked like the world's best and world's worst, and then to explain their decision. Overall, the children always preferred people who were smiling, looked friendly and who looked smart and professional. They didn't like pictures of people who were looking cross. - 'He looks like a doctor from what he is wearing' - 'The thing around his neck makes him look like a doctor' x 2 (picture was a doctor in a white coat with a stethoscope around his neck) - 'Better for them to wear a white coat than every day clothes' - 'Blue gown - looks like a doctor' - 'Wearing white coat so looks like a doctor - 'Nice shirt - looks like he would help people in danger' - 'I really want to see a girl doctor' (4 girls agreed with this, 3 boys wanted to see a man doctor, most didn't mind) - 'I like her smile and her hair' - 'Nice outfit' (picture was of a nurse in traditional uniform tunic) - 'She looks nice because she is smiling' x3	• 'Not catching something contagious from another patient' • 'Give you stickers' x3 • 'Helping people if there's a fire' • 'Important to be comfortable, needs to feel like home' x3 • 'Games – if something is sad but I am playing a game it makes it better because games make me happy' • 'Seeing the same person – happy, if you've broken your arm, if you can't get in/in a rush, means you have to be there at the same time' • 'Needs to be as quick as possible but I really want comfy chairs' • 'I love the hospital – free food' • 'More important than it being close to home is if it feels like home because [if not] you might feel a bit sick, but if it feels like home it will be much better. If it feels like home then you'll know it feels safe so you'll feel less sick' x 2 • 'I want it to be fast I guess, but not too fast or they might make mistakes' • 'My top one is 'explain it with games' – and chocolate! Because if they are explaining something really sad, I won't get sad because I will be playing with games which makes me happy'	• 'Trustworthy' • 'Knowledgeable' • 'Avoid sensory overload' • 'Not bland' [about food] • 'Not reserved' • Having the right medicines' x2 • 'Parent-like person who just comforts (rather than treats)' • 'Don't leave us on our own – no attention when on a ward' • 'Not being expected to do something you physically can't do'	

Reference groups and focus groups evidence for review question 4.1b What factors are important to babies, children and young people to improve their experience of healthcare? (Quantitative)

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

Age 11-14 reference group:

The young people aged 11-14 were provided with a blank diamond chart and slips of paper with factors relating to their healthcare experience. The factors available were:

- Friendly
- Close to home
- Fast diagnosis and treatment
- Asks me how I've been feeling
- I see the same people every time
- Explains things to me
- Explains things to my parent/carer
- Uses games and pictures
- Plays music in the waiting room
- Uses words I understand (no jargon)

These factors were selected by the provider running the reference groups based on previous work they had conducted with children and young people.

The young people were asked to stick the slips of paper on the diamond chart to show which factor was most important to them (the top row), which was least important (the bottom row), and which factors were of medium importance to them on the rows in between. A total of seven 11-14 year olds completed this exercise. The young people were also given blank slips of paper in case they wished to identify other priorities themselves and not use the pre-printed ones. A sample completed diamond chart is shown in Figure 5 and the collated results are shown in Table 29.

Figure 5: Sample completed diamond chart

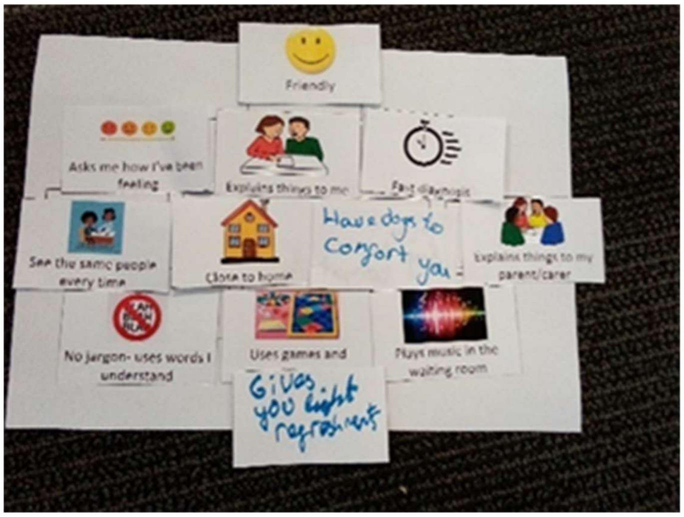


Table 29: Collated diamond chart results

	Young person 1	Young person 2	Young person 3	Young person 4	Young person 5	Young person 6	Young person 7
Level 1 Top priority	Friendly	Fast diagnosis	Fast diagnosis	Friendly	Plays music in the waiting room	Friendly	Friendly
Level 2	Ask me how I've been feeling	See the same people every time	Ask me how I've been feeling	See the same people every time	Uses games and pictures	Uses games and pictures	Ask me how I've been feeling
	Explains things to me	Explains things to me	Close to home	Close to home	Explains things to me	Close to home	Explains things to me
	Fast diagnosis	Explains things to my parent/carer	Friendly	BLANK	BLANK	No jargon -uses words I understand	No jargon -uses words I understand
Level 3	See the same people every time	Friendly	See the same people every time	Ask me how I've been feeling	Fast diagnosis	Ask me how I've been feeling	See the same people every time
	Close to home	No jargon -uses words I understand	Uses games and pictures	Use games and pictures	No jargon -uses words I understand	Plays music in the waiting room	Close to home
	Have dogs to comfort you	Plays music in the waiting room	BLANK	Plays music in the waiting room	Friendly	Explains things to my parent/carer	Explains things to my parent/carer
	Explains things to my parent/carer	Ask me how I've been feeling	Explains things to me	BLANK	Ask me how I've been feeling	Explains things to me	Fast diagnosis
Level 4	No jargon -uses words I understand	A lot of attention	No jargon -uses words I understand	No jargon -uses words I understand	See the same people every time	See the same people every time	Uses games and pictures
	Uses games and pictures	Uses games and pictures	Explains things to my parent/carer	Explains things to my parent/carer	Explains things to my parent/carer	Fast diagnosis	Cost-free
	Plays music in the waiting room	Gives you ??	BLANK	Explains things to me	BLANK	BLANK	Comforting

	Young person 1	Young person 2	Young person 3	Young person 4	Young person 5	Young person 6	Young person 7
Level 5 Bottom priority	Gives you light refreshments	Close to home	Plays music in the waiting room	Fast diagnosis	Close to home	BLANK	Plays music in the waiting room

Answers in bold were identified by individual young people as priorities and were not on the pre-printed slips

In order to determine the overall ranking of priorities from the members of the 11-14 years reference group, the factors were scored from 1 (level 5, bottom priority) to 5 (level 1, top priority), with a weighting factor applied to account for the fact that each child could select three priorities at level 2, four at level 3, and three at level 4. The weighting factors used are shown in Table 30 and the overall ranking of priorities in Table 31.

Table 30: Weighting factors

	Score	Weighting (to account for fact that different numbers of boxes on each level of diamond)
Level 1	5	77/84
Level 2	4	63/84
Level 3	3	56/84
Level 4	2	63/84
Level 5	1	77/84

Table 31: Overall ranking of priorities 11-14s

Factor	Overall weighted score
Friendly	24.8
Explains things to me	17.5
Fast diagnosis	17.1
Ask me how I've been feeling	17.0
See the same people every time	13.0
No jargon - uses words I understand	13.0
Uses games and pictures	13.0
Close to home	12.8
Plays music in the waiting room	12.4
Explains things to my parent/carer	11.5

Factor	Overall weighted score
Have dogs to comfort you	*2.0*
Cost-free	*1.5*
Comforting	*1.5*
A lot of attention	*1.5*
Gives you light refreshments	*0.9*

Answers in italics were identified by individual young people as priorities and were not on the pre-printed slips

Age 7-11 reference groups:

The children aged 7 to 11 years were provided with medal charts (gold, silver and bronze) upon which they could prioritise the three factors they felt were most important to improve their experience of healthcare. As for the 11-14 year olds they were provided with slips of paper with factors relating to their healthcare experience. The factors available were:

- Friendly
- Close to home
- Fast diagnosis and treatment
- Asks me how I’ve been feeling
- I see the same people every time
- Explains things to me
- Explains things to my parent/carer
- Uses games and pictures
- The place is comfortable and feels like home
- Uses words I understand (no jargon)

The option ‘Plays music in the waiting room’ was replaced for this group with the factor ‘The place is comfortable and feels like home’ based on the discussion with the 11-14 group who felt that playing of music was very specific, but they did want comfort and homeliness.

The children were asked to stick the slips of paper on the medal chart to show which factor was most important to them (the gold medal), which was next most important (the silver medal) and which was third most important (the bronze medal). A total of 31 7-11 year olds competed this activity. A sample completed medal chart is shown in Figure 6 and the collated results are shown in Table 32.

Figure 6: Sample completed medal chart

Table 32: Collated medal chart results

	Gold medal	Silver medal	Bronze medal		Gold medal	Silver medal	Bronze medal
Child 1	Fast diagnosis and treatment	No jargon - uses words I understand	The place is comfortable and feels like home	Child 16	The place is comfortable and feels like home	Fast diagnosis and treatment	Friendly
Child 2	I see the same people every time	Explains things to my parent/carer	Fast diagnosis and treatment	Child 17	The place is comfortable and feels like home	Fast diagnosis and treatment	Friendly
Child 3	Friendly	I see the same people every time	Fast diagnosis and treatment	Child 18	The place is comfortable and feels like home	Close to home	I see the same people every time
Child 4	Fast diagnosis and treatment	No jargon - uses words I understand	The place is comfortable and feels like home	Child 19	Uses games and pictures	Explains things to my parent/carer	Fast diagnosis and treatment

	Gold medal	**Silver medal**	**Bronze medal**		**Gold medal**	**Silver medal**	**Bronze medal**
Child 5	I see the same people every time	Asks me how I've been feeling	No jargon - uses words I understand	Child 20	I see the same people every time	The place is comfortable and feels like home	Close to home
Child 6	Friendly	The place is comfortable and feels like home	BLANK	Child 21	Friendly	The place is comfortable and feels like home	Explains things to me
Child 7	Explains things to my parent/carer	Uses games and pictures	Friendly	Child 22	Friendly	The place is comfortable and feels like home	Explains things to me
Child 8	The place is comfortable and feels like home	Explains things to my parent/carer	I see the same people every time	Child 23	Friendly	Asks me how I've been feeling	The place is comfortable and feels like home
Child 9	Friendly	Asks me how I've been feeling	Uses games and pictures	Child 24	Friendly	Explains things to my parent/carer	Asks me how I've been feeling
Child 10	Uses games and pictures	Close to home	No jargon - uses words I understand	Child 25	Friendly	Asks me how I've been feeling	Explains things to my parent/carer
Child 11	Friendly	Asks me how I've been feeling	No jargon - uses words I understand	Child 26	Explains things to my parent/carer	The place is comfortable and feels like home	Explains things to me
Child 12	Fast diagnosis and treatment	No jargon - uses words I understand	The place is comfortable and feels like home	Child 27	The place is comfortable and feels like home	Uses games and pictures	Friendly
Child 13	Friendly	No jargon - uses words I understand	The place is comfortable and feels like home	Child 28	Friendly	Explains things to me	Asks me how I've been feeling
Child 14	Friendly	The place is comfortable and feels like home	Fast diagnosis and treatment	Child 29	Friendly	The place is comfortable and feels like home	Asks me how I've been feeling
Child 15	Close to home	Asks me how I've been feeling	Explains things to me	Child 30	Friendly	Asks me how I've been feeling	The place is comfortable and feels like home

	Gold medal	Silver medal	Bronze medal		Gold medal	Silver medal	Bronze medal
				Child 31	Friendly	Asks me how I've been feeling	Explains things to my parent/carer

In order to determine the overall ranking of priorities from the members of this reference group combined, the factors were scored from 1 (bronze medal) to 3 (gold medal). Using this scoring system the overall ranking of priorities is shown in Table 33.

Table 33: Overall ranking of priorities 7-11s

Factor	Overall score
Friendly	49
The place is comfortable and feels like home	35
Asks me how I've been feeling	19
Fast diagnosis and treatment	17
Explains things to my parent/carer	16
I see the same people every time	13
Uses games and pictures	11
No jargon - uses words I understand	11
Close to home	8
Explains things to me	6

Age 4- 7 focus groups:

The children aged 4 to 7 years old were provided with slips of paper with factors relating to their healthcare experience. The factors available were:

- Friendly
- Close to home
- Fast – I don’t have to wait long
- Asks me how I’ve been feeling
- I see the same people every time
- Explains things to me
- Explains things to my parents
- Uses games and pictures

- The place is comfortable and feels like home
- Adults use words I understand

The children were asked to arrange the slips of paper in order to show which factor was most important to them at the top, and then in order to the least important factor at the bottom.   A total of 24 4 to 7 year olds competed this activity. A sample completed ranking list is shown in Figure 7 and the collated results are shown in Table 34

Figure 7: Sample completed ranking list

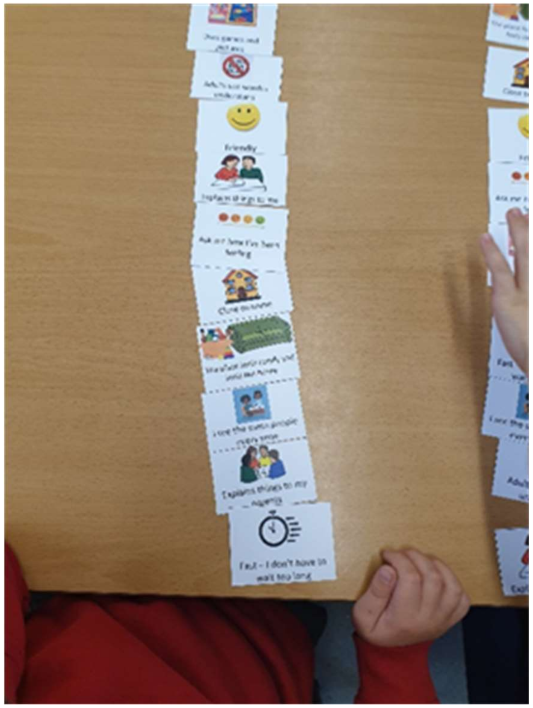


Table 34: Collated ranking of lists

	Most important factor									**Least important factor**
Child 1	Ask me how I've been feeling	The place feels comfy and feels like home	Friendly	Close to home	Uses games and pictures	Explains things to me	Explains things to my parents	I see the same people every time	Fast - I don't have to wait long	Adults use words I understand
Child 2	Close to home	Friendly	Uses games and pictures	The place feels comfy and feels like home	Explains things to me	Ask me how I've been feeling	Explains things to my parents			
Child 3	Uses games and pictures	Explains things to me	Friendly	I see the same people every time	Ask me how I've been feeling	Explains things to my parents	The place feels comfy and feels like home			
Child 4	The place feels comfy and feels like home	Close to home	Friendly	Ask me how I've been feeling	Uses games and pictures	Fast - I don't have to wait long	I see the same people every time	Adults use words I understand	Explains things to me	
Child 5	Uses games and pictures	Adults use words I understand	Friendly	Explains things to me	Ask me how I've been feeling	Close to home	The place feels comfy and feels like home	I see the same people every time	Explains things to my parents	Fast - I don't have to wait long
Child 6	Friendly	I see the same people every time	Ask me how I've been feeling	Explains things to my parents	Explains things to me	The place feels comfy and feels like home	Uses games and pictures	Fast - I don't have to wait long	Adults use words I understand	Close to home
Child 7	I see the same people every time	Friendly	Close to home	Explains things to me						
Child 8	Explains things to me	I see the same people every time	Explains things to my parents	Ask me how I've been feeling	Friendly	The place feels comfy and feels like home	Close to home	Adults use words I understand	Uses games and pictures	Fast - I don't have to wait long
Child 9	Ask me how I've been feeling	Uses games and pictures	Explains things to my parents	Explains things to me	Friendly	The place feels comfy and feels like home	I see the same people every time	Close to home	Fast - I don't have to wait long	Adults use words I understand
Child 10	Ask me how I've been feeling	Friendly	Uses games and pictures	Explains things to me	Close to home	Explains things to my parents	Adults use words I understand	I see the same people every time	Fast - I don't have to wait long	The place feels comfy and feels like home

	Most important factor									**Least important factor**
Child 11	Adults use words I understand	Uses games and pictures	Close to home	I see the same people every time	Explains things to me	Fast - I don't have to wait long				
Child 12	Uses games and pictures	Explains things to my parents	The place feels comfy and feels like home	Explains things to me	Friendly	I see the same people every time	Fast - I don't have to wait long	Adults use words I understand	Close to home	Ask me how I've been feeling
Child 13	Uses games and pictures	Friendly	Explains things to my parents	Ask me how I've been feeling						
Child 14	I see the same people every time	Uses games and pictures	The place feels comfy and feels like home	Close to home	Ask me how I've been feeling	Friendly				
Child 15	Explains things to my parents	Uses games and pictures	The place feels comfy and feels like home							
Child 16	Close to home	The place feels comfy and feels like home	Uses games and pictures	I see the same people every time	Fast - I don't have to wait long	Ask me how I've been feeling				
Child 17	Friendly	Fast - I don't have to wait long	Close to home	Uses games and pictures	The place feels comfy and feels like home	Explains things to me	I see the same people every time	Explains things to my parents	Ask me how I've been feeling	Adults use words I understand
Child 18	The place feels comfy and feels like home	Friendly	Close to home	Explains things to my parents	Explains things to me	Ask me how I've been feeling	I see the same people every time	Fast - I don't have to wait long	Uses games and pictures	Adults use words I understand
Child 19	Fast - I don't have to wait long	Close to home	I see the same people every time	Friendly	Uses games and pictures	Adults use words I understand	Explains things to my parents	The place feels comfy and feels like home	Explains things to me	Ask me how I've been feeling
Child 20	Friendly	Close to home								
Child 21	Explains things to my parents	Close to home	Friendly							

	Most important factor									**Least important factor**
Child 22	The place feels comfy and feels like home	Close to home	Ask me how I've been feeling	Uses games and pictures	Explains things to me	Friendly	Adults use words I understand	I see the same people every time	Explains things to my parents	Fast - I don't have to wait long
Child 23	Explains things to my parents	Friendly	The place feels comfy and feels like home	Explains things to me	Uses games and pictures	Close to home	I see the same people every time	Ask me how I've been feeling	Fast - I don't have to wait long	Adults use words I understand
Child 24	Close to home	Friendly	Fast - I don't have to wait long	Uses games and pictures	Ask me how I've been feeling	The place feels comfy and feels like home	Explains things to me	I see the same people every time	Explains things to my parents	Adults use words I understand

In order to determine the overall ranking of priorities from the members of this reference group combined, the factors were scored from 1 (least important) to 10 (most important) Using this scoring system the overall ranking of priorities is shown in Table 35.

Table 35: Overall ranking of priorities 4-7s

Factor	**Overall score**
Friendly	168
Uses games and pictures	153
Close to home	147
The place feels comfy and feels like home	125
Ask me how I've been feeling	113
Explains things to me	109
Explains things to my parents	108
I see the same people every time	107
Fast - I don't have to wait long	64
Adults use words I understand	49

Appendix N – Evidence from national surveys

Evidence from national surveys for review question 4.1a What factors are important to babies, children and young people to improve their experience of healthcare services? (Qualitative)

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

Table 36: Evidence from national surveys

Survey	Findings	Overall quality of the evidence
Association for Young People's Health. Young people's views on involvement and feedback in healthcare 2014	• No relevant findings were identified for this question	• N/A
Care Quality Commission. Children and young people's inpatient and day case survey 2018	FOOD AND DRINK: • 50% of 8-15 year olds said they liked hospital food; in a sub-group of children who had had cancer in last 5 years this was lower • 35% of parents of 0-7 year olds said they liked hospital food • 17% of parents of 0-15 year olds said they did not have access to hot drink facilities • 36% of parents were unable to prepare food in hospital PAIN: • 79% of children aged 8-15 years old who had pain felt that staff did everything they could to help	• Low
Child Outcomes Research Consortium. Child- and Parent-reported Outcomes and Experience from Child and Young People's Mental Health Services 2011-2015	• No relevant findings were identified for this question	• N/A
Health and Social Care Information Centre. Children's Dental Health Survey 2013. (Country	• No relevant findings were identified for this question	• N/A

Survey	**Findings**	**Overall quality of the evidence**
specific report for England, published 2015)		
HM Inspectorate of Prisons. Children in Custody 2016-2017	- No relevant findings were identified for this question	- N/A
National Children's Bureau. Listening to children's views on health provision 2012	- No relevant findings were identified for this question	- N/A
Opinion Matters. Declare your care survey 2018	- No relevant findings were identified for this question	- N/A
Picker Institute. Children and Young People's Patient Experience Survey 2018	- No relevant findings were identified for this question	- N/A
Picker Institute. Paediatric Emergency Department Survey 2015 and Children and Young People's Outpatient Survey 2015	- No relevant findings were identified for this question	- N/A
Picker Institute/NHS England/Bliss. Neonatal Survey 2014 *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).*	FEEDING: - If you wanted to express breast milk for your baby, were you given the support you needed from neonatal staff? Score = 86 - When you were in the neonatal unit, were you given the feeding equipment you needed for expressing, such as breast pump and sterilisation equipment? Score = 87 - If you wanted to breastfeed your baby, were you given enough support to do this from neonatal staff? Score = 84 - If you fed your baby formula milk, were you given enough support to do this from neonatal staff? Score = 85 ADMISSION TO NEONATAL CARE: - After you gave birth were you offered a photograph of your baby? Score = 63	- Moderate

Survey	Findings	Overall quality of the evidence
	• After you gave birth, were you ever cared for in the same ward as mothers who had their baby with them? Score = 55 • After your baby was admitted to the neonatal unit, were you able to see your baby as soon as you wanted? Score = 91	
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	FOOD: • Several teenagers aged 13 to 17 discussed that the quality of food in hospital was a major concern. Quotes: 'The only problem (at hospital 1) was the food. That was also the case in (hospital 2). But there, my mum could buy better food outside and bring it to me.' (M16) 'In (hospital 1) the food was dire. It was micro-waved and really hard, but I didn't know what to say. It's not like they're going to change it overnight. In (hospital 2) the food was very good.' (F15)	• Low

N/A: not applicable

Evidence from national surveys for review question 4.1b What factors are important to babies, children and young people to improve their experience of healthcare? (Quantitative)

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

All evidence from the grey literature review of national surveys identified for this review question is included in Table 36.