National Institute for Health and Care Excellence

FINAL

Babies, children and young people's experience of healthcare

[B] Communication by healthcare staff

NICE guideline NG204

Evidence reviews underpinning recommendations 1.2.1 to 1.2.16 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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Review question

How should healthcare staff communicate with babies, children and young people, and the parents or carers of babies and young children?

Introduction

Good communication with babies, children, young people and the parents or carers of babies and young children is essential and it is vital for healthcare professionals to establish rapport and good communication from the very first contact and throughout healthcare. Effective communication can support children and young people to understand their health condition, treatment options, treatment plans, and reduce anxiety and fear.

Communication is also vital to ensure a thorough understanding to allow for informed consent and shared decision-making, especially in circumstances where the issues to be considered are difficult or emotional.

The aim of this review is to identify the preferred way for healthcare staff to communicate with babies, children and young people, and the parents or carer of babies and young children.

Summary of the protocol

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

Table 1: Summary of the protocol

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 communication with healthcare staff
Primary outcome	Themes will be identified from the literature. The committee identified the following potential themes (however, not all of these themes may be found in the literature, and additional themes may be identified): • Absence of continuity of communication with staff throughout the healthcare journey in short- or long-term (for example, staff does not explain aim or reasons for emergency procedure) • Appropriate and multiple opportunities to ask staff questions about healthcare condition and treatment options, • Avoiding use of medical jargon • Importance of feeling a personal connection to healthcare staff • Lack of consistency in what is communicated • Lack of appropriately-trained staff • Provision of interpreter • Sensitivity of staff to personal and family circumstances

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:

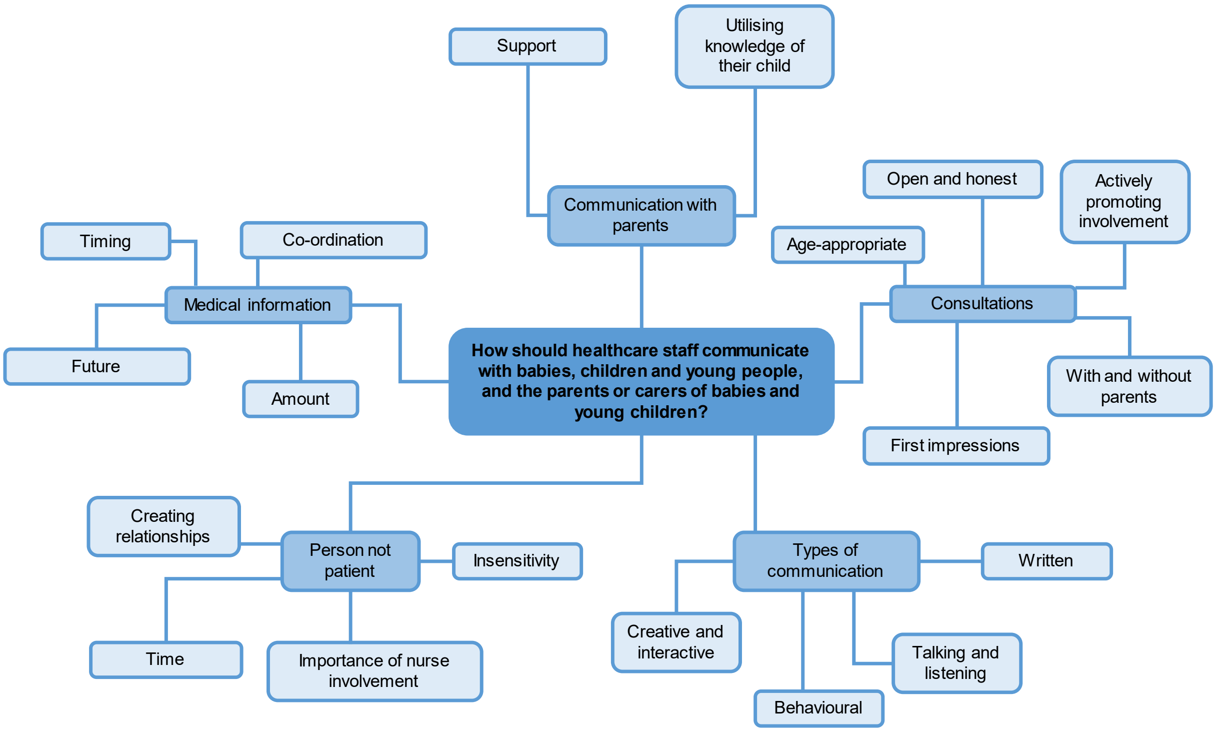
- Understanding how children and young people, or the parents or carers of babies and very young children prefer healthcare staff to communicate with them.

A systematic review of the literature was conducted using a combined search. Thirteen studies were included in this evidence review: 8 studies used semi-structured interviews (Arnott 2012, Boyden 2013, Heath 2015, Law 2020, McCormack 2010, Sharkey 2016, Taylor 2010, Wood 2018); 2 used participatory-based approaches (Curtis-Tyler 2012, Gibson 2010); 1 study used mixed-methods (Lowes 2015); and 1 systematic review included qualitative, quantitative and mixed-methods studies (Robards 2018). With the exception of Robards 2018, which included studies from the US, Australia, Canada, New Zealand and Portugal, the remaining 12 studies were conducted in the UK.

The included studies are summarised in Table 2.

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

Figure 1: Theme map



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

Excluded studies

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

Summary of studies included in the evidence review

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

Table 2: Summary of included studies

Study	Population	Methods	Themes
Arnott 2012 **Study design** Semi-structured interview **Aim of the study** To identify unmet information and communication needs of parents whose child has had a suspected	N=45 parental proxies of 44 babies, children, or young people ○ Only parents of children under 5 years old are included in this review **Characteristics** Age of child (range): 0-17 years	**Recruitment** 2 sampling routes • Adverse Drug Reaction programme at UK paediatric centre • Yellow Card scheme (UK drug surveillance system) **Data collection** Semi-structured interviews	• Medical information: Co-ordination • Medical information: Timing • Medical information: Future • Types of communication: Written • Consultations: clear and Honest • Communication with parents: Utilising knowledge of their child

Study	Population	Methods	Themes
adverse drug reaction. Liverpool, UK	Gender of child (M/F): 24/20	**Analysis** Modified grounded theory	
Boyden 2013 **Study design** Semi-structured interview **Aim of the study** To explore the experiences of children using a local learning disability-CAMHS service, in order to produce a set of quality standards in line with Department of Health guidelines and national legal requirements. Derbyshire, UK	N=7 children and young people **Characteristics** Age (range): 11-17 years Gender (M/F): 5/2	**Recruitment** Participants suggested by CAMHS team **Data collection** Semi-structured interviews **Analysis** Thematic analysis	• Person not patient: Creating relationships • Types of communication: Talking and listening • Types of communication: Creative and interactive • Types of communication: Behavioural • Consultations: Age-appropriate • Consultations: First impressions
Curtis-Tyler 2012 **Data collection** Participatory-based approaches, home visits, discussion groups and observation **Aim of the study** To explore the experiences of children under 10 years who live with Type 1 diabetes. London, UK	N=17 children **Characteristics** Age (range): 4-11 years Gender (M/F): 9/8	**Recruitment** Convenience sampling where study invitations were sent to children's homes and outpatient clinics. Participants self-selected to join the study. **Data collection** Home visits with participatory-based approaches, clinic appointment observation, passive observation of waiting rooms and discussion groups. **Analysis** Ground theory approach	• Person not patient: Importance of nurse involvement • Types of communication: Talking and listening
Gibson 2010 **Study design** Participatory-based activities **Aim of the study**	N=38 children and young people **Characteristics** Age (range): 4-19 years	**Recruitment** Paediatric cancer patients identified by clinicians, notices at parent support groups and posters in clinical areas of 3 UK Principal Cancer Treatment sites	• Medical information: Amount • Person not patient: Insensitivity • Person not patient: Creating relationships

Study	Population	Methods	Themes
To examine the views of children and young peoples on cancer care and to present a conceptual model of communication and information sharing. UK (exact location not specified)	Gender (M/F): 18/20	**Data collection** Three age-appropriate participatory methods used: • Play and puppets (4-5 years old) • Drawing and writing techniques (6-12 years old) • Activities day and interviews (13-19 years old) **Analysis** Inductive thematic analysis	• Person not Patient: Importance of nurse involvement • Types of communication: Talking and listening • Types of communication: Behavioural • Consultations: Age-appropriate • Consultations: Actively promoting involvement • Consultations: Clear and honest • Communication with parents: Support
Heath 2015 **Study design** Semi-structured interview **Aim of the study** To explore babies, children and young people's (and parents') views of paediatric outpatient care, focusing on how healthcare setting may impact experiences. Birmingham/West Midlands, UK	N=14 children and young people • n=8 hospital outpatient • n=6 community clinic outpatient **Characteristics** Not reported	**Recruitment** Purposive sampling of families in waiting area of paediatric clinic **Data collection** Semi-structured interviews **Analysis** Descriptive phenomenology	• Person not patient: Time • Person not patient: Insensitivity • Consultations: First impressions • Communication with parents: Utilising knowledge of their child
Law 2020 **Study design** Semi-structured interview **Aim of the study** To understand young people's concept of mental health recovery. East Anglia and Greater Manchester, UK	N=23 young people • n=15 <18 years • n=8 >18 years ○ Only the views of the young people under 18 years are included in this review. **Characteristics** Age (years, n): • 14-17=15 • 18-21=5 • 22-25=3	**Recruitment** Convenience sampling of 2 regional mental health services. **Data collection** Semi-structured interviews **Analysis** Thematic analysis	• Person not patient: Creating relationships • Types of communication: Talking and listening • Consultations: Actively promoting involvement

Study	Population	Methods	Themes
	Gender (M/F/non-binary): 4/18/1		
Livesley 2013 **Study design** Ethnographic, including participatory activities and fieldwork **Aim of the study** To explore children's experiences of, and knowledge about, being a hospital in-patient. North England, UK	N=17 children and young people • n=6 phase 1 • n=9 phase 2 **Characteristics** *Phase 1* Age (range): 9-15 years Gender (M/F/not reported): 3/2/1 *Phase 2* Age (range): 5-14 years Gender (M/F): 3/7 • Study reports that there were 9 participants in Phase 2 but provides details of characteristics for 10 participants.	**Recruitment** Purposive sampling from hospital records and patients admitted to paediatric hospital study ward **Data collection** Age-appropriate home-based participatory activities (Phase 1) and subsequent field work on paediatric hospital ward (Phase 2) **Analysis** Constant comparative method	• Person not patient: Creating relationships • Person not patient: Time • Person not patient: Insensitivity • Types of communication: Behavioural
Lowes 2015 **Study design** Free-text questionnaire **Aim of the study** To examine experience of children and adolescents living with and managing Type 1 diabetes, and attending specialist paediatric diabetes services Nationwide, UK	• N=518 children and young people completed baseline questionnaires ○ n=259 in intervention group ○ n=259 in control group • N=390 children and young people completed 1 year follow- up questionnaires: ○ n=185 in intervention group ○ n=205 in control group **Characteristics** Age (range): 7-15 years Gender: Not reported	**Recruitment** Participants taking part in DEPICTED cluster-randomised control trial study, who were recruited from 26 secondary and tertiary care paediatric diabetes services **Data collection** Age-appropriate free-text questionnaires at baseline and 1-year follow-up **Analysis** Qualitative descriptive analysis	• Medical information: Amount • Person not Patient: Importance of nurse involvement • Consultations: With and without parents

Study	Population	Methods	Themes
McCormack 2010 **Study design** Semi-structured interview **Aim of the study** To explore the impact of chronic health conditions on young people, their lives, their families and their interactions with healthcare services. Cornwall and Devon, UK	N=3 young people **Characteristics** Age (range): 12-18 years Gender: Not reported	**Recruitment** Participants taking part in a documentary about the impact of living with chronic illnesses. **Data collection** Semi-structured interviews **Analysis** Thematic analysis	• Medical information: Going forward • Person not patient: Insensitivity • Person not patient: Creating relationships
Robards 2018 **Study design** Systematic review **Aim of study** To examine how young people who are marginalized access and engage with health services and navigate health-care systems in high-income countries Multiple countries	K=68 studies Range of sample size: N=3 to 1388 **Characteristics** Type of study (k): • Qualitative=44 • Quantitative=16 • Mixed-methods=8 ○ This study incorporated all their results (qualitative and quantitative) into a narrative summary, which was then used in the findings of this review. Participants (k): • Young people=61 • Professionals=11 Parents=7 ○ Although the study notes that their themes were identified by all the participants in their population (marginalised young people	**Recruitment** Not applicable **Data collection** Systematic literature search **Analysis** Data extraction, quality appraisal of studies, and thematic analysis	• Person not patient: Insensitivity • Person not patient: Creating relationships • Consultations: First impressions • Consultations: Actively promoting involvement • Types of communication: Listening • Medical information: Co-ordination

Study	Population	Methods	Themes
	up to age 24 years old, parents and healthcare professionals), views of people > 18 years old, parents and health professionals will also have been included in their results. Our findings have been downgraded for relevance where applicable.		
Sharkey 2016 **Study design** Semi-structured interview **Aim of the study** To explore the experiences of healthcare professionals and parents when communicating with children who have 'communication difficulties' on a paediatric inpatient ward. South West England, UK	N=17 parental proxies for children with 'communication difficulties' **Characteristics** Age of child (range): 5 to 16 years Gender of child (M/F): Not reported	**Recruitment** Researchers identified parents of disabled children admitted to 2 district general hospitals in England and displayed posters in wards and parent rooms **Data collection** Semi-structured interviews **Analysis** Framework analysis	• Medical information: Co-ordination • Person not patient: Time • Person not patient: Creating relationships • Types of communication: Creative and interactive • Types of communication: Listening • Types of communication: Talking • Communication with parents: Utilising knowledge of their child
Taylor 2010 **Study design** Semi-structured interview **Aim of the study** To explore the views of children and their parents/carers regarding their involvement in paediatric consultations.	N=43 children, young people and parents • n=20 children and young people • n=23 parents ○ Only the views of children and young people included in this review **Characteristics** Age [median (range)]: 10 (7-16) years	**Recruitment** Consecutive sampling of families attending 1 of 2 paediatric in- and out-patient clinics **Data collection** Semi-structured interviews with topic guide **Analysis** Thematic (Framework) analysis by 2 researchers with 3rd researcher checking process and methodology	• Medical information: Going forward • Medical information: Amount • Person not patient: Time • Consultations: Actively promoting involvement • Consultations: With and without parents • Consultations: Age-appropriate

Study	Population	Methods	Themes
Northampton and London, UK	Gender of child (M/F): 5/15		
Wood 2018 **Study design** Semi-structured interview **Aim of the study** To determine whether adolescents and their families can articulate their experiences of their ICU or high dependency unit visit, and to identify the factors that are important to them during such visits. UK	N=17 young people and parents • n=8 mother-adolescent dyads • n=1 mother ○ Views and experiences of the mothers were included in this review as they were reflecting on a period of time when their child may not have been able to participate in healthcare conversations and decisions while in ICU. **Characteristics** Age of children (years, n): • 14=1 • 15=3 • 16=2 • 17=2 • 19= 1 Gender: Not reported.	**Recruitment** Purposive sampling using local specialist nurses **Data collection** Semi-structured interviews **Analysis** Framework thematic analysis	• Person not patient: Creating relationships • Person not patient: Insensitivity • Consultations: Actively promoting involvement • Consultations: Age-appropriate

CAMHS: Child and Adolescent Mental Health Service; F: Female; ICU: Intensive care unit; M: Male; N: Number; vs; versus

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

Quality assessment of studies included in the evidence review

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

Main theme 1: Medical information

- Sub-theme 1.1: Timing. The overall confidence in this sub-theme was judged to be very low.
- Sub-theme 1.2: Co-ordination. The overall confidence in this sub-theme was judged to be very low.
- Sub-theme 1.3: Amount. The overall confidence in this sub-theme was judged to be moderate.

- Sub-theme 1.4: Future. The overall confidence in this sub-theme was judged to be very low.

Main theme 2: Person not patient

- Sub-theme 2.1: Creating relationships. The overall confidence in this sub-theme was judged to be high.
- Sub-theme 2.2: Time. The overall confidence in this sub-theme was judged to be high.
- Sub-theme 2.3: Importance of nurse involvement. The overall confidence in this sub-theme was judged to be low.
- Sub-theme 2.4: Insensitivity. The overall confidence in this sub-theme was judged to be high.

Main theme 3: Type of communication

- Sub-theme 3.1: Creative and interactive. The overall confidence in this sub-theme was judged to be very low.
- Sub-theme 3.2: Behavioural. The overall confidence in this sub-theme was judged to be moderate.
- Sub-theme 3.3: Talking and listening. The overall confidence in this sub-theme was judged to be high.
- Sub-theme 3.4: Written. The overall confidence in this sub-theme was judged to be very low.

Main theme 4: Consultations

- Sub-theme 4.1: First impressions. The overall confidence in this sub-theme was judged to be moderate.
- Sub-theme 4.2: With and without parents. The overall confidence in this sub-theme was judged to be very low.
- Sub-theme 4.3: Actively promoting involvement. The overall confidence in this sub-theme was judged to be high.
- Sub-theme 4.4: Open and honest. The overall confidence in this sub-theme was judged to be low.
- Sub-theme 4.5: Age-appropriate. The overall confidence in this sub-theme was judged to be high.

Main theme 5: Communication with parents

- Sub-theme 5.1: Utilising knowledge of their child. The overall confidence in this sub-theme was judged to be low.
- Sub-theme 5.2: Support. The overall confidence in this sub-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 evidence from the reference groups and focus groups

Age groups	• <7 years

	• 7-11 years • 11-14 years
Areas covered	• Qualities of healthcare staff • Healthcare staff verbal and non-verbal communication style
Illustrative quotes	• ‘I like it when doctors are friendly and good at their job’ • ‘If it does hurt you, you can tell them and they will listen’ • ‘If they use the complicated words I prefer if they [health professionals] talk to mum and dad but if they use words I understand I prefer them talking to me’ • ‘Don’t know what the instrument is and when I don’t know what it is and then they use it on me, it feels a bit strange and scary’ • ‘Make eye contact’ • ‘Kind staff –explanations, so know what is happening’

See the full evidence summary in appendix M.

Evidence from national surveys

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

Table 4: Summary of the evidence from national surveys

National surveys	• Care Quality Commission. Children and young people’s inpatient and day case survey 2018 • Child Outcomes Research Consortium. Child- and Parent-reported Outcomes and Experience from Child and Young People’s Mental Health Services 2011-2015 • National Children’s Bureau. Listening to children’s views on health provision 2012 • Picker Institute. Paediatric Emergency Department Survey 2015 and Children and Young People’s Outpatient Survey 2015 • 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	• Communication by healthcare staff towards the following groups: o Children and young people in hospital as an inpatient or as a day case o Young people with disabilities or severe conditions o Parents with babies in the neonatal unit
Key findings	• Children and young people mostly felt listened and understood by healthcare staff, although some felt that doctors didn’t use language they could understand • Young people with disabilities felt that there should be more resources and systems in place adapted for those with communication impairments or learning difficulties • Parents of babies in the neonatal unit mostly felt supported by healthcare staff • Young people with severe conditions felt that they had a positive experience of how the diagnosis and treatment plan was discussed and communicated to them

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 preferences of children and young people in relation to communication by healthcare professionals. 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:

- Absence of continuity of communication with staff throughout the healthcare journey in short- or long-term (e.g. staff does not explain aim or reasons for emergency procedure)
- Appropriate and multiple opportunities to ask staff questions about healthcare condition and treatment options,
- Avoiding use of medical jargon
- Importance of feeling a personal connection to healthcare staff
- Lack of consistency in what is communicated
- Lack of appropriately-trained staff
- Provision of interpreter
- Sensitivity of staff to personal and family circumstances

The themes which emerged from the evidence review provided data relating to most of these themes, and were related to communication within a consultation setting, how medical information was communicated, the importance of communicating to a person as an individual not just as a patient, the role of communication with parents, and the best types of communication.

The committee did not prioritise any of the themes above other ones and considered all the evidence valuable in making their recommendations.

The quality of the evidence

The quality of the evidence for the systematic review was assessed using GRADE-CERQual, and the quality of the methodology of the individual studies was assessed using the relevant Critical Appraisal Skills Programme (CASP) checklists.

The quality of evidence ranged from very low to high. Sub-themes were generally downgraded because of the methodological limitations of the included studies. Examples of these are lack of information regarding recruitment methods or how interviews were conducted. Lack of reflexivity in data analysis was also a common limitation. Themes were downgraded for coherence in the study findings. For example, the evidence for certain themes were closely interlinked and may have lost some nuances in the synthesis and separation. Additionally, themes that were mainly identified in the systematic review (Robards 2018) were also downgraded due to relevance of evidence as the population for this review included evidence from health professionals and young people aged up to 24 years old. Finally, evidence was also downgraded due to concerns about the adequacy of data, as some themes only had relatively small amounts of evidence contributing to the finding.

There was no evidence relating to babies less than 1-year-old.

Benefits and harms

The evidence from the systematic literature review on the theme of consultations identified that first impressions are important, and children want to be greeted in a positive and friendly manner. The committee discussed that creating a good first impression was important to ensure ongoing and effective two-way communication between the healthcare professional and the child or young person. Feedback from stakeholders suggested that recommendations should include introductions and finding out how a child or young person wished to be addressed, and the committee agreed this would be usual practice and so they included this detail in their recommendations.

There was evidence from the theme of ‘person not patient’ that children and young people wanted their healthcare practitioners to get to know them as individuals. The committee also highlighted that using people’s names was very important in creating a friendly environment. In particular, the committee agreed that it could be disrespectful or even upsetting if, when talking to other staff, babies, children and young people were referred to using their diagnosis or by a bed number instead of their name. However, there was some concern from the committee that using names of babies, children and young people between healthcare professionals could risk confidentiality in open clinical environments, such as wards, and that some caution may be needed when using both first name and surname.

There was evidence from the sub-theme of time that children and young people appreciated healthcare professionals having the time to communicate with them, and not appearing too busy to be able to do so. This was raised as a particular concern by the parents of children with communication difficulties, who reported that additional time may be required to communicate effectively with their children. There was evidence from the types of communication theme that listening was as important as talking and that healthcare professionals should take the time to build a rapport, allow children and young people to express views or feelings such as fear or embarrassment without being judged, and that healthcare professionals should respond with empathy, reassuring them that these feelings or concerns were very common. The committee agreed that all these factors were important and included them in their recommendations.

The sub-theme of insensitivity provided evidence that children and young people wanted communication to be culturally aware, take into account their feelings, and that poor communication could lead to embarrassment and distress.

Evidence from the sub-theme of age-appropriate showed that children and young people wanted communication to be tailored to their age, needs or ability to understand and the committee agreed that communication may need to change as children got older, with appropriate changes in language and vocabulary. Further evidence from the theme on types of communication showed that different forms of communication were preferred by different children and young people, and that creative and interactive methods could be useful (such as modelling dough, pictures or photos). This may be related to developmental age, but also personal preference. The committee therefore agreed that the recommendations should include discussing how a child or young person wanted to be communicated with. This was particularly important for children who had specific needs relating to communication (for example, if English was not their first language) and those who need to use other forms of communication, such as non-verbal communication, and that in cases such as this a foreign language or sign language interpreter, or other tools and specialist support such as picture boards or computer-based systems may be required. In particular, the committee were aware that for children or young people who did not communicate verbally, identifying how they indicated ‘yes’ or ‘no’ could enable direct conversations and discussions to take place with them. The committee also recognised that some parents or carers may have communication needs of their own which would need to be taken into consideration. The committee also discussed communication with babies and young children and agreed that verbal communication with babies and young children was important and could provide reassurance. Non-verbal communication such as containment holding (placing one hand around baby’s head and the other around their bottom and holding the position very still) could also be used.

The theme on communication with parents identified some conflicting evidence. Parents wanted healthcare staff to utilise the parents’ knowledge of their children to improve the healthcare experience, especially for children with communication difficulties. However, other parents said it was important for healthcare professionals to learn to communicate with their children in whatever way was necessary, and to not rely on parents or carers always being present. The committee acknowledged the importance of both of these views but did not make a separate recommendation based on this evidence as they agreed it was already covered by the recommendation on identifying the preferred form of communication for each baby, child, young person, parent or carer.

There was some evidence from the sub-theme of nurse involvement that suggested that children and young people may be more comfortable talking to nurses than doctors, and that nurses may be more patient-focused. The committee discussed that it was necessary for communication to be carried out by the appropriate person, depending on the clinical circumstances, subjects to be discussed, and preferences of the child, young person, parent or carer. The committee also discussed that different staff may have differing competence and expertise at communication, but that all staff should be trained to communicate effectively and should demonstrate competency.

The sub-theme of behavioural communication provided evidence that children and young people appreciated healthcare professionals who made eye contact, focused on them as a person, and read their behavioural cues. The committee discussed that behavioural and physical cues were important, particularly for babies and younger children or those with communication difficulties, and that healthcare professionals should be aware of these. As part of this discussion the committee also agreed, based on their experience, that parents and carers should be asked what is normal for their child in order to ascertain what non-verbal behaviour is abnormal, and that there may be occasions where children and young people do not wish to communicate, and that this should be respected, but that other multiple opportunities to discuss things should be offered.

Based on their experience, the committee agreed that children and young people want to speak to the same person whenever possible, and not have to repeatedly share their stories. As such the committee agreed that consistency in who an individual sees is important, and if this cannot be the same person, it should be the same team of healthcare professionals. Professionals should ensure that information is communicated between themselves so that trauma in repeating stories is minimised, helping towards a positive experience and helping trust to be built. However, the committee discussed that recommendations on this topic would fit better on the section of the guideline relating to coordination and continuity of care and so placed these recommendations in that section.

Over-arching messages from a number of the evidence themes related to communication being friendly, healthcare professionals being kind, and communication being two-way, with a collaborative approach. Evidence from the sub-theme on ‘honest and open communication’ showed that children and young people also appreciated being told things in a transparent and open manner. The committee agreed that communication should be undertaken in a compassionate and respectful manner at all times. The evidence also showed how children and young people appreciate receiving information in an upbeat and positive way, where appropriate. The committee acknowledged this was not always possible, as sometimes bad news must be given, but agreed that even bad news can be given in a kind and compassionate way. The committee highlighted the NICE guideline on End of life care for infants, children and young people with life-limiting conditions: planning and management as this contain recommendations and guidance on communicating with children and young people with life-limiting conditions.

As well as the evidence from the systematic review, the committee considered evidence from the national surveys of children’s experience. There was mainly positive feedback from children and young people about communication from staff, staff talking directly to them, the ease of asking questions and having them answered, and that staff listened to them. However, children and young people with disabilities recommended that staff should receive more training on how to communicate with them. The committee discussed that this evidence confirmed the evidence from the systematic review, and confirmed the recommendation on ensuring that communication was tailored to an individual’s preferred method and in a way they could understand.

As there was no systematic review evidence for babies under 1 year, the committee discussed the national survey of parents of babies on neonatal units. This showed that parents were happy that communication with healthcare professionals was good – staff introduced themselves, and were generally available to talk to parents, although the score for the availability of doctors was lower than scores for other aspects of communication. There was also evidence that parents were happy that their babies were called by their first name, which reinforced the committee’s experience. The committee did not make a separate recommendation about communication on the neonatal unit, as the key points were already included in their recommendations, which applied to all ages.

The committee also reviewed the feedback from the reference groups and focus groups relating to communication. The key messages from all the groups of different ages were that they liked healthcare professionals to be friendly and welcoming. This was mentioned several times and in different ways. They also wanted healthcare professionals to be polite, to say hello, to make eye contact and to make them feel relaxed. They also wanted healthcare professionals to have time, to ask them how they were feeling and to read behavioural cues. The committee agreed that this evidence reinforced the evidence from the systematic review. The evidence also mentioned that children and young people wanted things to be explained in a clear way, using words they could understand, and the committee agreed this had already been covered by their recommendations.

Finally, the committee discussed potential harms identified by the evidence or from their recommendations. The committee noted that poor communication from unskilled healthcare professionals could lead to a poor experience of healthcare. The committee also noted that using parents to communicate with children and young people, particularly those with communication difficulties, could impact on the privacy of the children and may even lead to safeguarding concerns in some instances.

Cost effectiveness and resource use

There was no existing economic evidence for this review. The committee discussed that implementing the recommendations would require healthcare professionals to have more time to communicate. In practice, this may require longer consultation times, which could create a resource impact on the health service. However, the committee noted that in many settings the recommendations represented standard practice and this is not expected to result in additional resources. The committee also discussed that ensuring all staff were competent to communicate effectively may require additional resources, although there is already various training available for staff around communication skills in the NHS.

Other factors the committee took into account

There was some overlap between the evidence for this review and the review on information, as some of the evidence related to the communication of information. For example, there was evidence on the use of written information to supplement verbal, the timing of information (particularly when children were very ill), the amount of information supplied, and the content of information. Recommendations on these areas had already been made by the committee and the committee reviewed these and used the additional evidence from this review to make some minor amendments to the recommendations they had already drafted on access to information.

Recommendations supported by this evidence review

This evidence review supports recommendations 1.2.1 to 1.2.16 in the NICE guideline.

References

Arnott 2012

Arnott, J., Hesselgreaves, H., Nunn, A. J., Peak, M., Pirmohamed, M., Smyth, R. L., Turner, M. A., Young, B., Enhancing Communication about Paediatric Medicines: Lessons from a Qualitative Study of Parents'; Experiences of Their Child's Suspected Adverse Drug Reaction, Plos one, 7(10), 2012

Boyden 2013

Boyden, P., Muniz, M., Laxton-Kane, M., Listening to the views of children with learning disabilities: An evaluation of a learning disability CAMHS service, Journal of Intellectual Disabilities, 17, 51-63, 2013

Curtis-Tyler 2012

Curtis-Tyler, K., Facilitating children's contributions in clinic? Findings from an in-depth qualitative study with children with Type 1 diabetes, Diabetic medicine, 29, 1303-1310, 2012

Gibson 2010

Gibson, F., Aldiss, S., Horstman, M., Kumpunen, S., Richardson, A., Children and young people's experiences of cancer care: A qualitative research study using participatory methods, International journal of nursing studies, 47, 1397-1407, 2010

Heath 2015

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

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

Livesley 2013

Livesley, J., Long, T., Children's experiences as hospital in-patients: Voice, competence and work. Messages for nursing from a critical ethnographic study, International journal of nursing studies, 50, 1292-1303, 2013

Lowes 2015

Lowes, L., Eddy, D., Channon, S., McNamara, R., Robling, M., Gregory, J. W., The experience of living with type 1 diabetes and attending clinic from the perception of children, adolescents and carers: analysis of qualitative data from the DEPICTED study, Journal of pediatric nursing, 30, 54-62, 2015

McCormack 2010

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

Robards 2018

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

Sharkey 2016

Sharkey, S., Lloyd, C., Tomlinson, R., Thomas, E., Martin, A., Logan, S., Morris, C., Communicating with disabled children when inpatients: barriers and facilitators identified by parents and professionals in a qualitative study, Health expectations : an international journal of public participation in health care and health policy, 19, 738-750, 2016

Taylor 2010

Taylor, S., Haase-Casanovas, S., Weaver, T., Kidd, J., Garralda, E. M., Child involvement in the paediatric consultation: a qualitative study of children and carers' views, Child: care, health and development, 2010, 678-685, 2010

Wood 2018

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

Appendices

Appendix A – Review protocol

Review protocol for review question: How should healthcare staff communicate with babies, children and young people, and the parents or carers of babies and young children?

Table 5: Review protocol

Field	Content
PROSPERO registration number	CRD42019145539
Review title	Communicating with babies, children, and young people
Review question	How should healthcare staff communicate with babies, children and young people, and the parents or carers of babies and young children?
Objective	To establish how healthcare staff should communicate with babies, children, young people and their parents or carers.
Searches	The following databases will be searched: • CENTRAL • 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 • 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 and young people's experience of healthcare
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 communication with healthcare staff
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 responses 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 both high- and non-high income countries, as defined by the World Bank, will only be included if the source of themes and evidence from high-income countries can 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	STUDY DESIGN • Studies using quantitative methods only (including surveys that report only quantitative data) • Surveys using mainly closed questions or which quantify open ended answers for analysis TOPIC OF STUDY Studies on the following topics will also be excluded:

Field	Content
	• Discussions about consent, confidentiality and privacy with respect to non-NHS commissioned health promotion interventions • Non-NHS commission health promotion interventions • UK Law and legal protections relating to consent, privacy and confidentiality for babies, children and young people. This will include (but will not be limited to) Fraser competence, Mental Capacity Act 2005, and Child Abuse and Prevention Act 1974 • Views and experiences of healthcare professionals and service managers • Views and experiences of people reporting on shared decision making in the context of 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 o 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) o Weight management: lifestyle services for overweight or obese children and young people (PH47) • Pregnancy, including routine antenatal, intrapartum or postnatal care: o Antenatal and postnatal mental health: clinical management and service guidance (CG192)

Field	Content
	○ 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 adult's 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 children and young people are talking should be generalizable to the wider healthcare context (e.g. a study on the views on and experience of communication with healthcare professionals whilst receiving chemotherapy would be included, whilst a study on experience of chemotherapy would be too narrow and not generalizable to wider healthcare context and therefore excluded). Recommendations will apply to those receiving care in all settings where NHS- or local authority- commissioned healthcare is provided (including home, school, community, hospital, specialist and transport settings). Specific recommendations for groups listed in the Equality Considerations section of the scope may be also be made as appropriate.

Field	Content
Primary outcomes (critical outcomes)	Themes will be identified from the literature. The committee identified the following potential themes (however, not all of these themes may be found in the literature, and additional themes may be identified): • Absence of continuity of communication with staff throughout the healthcare journey in short- or long-term (e.g. staff does not explain aim or reasons for emergency procedure) • Appropriate and multiple opportunities to ask staff questions about healthcare condition and treatment options, • Avoiding use of medical jargon • Importance of feeling a personal connection to healthcare staff • Lack of consistency in what is communicated • Lack of appropriately-trained staff • Provision of interpreter • Sensitivity of staff to personal and family circumstances The following themes will not be covered by this review, despite relating to communication in healthcare: • Availability of information in different formats (reviewed in RQ 2.1) • Barriers to, and facilitators of, access to healthcare (reviewed in RQ 8.1) • Barriers to, and facilitators of, continuity of healthcare (reviewed in RQ 8.2) • Confidentiality, privacy and consent for children and young people in healthcare (reviewed in RQ 1.3) • Involvement in health care and informed, shared decision making (reviewed in RQ 1.1) • Physical healthcare environment (reviewed in RQ 6.1)
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. • 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 (Critical Skills Appraisal Programme) Qualitative checklist. Risk of bias of systematic reviews of Qualitative studies will be assessed

<table>
<tr><th>Field</th><th colspan="2">Content</th></tr>
<tr><td></td><td colspan="2">using the CASP 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.</td></tr>
<tr><td>Strategy for data synthesis</td><td colspan="2">• 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 synthesised 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 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.</td></tr>
<tr><td>Analysis of sub-groups</td><td colspan="2">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)

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>Intervention</td></tr>
<tr><td>☐</td><td>Diagnostic</td></tr>
<tr><td>☐</td><td>Prognostic</td></tr>
<tr><td>☒</td><td>Qualitative</td></tr>
<tr><td>☐</td><td>Epidemiologic</td></tr>
<tr><td>☐</td><td>Service Delivery</td></tr>
<tr><td>☐</td><td>Other (please specify)</td></tr>
</table>

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<tr><td>Country</td><td colspan="3">England</td></tr>
<tr><td>Anticipated or actual start date</td><td colspan="3">23 September 2019</td></tr>
<tr><td>Anticipated completion date</td><td colspan="3">07 April 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>
<tr><td>Named contact</td><td colspan="3">5a. Named contact
National Guideline Alliance
5b. Named contact e-mail
Infant&younghealth@nice.org.uk
5e Organisational affiliation of the review
National Institute for Health and Care Excellence (NICE) and National Guideline Alliance</td></tr>
<tr><td>Review team members</td><td colspan="3">NGA Technical Team</td></tr>
<tr><td>Funding sources/sponsor</td><td colspan="3">This systematic review is being completed by the National Guideline Alliance, which receives funding from NICE.</td></tr>
<tr><td>Conflicts of interest</td><td colspan="3">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.</td></tr>
</table>

Field	Content	
Collaborators	Development of this systematic review will be overseen by an advisory committee who will use the review to inform the development of evidence-based recommendations in line with section 3 of Developing NICE guidelines: the manual. Members of the guideline committee are available on the NICE website: https://www.nice.org.uk/guidance/indevelopment/gid-ng10119/documents	
Other registration details	-	
Reference/URL for published protocol	https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=145539	
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; Infants; Consent: Privacy: Confidentiality	
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 Skills Appraisal Programme; CDSR: Cochrane Database of Systematic Reviews; 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; PROSPERO: International prospective register of systematic reviews

Appendix B – Literature search strategies

Literature search strategies for review question: How should healthcare staff communicate with babies, children and young people, and the parents or carers of babies and young children?

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.
25	((walk-in or "urgent care") adj2 (centre* or center* or clinic* or service*)).tw.

#	Searches
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
72	45 and 71
73	limit 72 to (yr="2009 - current" and english language)
74	exp United Kingdom/

#	Searches
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
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

#	Searches
112	102 not 111
113	animals/ not humans/ use ppez
114	animal/ not human/ use emez
115	nonhuman/ use emez
116	"primates (nonhuman)"/
117	exp Animals, Laboratory/ use ppez
118	exp Animal Experimentation/ use ppez
119	exp Animal Experiment/ use emez
120	exp Experimental Animal/ use emez
121	animal research/ use 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

#	Search
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
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

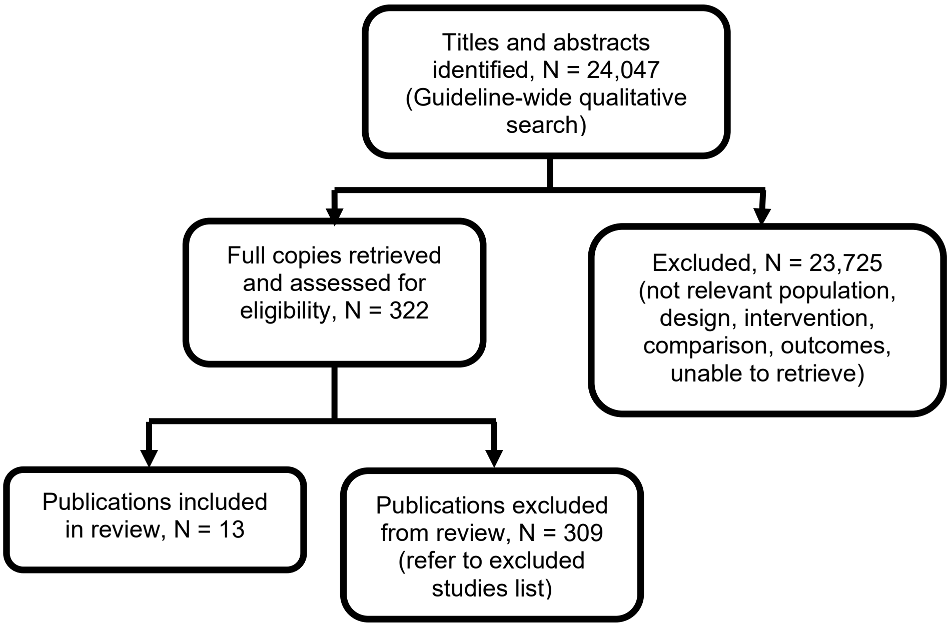
#	Search
57	(hospital* or inpatient* or outpatient*):ti,ab,kw
58	(health* near/3 (care or center* or centre* or clinic* or facility or facilities or service* or setting* or specialist*)):ti,ab,kw
59	((dental or communit* or emergency or hospital* or home or intensive or high-dependen* or mental* or primary 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
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

#	Search
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 2020
116	MeSH descriptor: [United Kingdom] explode all trees
117	(national health service* or nhs*):ti,ab,kw
118	(english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) near/5 english)):ti,ab,kw
119	(gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*):ti,ab,kw
120	(gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*):so
121	(bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))):ti,ab,kw
122	(bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's"):ti,ab,kw
123	(aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's"):ti,ab,kw
124	armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's":ti,ab,kw
125	#116 OR #117 OR #118 OR #119 OR #120 OR #121 OR #122 OR #123 OR #124
126	MeSH descriptor: [Africa] explode all trees
127	MeSH descriptor: [Americas] explode all trees
128	MeSH descriptor: [Antarctic Regions] explode all trees
129	MeSH descriptor: [Arctic Regions] explode all trees
130	MeSH descriptor: [Asia] explode all trees
131	MeSH descriptor: [Oceania] explode all trees
132	#126 OR #127 OR #128 OR #129 OR #130 OR #131
133	MeSH descriptor: [United Kingdom] explode all trees
134	MeSH descriptor: [Europe] this term only
135	#133 OR #134
136	#132 not #135
137	#125 not #136
138	#115 AND #137 with Cochrane Library publication date Between Jan 2009 and Aug 2020

Appendix C – Clinical evidence study selection

Study selection for: How should healthcare staff communicate with babies, children and young people, and the parents or carers of babies and young children?

Figure 2: Study selection flow chart



Appendix D – Clinical evidence tables

Evidence tables for review question: How should healthcare staff communicate with babies, children and young people, and the parents or carers of babies and young children?

Table 6: Evidence tables

Study details	Participants	Methods	Themes and findings	Limitation
Full citation Arnott, J., Hesselgreaves, H., Nunn, A. J., Peak, M., Pirmohamed, M., Smyth, R. L., Turner, M. A., Young, B., Enhancing Communication about Paediatric Medicines: Lessons from a Qualitative Study of Parents' Experiences of Their Child's Suspected Adverse Drug Reaction, Plos one, 7 (10) (no pagination), 2012 **Ref Id** 1052885 **Country/ies where the study was carried out** Liverpool, UK	**Sample size** N=45 parental proxies of 44 babies, children, or young people - Only parents of children under 5 years old are included in this review **Characteristics** Age: Not reported. Gender (M/F): 4/41 **Inclusion criteria** Parents: - Of children with suspected ADRs - Could be approached before discharge **Exclusion criteria**	**Setting** In the community **Sample selection** 2 sampling routes used to ensure maximum variability. The first route was through 2 cohort studies that formed part of an ADRs programme at a UK paediatric centre. The second route was through the Yellow Card Scheme, a national drug surveillance system allowing individuals to report suspected adverse drug reactions directly to the relevant UK authority. Recruitment occurred in parallel with data analysis and was stopped when data saturation was reached. **Data collection** Face-to-face semi-structured interviews, about 60 (20 min-100 min) minutes and conducted 2-56 weeks after the suspected adverse drug reaction. 3 interviews took place in the	**Author's themes:** - With few exceptions, parents were critical about ADR management and communication - Parents of children with cancer were positive about ADR communication - Implications of poor communication about suspected ADRs - How parents thought communication about suspected ADRs should be handled **Findings** Clinician's communication surrounding a child's suspected adverse drug reaction was often poor - there was a lack of communication from medical personnel that might help parents to understand the physical signs and symptoms of the ADR and understand what clinicians were doing to treat them. If they did receive information, it was often contradictory and poorly co-	**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. Healthcare professionals have structured guidelines to follow regarding suspected adverse drug reactions but there is a lack of knowledge regarding the experience from a parent's point of view. Due to this paucity of evidence, the study was designed to explore all aspects of the parental experience of adverse drug reactions. *Q4: Was the recruitment strategy appropriate to the aims of the research?* Can't tell. Inclusion criteria very broad, although this does match the aim of the study. The study initially

Study details	Participants	Methods	Themes and findings	Limitation
Study type Qualitative **Aim of the study** To inform the minimal literature on communication during adverse drug reactions (ADRs) in children, identifying any unmet psychological and information needs from parents. **Study dates** Not reported. **Source of funding** This study received support from the United Kingdom Institute for Health Research.	• Family experiencing distress • Concerns over child protection	hospital, the rest in participant's homes. An interview schedule was employed to explore parent's experiences surrounding their child's adverse drug reaction but was flexible to allow interviewers to promote a conversational atmosphere. It also meant that any newly identified themes as they emerged. **Data analysis** Modified grounded theory. Interviews were audio-recorded and transcribed verbatim. 1 researcher read the transcripts several times alongside field notes taken during the interviews, creating themes the captured the content and meaning of the interviews. The interviewer referred back to the transcripts as a whole, to ensure that the meaning of interpretations were consistent with the original content. 2 other researchers further developed the analysis by reading a sample of transcripts, testing and developing the analysis alongside discussions with the lead analyst. Rigour was introduced by using respondent validation, exploring deviant cases, and checking the coherence of the analysis and its potential to influence practice.	ordinated between healthcare staff e.g. one doctor attributing a symptom to a medicine while another doctor attributed it to an underlying medical condition. Uncertainty surrounding the ADR and treatment was unconsciously communicated to parents by a lack of clear advice. Some parents reported that, when clinicians couldn't explain what was happening to their child that they felt as though they were being lied to ('fobbed off'). Communication could be poorly timed e.g. parents receiving detailed information at time when they were pre-occupied with a critically ill child. Conversely, at times when they were less anxious and had more time to digest information, communication was less forthcoming. Parents commonly reported that their concerns were dismissed by healthcare staff. Yellow Card parents (i.e. ones that could self-report suspected ADRs) reported this far more frequently, worrying that clinicians quickly dismissed their concerns that the symptoms could be due to an ADR before fully exploring the possibility. Parents of children undergoing cancer treatment felt very well supported by how healthcare staff communicated to them about the	used the ADRs in Children programme as a sample population, where they specifically sampled for maximum variability. This was explained as being due to the fact that there has been little qualitative research on this topic. As healthcare professionals are the ones reporting into this programme, there was some concern regarding the possibility of clinician gatekeeping within the sample. The study tried to combat this bias by including Yellow Card scheme, which allows self-referral. However, no information is presented regarding response rates and the researchers were not able to access demographic information on non-respondents. *Q5: Were the data collected in a way that addressed the research issue?* Can't tell. Interviews conducted by telephone as parents resided all across the UK, although no discussion about how the distance and lack of physical cues may have affected the analysis of the data. Interviews were semi-structured and well described (interview guide published as supplementary material). Interviews were designed to be conversational, allowing for exploration of novel topics. Audio-recordings of the interviews were transcribed verbatim (including verbal inflections) and field notes were used. No discussion on saturation of data or deviations from the protocol. Interviews were conducted up to 56

Study details	Participants	Methods	Themes and findings	Limitation
			medication their child was being prescribed. Parents believed the ADRs were taken seriously, with good systems in place to manage such events. Communication was very good, with clinicians discussing the possibility of ADRs in an early and timely manner, what symptoms to look out for, and advice on what to do if they suspected one. The lack of communication surrounding ADRs at the time of prescription prevented parents being fully involved in decisions surrounding their child's care. For example, a lack of communication about the side effects of morphine meant that one parent continued to give her child morphine in order to reduce their agitation, when it could have been that her agitation was caused by an itching reaction to the morphine itself. Parents reported uncertainty around the possibility of a repetition of ADRs, as well as possible long-term effects of ADRs. Parents also reported feelings of responsibility, both for the initial ADR and for preventing recurrences. Experiencing a suspected ADRs led to some parents having concerns about use of future prescription medications, including morphine, painkillers and vaccines.	weeks after the suspected adverse drug reaction, which may have caused an element of recall bias in the data. *Q6: Has the relationship between researcher and participants been adequately considered?* Can't tell. Mentions that extensive field notes were taken throughout the interviews, including information on participant's interactions and behaviour (both verbal and non-verbal). However, relationship between the researcher and interviewees has not been discussed, or potential bias acknowledged. *Q7: Have ethical issues been taken into consideration?* Yes. All participants gave written informed consent. Study approved by UK National Health Service research ethics committee. *Q8: Was the data analysis sufficiently rigorous?* Yes. In-depth description of data analysis process presented, with a clear description of how codes, themes and sub-themes were developed. Number of techniques were used to enhance rigour of the analysis, including respondent validation and discussion among the authors to judge the coherence of emerging themes. Deviant cases were explored and contradictory findings were discussed where appropriate. An adequate amount of data was

Study details	Participants	Methods	Themes and findings	Limitation
			Parents wanted clinicians to help them understand their child's ADR, paced and timed in a way that could help them best absorb the information. Helping them understand what the ADR meant for their child's long-term healthcare was very important, along with what steps they could take to help prevent ADRs occurring in the future (including what medications they should now avoid). Parents were cognisant that medication comes with a certain level of risk, and that doctors had a number of challenges with diagnosing ADRs. Several parent's mentioned that they would like simple, accessible and reliable information on ADRs to be given with the prescription.	presented to support the reported findings. *Q9: Is there a clear statement of findings?* Yes. Good, detailed explanation of findings within the identified themes, with regular referral back to the original research question. Good discussion surrounding evidence for the study's findings, but less so contradicting them. Discussion around credibility of findings. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* Yes. 1. Yes. Details how the study findings fit in with current literature and the UK population, and how they can be used to inform best practice. 2. Can't tell. The study sampled for maximum variability but lack of reported demographic data makes this difficult to assess. Additionally, the topic is very specific. *Overall judgement of quality:* Moderate concerns **Other information** Parents of children over 5 also included in the sample but they are outside of our protocol so not extracted where possible.
Full citation Boyden, P., Muniz, M., Laxton-Kane,	**Sample size** N=7 children and young people	**Setting** Child and adolescent mental health services	**Author's themes:**	**Limitations (assessed using the CASP checklist for qualitative studies).**

Study details	Participants	Methods	Themes and findings	Limitation
M., Listening to the views of children with learning disabilities: An evaluation of a learning disability CAMHS service, Journal of Intellectual Disabilities, 17, 51-63, 2013 **Ref Id** 987405 **Country/ies where the study was carried out** Derbyshire, UK **Study type** Qualitative **Aim of the study** To explore the experiences of children using a local learning disability-CAMHS service, in order to produce a set of quality standards in line with Department of Health guidelines and national legal requirements.	**Characteristics** Age (range): 11-17 years Gender: Not reported. **Inclusion criteria** Participants had to: • Be aged 11-17 years old • Have moderate learning disabilities • Be living in the community • Have used the CAMHS service within previous 3 months • Have adequate verbal skills to complete interviews • Be able to contribute novel information and express own opinions **Exclusion criteria** None applied.	**Sample selection** Convenience sampling of participants suggested by the CAMHS team. No further details reported. **Data collection** Semi structured interviews, roughly 20-40 minutes. All were conducted at a school, home or clinic setting. An interview schedule was developed and piloted on 2 participants. Subsequent changes were made to ensure the questions were easy to understand, jargon was removed and simple sentence structures were employed. Alternatively phrased questions and representative visual aids were used in addition to the interview guide in case participants were unable to answer any specific questions. Questions about rankings were presented in smiley face format i.e. smiling, frowning and neutral faces for acceptable, unacceptable and neutral options respectively. **Data analysis** Thematic analysis. Researchers familiarised themselves with the data, identified initial codes and organised them into higher order	• Experience of the service - rapport with the service members • Communication - the value of talking • Communication - metaphors and creativity • Difficulties encountered **Findings** All participants reported feeling scared and anxious the first time they met with a CAMHS professional. Certain things were reported as helping to put children at ease. These included handshakes, how the staff dressed, high fives, humour and smiling. In turn, these helped to build a good relationship with the healthcare staff. Participants liked talking about their interests and when these were incorporated into their visits e.g. giving them a copy of their favourite comic or talking about a band they liked. Simply talking is very valued by children using the service, although a few participants were unable to explain why this helped. Use of creative and interactive tools (e.g. books, playdough, drawing, puppets, games, humour) helped children to communicate their feelings and	*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. Questionnaires and surveys can be ineffective research tools when applied to young people with learning difficulties due to the reading, writing and comprehension skills needed, but they are able to interact with an interviewer and share their experiences. *Q4: Was the recruitment strategy appropriate to the aims of the research?* Yes. Convenience sampling was used, and potential participants were suggested by members of the CAMHS team. There is a lack of information on how participants were approached, response rates and demographics of individuals who chose not to participate. However, specifically mentioned that young people with other conditions (e.g. epilepsy) were not excluded in order to make the sample as representative of the service as possible. *Q5: Were the data collected in a way that addressed the research issue?* Can't tell. Detailed description of the

Study details	Participants	Methods	Themes and findings	Limitation
Study dates Not reported. **Source of funding** No specific grant from any funding agency in the public, commercial or not-for-profit arenas.		themes. No further details reported.	thoughts to the CAMHS professionals. These could include a traffic light system to understand acceptable (green) behaviour or unacceptable (red) behaviour. A certain level of creativity was helpful to engage with the children, with one child reporting that the use of imagery and metaphors helped them to understand the feeling anger. Participants reported a few things that could be improved when accessing the service. One child was disappointed that the professional was writing a lot in front of them, as they were unsure why they were writing things down and what the long words they used meant. Some participants wished for more sessions, although it was unclear whether this was due to participants liking the social aspect of meeting with CAMHS and whether this was what they wanted to keep going.	development and format of the interview guide. The schedule was piloted with the first 2 participants and amended to ensure that questions were easy to understand and had good face validity. Questions were accompanied by visual aids and alternatively re-phrased questions to ensure participants understood. However, no information is provided on the content of the interview. No. No justification provided for interview setting (participants' homes, school and clinic). Also no mention of whether field notes were taken or if audio-recordings were used. No mention of data saturation. *Q6: Has the relationship between researcher and participants been adequately considered?* No. No description of potential bias/influence between researcher and participants. *Q7: Have ethical issues been taken into consideration?* Can’t tell. Paper reports clinical service evaluations do not have to obtain NHS ethics. Parental and individual consent obtained, authors informed Trust's Research & Development department and followed routine ethical procedures when involving participants with learning disabilities. *Q8: Was the data analysis sufficiently rigorous?* No. Description of the analysis process is brief. Thematic

Study details	Participants	Methods	Themes and findings	Limitation
				analysis was used but with little detail of how codes, themes and sub-themes emerged from the raw transcripts. No critical examination of the researcher's own role in the process or techniques used to mitigate potential bias and influence during analysis. However, contradictory data is presented and discussed where appropriate. An adequate amount of data was presented to support the reported findings. *Q9: Is there a clear statement of findings?* No. Good discussion surrounding methodological issues. There is no mention of how many researchers were involved in the analysis. Headings and quotes are presented with very little discussion or explanation surrounding the themes. Findings are discussed in relation to the original research question, including development of service standards, which are constructed but not reported. Discussion around credibility of findings. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* Yes. 1. Yes. Details how the study findings fit in with current literature and the UK population, and how they can be used to inform best practice. Results helped to develop 4 standards of service delivery in CAMHS Chesterfield which the author's hope to expand to other

Study details	Participants	Methods	Themes and findings	Limitation
				services. 2. Yes. Small study size of 7 participants but author's note that this represents a third of a typical 3-month caseload. Sample included people with dual diagnoses but did not sample people with severe learning disabilities and little/no verbal skills. *Overall judgement of quality:* Moderate concerns **Other information** None.
Full citation Curtis-Tyler, K., Facilitating children's contributions in clinic? Findings from an in-depth qualitative study with children with Type 1 diabetes, Diabetic medicine, 29, 1303-1310, 2012 **Ref Id** 988197 **Country/ies where the study was carried out** London, UK	**Sample size** N=17 children **Characteristics** Age (range): 4-11 years Gender (M/F): 9/8 Ethnicity (n): • White English = 4 • White British = 1 • Arabic = 2 • African = 1 • African Portuguese = 1 • Bengali British = 1 • Lithuania = 1 • Somali = 6	**Setting** Paediatric diabetes clinics and in the community **Sample selection** Researcher was independent, not connected to clinical research teams. Convenience sampling used with invitations in 11 languages sent to children's homes, and 42 information sheets distributed to 12 outpatients clinics over 4-month period. Participation was self-selecting. Children and carer consent obtained and participation terminated if child decided to withdraw. **Data collection** All children spoke English. Fieldwork consisted of 2 (mostly	**Author's themes:** • How is the condition understood? • Contexts for hearing children's views **Findings** Children with Type 1 diabetes viewed themselves as active, reliable contributors to care at home alongside their mothers. However, in clinic they felt peripheral and were typically discussed in the third-person, only being asked about non-illness related aspects of their lives. Suggestions about their own care were typically ignored by both parents and staff. Majority of children did not view consultations as something to which they contribute to.	**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 provided for use of mixed qualitative approach. *Q4: Was the recruitment strategy appropriate to the aims of the research?* Can't tell. No detailed discussion about recruitment rationale and drop outs.

Study details	Participants	Methods	Themes and findings	Limitation
Study type Home visits, discussion groups and observation; qualitative **Aim of the study** To explore the experiences of children under 10 years who live with Type 1 diabetes. **Study dates** Not reported **Source of funding** This study received support from NHS Trust charitable foundation.	**Inclusion criteria** Participants had to: • 11 years-old or under • Receiving care for Type 1 diabetes in one of two paediatric diabetes clinics in large, multicultural city **Exclusion criteria** Not reported	home) visits of ~45min with each child/set of siblings (one participant preferred 4 slower-paced visits); participant observation of one clinic appointment (2 children were observed twice and 2 children asked not to be observed); non-participant observation in waiting room; two discussion groups for children to comment on researcher's finings. During home visit, researcher observed and talked with children about daily experience of diabetes. Children chose pseudonyms and play-based approach, and children's own drawings/photographs, used to prompt discussion when appropriate. Interpreter used in 2 cases to allow communication with mother of child. Children given disposable camera to document 'important' things in their lives. Eleven children participated in discussion groups. QSR NUD*IST software used to record, transcribe and enter home visits; field notes on observations in children's homes and outpatients kept and copied for hand coding. **Data analysis** Constant comparative/grounded theory method used to identify		*Q5: Were the data collected in a way that addressed the research issue?* Yes. *Q6: Has the relationship between researcher and participants been adequately considered?* Yes. *Q7: Have ethical issues been taken into consideration?* Yes. *Q8: Was the data analysis sufficiently rigorous?* Can't tell. Themes/categories are not presented explicitly and are not discussed in any detail. *Q9: Is there a clear statement of findings?* Yes. *Q10: Is the research valuable for the UK?* Yes. 1. Yes, contextualises research findings in literature and offers recommendations for good practice. 2. Yes. Findings unlikely to be specific for children with Type 1 diabetes. *Overall judgement of quality:* Moderate concerns. **Other information** Participants given laminated copies of drawings and £15 thank you voucher.

Study details	Participants	Methods	Themes and findings	Limitation
		themes and patterns emerging from data and related to extant literature, with differences according to proportion of life lived with condition, age, ethnicity and gender actively sought. Data saturation achieved with sample size without need to recruit excessive participants or waste participants/staff time.		
Full citation Gibson, Faith, Aldiss, Susie, Horstman, Maire, Kumpunen, Stephanie, Richardson, Alison, Children and young people's experiences of cancer care: A qualitative research study using participatory methods, International journal of nursing studies, 47, 1397-1407, 2010 **Ref Id** 1056148 **Country/ies where the study was carried out**	**Sample size** N=38 children and young people **Characteristics** Age (range): 4-19 years Gender (M/F): 18/20 Ethnicity (n): • White British = 19 • White other = 2 • Mixed (white and Black Caribbean) = 2 • Asian other = 2 • White Irish = 1 • Black African = 1 • Asian Pakistani = 1	**Setting** Variety of settings throughout cancer journey **Recruitment details** Purposive sampling of children with cancer at 3 UK Primary Care Trusts was used to ensure a diverse range of ethnicity, gender, age, social background and stage of cancer journey (diagnosis, during treatment and up to 18 months from treatment, palliative care). Clinicians helped to identify participants in addition to notices at parent support groups and posters in clinical areas. The study aimed to recruit 2 children under 5 years old, 3 children aged 6-12 years old and 3 young people aged 13-19 years old at each stage of the journey. **Data collection**	**Author's themes:** • Asking and telling - getting the balance right • Worrying about now and the future • The triad of support **Findings** All young children were given information on their diagnosis and treatment by their parents. None received this information from their clinician. They reported asking their parents if they wanted to know anything specific about their treatment. However, older children wanted to be spoken to and given information from hospital staff directly, without their parents acting as intermediaries. Older children also wanted professionals to use more grown up language when speaking to them e.g. 'ametop' rather than 'magic cream' to describe a topical medication. Many of the	**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. The study aimed to explore healthcare needs and preferences of children across a wide range of ages (4-19 years old). A variety of participatory-based research used in order to ensure the most effective method is used for each age group. *Q4: Was the recruitment strategy appropriate to the aims of the research?* Yes. Inclusion criteria well described and matched the aim of the study. Purposive sampling used in

Study details	Participants	Methods	Themes and findings	Limitation
UK (exact location not specified) **Study type** Qualitative **Aim of the study** To explore how a child's healthcare needs and preferences changes throughout childhood and develop a conceptual model to describe findings. **Study dates** Not reported. **Source of funding** This study received support from Macmillan Cancer Support.	Cancer diagnosis: all acute Lymphoblastic Leukaemia Stage of cancer journey (n): • Currently on treatment = 20 • At the end of treatment = 9 • 6-18 months following successful treatment = 9 **Inclusion criteria** Not reported. **Exclusion criteria** • Individuals judged by healthcare staff to be too unwell.	3 participatory-based techniques of data collection, with questions and prompts designed around age and stage in cancer journey of participants. • Play and puppets (4-5 years old): Puppets were used to explore children's experiences. An inpatient ward play specialist carried out the data collection, with a 2nd researcher observing the interviews and making field notes. • Draw and write technique (6-12 years old): Participants were given drawing materials at the beginning of the interviews, and asked to complete a drawing. The prompts used were adapted to the age of the children, and their treatment stage. They were asked to describe their drawings and the researcher asked further questions about their experiences. Field notes were made during the interview. • Activities day and interviews (13-19 years old): 2 researchers held a 4 hour activities day at an external food venue, attended by 4 young people (aged 13-15 years old). This consisted of peer interviews (using a researcher-provided interview	older children felt that they were not given enough information about their treatment and cancer, preferring open and honest communication. However, conversely, some of these older children found medical information to be overwhelming. They thought that medical staff should be more sensitive to cues showing when they did or did not want to talk e.g. making eye contact or having curtains drawn respectively. Children found asking questions was especially challenging and wanted to staff to encourage them in this. Children felt that being given information about waiting for treatment was an important issue. Some patients mentioned specifically about more information needed regarding steroids, and the side effects that they might experience while taking them. When some children were worried, they spoke to their parents and siblings about their feelings. However, many children said that they wouldn't tell anyone about their concerns because they didn't want to be judged by health professionals. Family, friends and hospital staff were all mentioned as areas of support and helping participants	order to ensure participants had a range of ages, gender, ethnicity and stage of cancer journey. Only aimed to recruit 2 children in the under 5 age category for each stage of the cancer journey (compared to 3 children for the other 2 age groups) as they were aware that this age group would likely be more resource intensive. However, healthcare staff helped to recruit participants which may have introduced some selection bias. NB. No children were recruited for the palliative care cancer stage but this is out of our scope so does not affect the quality appraisal. *Q5: Were the data collected in a way that addressed the research issue?* Yes. A range of techniques were used across all age ranges to ensure that participants had an acceptable form of feedback presented to them. Techniques were all well-described and justified. There was a change from the protocol for children aged 16-19 - data collection was originally meant to be via an activity day but it proved difficult to arrange a suitable day for participants. However, no mention of data saturation. *Q6: Has the relationship between researcher and participants been adequately considered?* No. No description of potential bias/influence between researcher and participants.

Study details	Participants	Methods	Themes and findings	Limitation
		guide), a group discussion, a focus group and a written task asking about what factors are important to their experience of healthcare. A range of questioning was used to ensure that each participant had a mode of response that they felt comfortable with. A 2nd activities day had been planned for 16-19 year old attendees but scheduling a date proved difficult. Instead, 2 researchers conducted individual interviews with this age group, either at the hospital or at home. **Data analysis** Inductive thematic analysis. Peer interviews and focus groups of the 13-19 year old groups were audio-recorded. Group discussions were recorded as spider diagrams. 2 levels of data analysis occurred. The 3 researchers involved in data collection developed initial codes, themes and categories from the data, with another researcher verifying the results. A 4th researcher commented on the themes and any disagreement was resolved with group discussion. Results were originally analysed within the 3 age groups before being brought together into 6 overarching	through 'hard times'. Children at all ages recognised parental worries and suggested healthcare professionals should specifically make an effort to help them cope during their child's treatment. Young children rarely mentioned healthcare staff unless they were prompted by researchers but older children and young people mentioned that they liked when professionals listened to them and made an effort to get to know them as 'people' by chatting to them about their life. This made them feel as though they were 'a person and not a patient'. Nurses were especially important in day-to-day communication for the participants. They were described as 'kind', 'fun' and 'helpful'. Young people looked forward to talking with them and young children looked forward to playing with them. Participants knew nurses better than doctors, feeling more comfortable talking with them. This could possibly be due to the fact nurses spent more time on the ward, whereas doctors were 'more formal', busy and changed wards more often. It was important that hospital staff were sensitive to the needs and feelings of patients, that nurses were reliable. If staff were not sensitive to this, it was distressing, embarrassing and	*Q7: Have ethical issues been taken into consideration?* Yes. Individual informed consent obtained (as well as parental for under 16s). Discussions with parents of younger children were before data collection in order to ensure language was consistent with family discourse. Study was approved by relevant Local Research Ethics Committees within the NHS Trusts where data was collected, as well as Institute of Child Health/Great Ormond Street Multi-Research Ethics Committee. *Q8: Was the data analysis sufficiently rigorous?* Can’t tell. In-depth description of data analysis process presented, with a clear description of how codes, themes and sub-themes were developed (especially the thread of changing needs across ages). The 3 researchers involved in data collection developed the initial themes, with another 2 researchers checking themes and making comments (no further information of what this entailed). No critical examination of the researcher's own role in the process or techniques used to mitigate potential bias and influence during analysis. Contradictory data is not presented for discussion. An adequate amount of data was presented to support the reported findings or certain themes (e.g. 3.2 Play, toys and school work), but noticeably absent for other

Study details	Participants	Methods	Themes and findings	Limitation
		themes. The 2nd layer of analysis involved identifying 1 key theme threading through the data, which was then examined across all the lower-level themes to enable a multi-faceted interpretation of the results.	annoying. Insensitivity revolved mainly around being examined, not explaining things and, for young people, not being left alone when they wanted to be.	themes (e.g. 3.6 A conceptual model of communication). *Q9: Is there a clear statement of findings?* Yes. Good, detailed explanation of findings within the identified themes, with regular referral back to the original research question. Good discussion surrounding evidence for the study's findings, but less so contradicting them. There is a lack of information on credibility of findings. Details of data analysis show that multiple researchers were involved in the development of codes and themes, which increases rigour. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* Yes. 1. Yes. Details how the study findings fit in with current literature and the UK population, and how they can be used to inform best practice. Directions for future research mentioned. 2. Can’t tell. Participants were from a range of age groups and stages of cancer journey. Quite a specific population but may be generalizable to other chronic diseases. Small sample size limits transferability. *Overall judgement of quality:* Moderate concerns **Other information**

Study details	Participants	Methods	Themes and findings	Limitation
				Participants were given a toy or a voucher as a token for participating. They were not informed of this until after they had participated in order to avoid coercion.
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 **Ref Id** 989549 **Country/ies where the study was carried out** Birmingham/West Midlands, UK **Study type** Qualitative **Aim of the study** To explore babies, children and young	**Sample size** N=27 • n=14 children and young people ○ n=8 hospital outpatient ○ n=6 community clinic outpatient • n=13 adults ○ n=7 hospital outpatient ○ n=6 community clinic outpatient - Only the views of children and young people were included in the review **Characteristics** Not reported. **Inclusion criteria** Not reported. **Exclusion criteria** Not reported (although a lower age limit of	**Setting** Outpatient clinics in hospital, health centre and children's centre **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 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**	**Author's themes:** • A therapeutic environment • Interpersonal interactions **Findings** The more relaxed environment present in community clinics facilitates a more detailed discussion with healthcare practitioners, where children do not feel rushed. Healthcare professionals should be welcoming, respectful of families beliefs, and listen parents when they say what is usual for individual children. It is not just the communication of healthcare professionals that impact a child's satisfaction with a consultation. Receptionist and support staff should be friendly and cheerful.	**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?* 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

Study details	Participants	Methods	Themes and findings	Limitation
people's (and parents') views of paediatric outpatient care, focusing on how healthcare setting may impact experiences. **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 for Birmingham and Black Country programme.	'approximately 8 years' was noted).	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.		poorly described. Interviews were driven by interviewee so no use of topic guides, and no mention of the methods deviating 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 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

Study details	Participants	Methods	Themes and findings	Limitation
				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 review question in highlighting other areas important to BCYP experience not previous identified means all are important. *Overall judgement of quality:* Moderate concerns **Other information** None.
Full citation Law, H., Gee, B., Dehmahdi, N., Carney, R., Jackson, C., Wheeler, R., Carroll, B., Tully, S., Clarke, T., What does recovery	**Sample size** N=23 young people • n=15 under 18 years • n=8 over 18 years ○ Only the views of young people	**Setting** In the community **Sample selection** Participants recruited using convenience sampling from Norfolk and Suffolk NHS Foundation Trust (n=11) and	**Author's themes:** • Meaningful alliance • Collaborative approach **Findings** As with adults, young people viewed recovery from mental health difficulties as an	**Limitations (assessed using the CASP checklist for qualitative studies).** *Q1: Was there a clear statement of the aims of the research?* Yes.

Study details	Participants	Methods	Themes and findings	Limitation
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 **Country/ies where the study was carried out** East Anglia and Greater Manchester, UK **Study type** Semi-structured interview; qualitative **Aim of the study** To understand young people's concept of mental health recovery. **Study dates** Not reported **Source of funding** Not reported	under 18 years are included in this review. **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 - Duration of access to mental health services (years, n): ○ <1 = 5 ○ 1-3 = 10 ○ 4-7 = 4 ○ >7 = 4 **Inclusion criteria** Participants had to:	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** 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 MH 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. **Data analysis** Thematic analysis conducted to understand each participant's unique perspective. Analysis data-driven and coding using participant's own language	individualised, continuing journey to stability although there was variation in whether they thought it possible or helpful, and whether the goal of recovery consisted in reduction/disappearance of symptoms or learning to live with them. Goal of recovery for young person not always same as that of others (e.g. health professionals, parents). Facilitators to recovery included having a meaningful alliance with healthcare staff and being engaged in a collaborative approach to their own recovery.	*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. *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? (1. Contribution to literature and 2. Transferability)* Yes. 1. Yes,

Study details	Participants	Methods	Themes and findings	Limitation
	- Be aged between 14 and 25-years old. - Speak English - Be currently receiving services from mental health trusts **Exclusion criteria** Not reported.	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 and naming of themes. Any discrepancies discussed by all authors. Process of reflexivity used to bracket researchers own beliefs/preconceptions.		discusses in context of literature. 2. 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** Participants were compensated for their participation in study with a £10 gift card. Study also involved participants 18-25 years old. However, these participants are outside the protocol population and data was not extracted where possible.
Full citation Livesley, J., Long, T., Children's experiences as hospital in-patients: Voice, competence and work. Messages for nursing from a critical ethnographic study, International journal of nursing studies, 50, 1292-1303, 2013 **Ref Id**	**Sample size** N=17 children and young people - n=6 Phase 1 - n=9 Phase 2 **Characteristics** - Age: 5-15 years old Gender: Not reported. **Inclusion criteria**	**Setting** Hospital paediatric inpatient ward **Sample selection** Purposive sampling. - Phase 1 59 children meeting the inclusion criteria were identified from hospital records. The 6 who responded within the time frame were recruited. - Phase 2 The parents of children who were admitted to the nephro-urology ward and met the inclusion criteria were	**Author's themes:** - Different worlds - Child–nurse relationships - The challenge: children's voice and competence **Findings** During the study, one child become frightened when a nurse approached their bed on the side where their catheter drainage box was. The nurse dismissed the idea of it being able to hurt the child without trying to understand the reason behind the patient's reaction.	**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. Critical ethnographic approach was chosen in order to place children at the centre of the research,

Study details	Participants	Methods	Themes and findings	Limitation
990659 **Country/ies where the study was carried out** North England, UK **Study type** Qualitative study **Aim of the study** To explore children's insight into their hospital in-patient experience and define their voices in hospital qualitative research. **Study dates** Not reported. **Source of funding** None.	Phase 1: Participants had to: • Aged 5-16 years old • Be admitted as in-patients during the last 18 months to study ward • Admitted for at least 24 hours • Live within 1 hour driving distance from hospital Phase 2: Participants had to: • Be admitted as in-patients to the study ward • Be under the care of urology team **Exclusion criteria** Not reported.	introduced to the study and given an information leaflet. No parents or children declined to take part. **Data collection** Critical ethnographic approach, enabling children to comment on their individual healthcare experiences and to shape the research study. All data collection was completed by 1 researcher using a variety of age-appropriate methods e.g. storytelling, games, crafting, drawing and sentence completion. The study was separated into 2 phases. • Phase 1 A reconnaissance phase that explored children's memories of being hospital inpatients. Interviews were conducted in participants' home and developed spontaneously. Conversations were led by the children. Areas of interest included hospital admission and the children's experience whilst inpatients. • Phase 2 Informed by the results from phase 1. Field work in a nephro-urology ward situated in a specialist paediatric tertiary-referral hospital, conducted in 4-6 hour blocks (between 07:00-00:00) over 6 months. The	During the study, it became apparent that there was a constant balance for nurses between creating relationships with patients and the amount of time they had. In 1 instance, a nurse was busy organising for the transfer of a new patient from a high dependency unit when a child was communicating that they wanted their pad changed. The patient in question had a long surgical history and was worried about getting an infection in their stiches which would prevent them going home and returning to 'normal' life. The admission information failed to elicit the views and feelings of the patient, instead focusing solely on medical information. The nurse described the patient as 'stroppy' while the patient was left feeling sad and that they 'weren't being treated properly'. Another patient was wincing on their bed, explaining that they were in a lot of pain. They had told their nurse but were left waiting as the nurses were far too busy. The study reports multiple occurrences of patients trying and failing to get the attention of healthcare staff who were too busy. During the study, after a particularly busy shift, one	and allow them to help shape the study. The results of phase 1 (retrospective experiences of children as in-patients) were specifically used to inform the fieldwork of phase 2 (where researchers were on the ward). *Q4: Was the recruitment strategy appropriate to the aims of the research?* Yes. Inclusion criteria well described and matched the aim of the study. States that the study demographics were consistent with children using nephro-urology in-patient services. Phase 1 Possible children were identified from hospital records and contacted. Roughly a 10% response rate. Phase 2 Parents of children who were on the study ward and met the inclusion criteria were introduced to the study. Mentions that no families declined to participate. *Q5: Were the data collected in a way that addressed the research issue?* Can’t tell. Phase 1 A variety of data collection methods were used to ensure that each participant had an acceptable form of feedback. Interview content broadly described but, as it was designed to develop spontaneously, no interview guide was used. Conversations were audio-recorded and transcribed verbatim. Phase 2 Fieldwork observation used and justified as immersing themselves in the ward environment. However, methods were not specific. No

Study details	Participants	Methods	Themes and findings	Limitation
		researcher first became acquainted with the layout of the ward, sitting in the centre to immerse themselves before moving to the bedside of individual children. The researcher played games with participants, or were taken on a tour of the ward/hospital by the children. Extensive fieldwork notes were recorded immediately after each session. **Data analysis** Constant comparative methods. • Phase 1 Interviews were audio-recorded and transcribed verbatim using a confidential professional transcription service. 2 researchers read the transcripts and compiled a general overview of the major themes. This was then used to develop a set of questions to ask participants, attitudes to observe and topics to avoid in phase 2. • Full study After phase 1, data from both phases were analysed together using a constant comparative method. Researchers (no mention of how many) immersed themselves in the data, listening to the audio-recordings and reading	healthcare professional turned the lights off on the ward without any communication to patients.	mention of how much time spent with what children, what was included in the interview prompts, or any modifications during the study. Fieldwork notes were taken after the session, introducing an element of recall bias. *Q6: Has the relationship between researcher and participants been adequately considered?* No. No description of potential bias/influence between researcher and participants. This is particularly concerning in phase 2 of the study, which consisted of fieldwork on the ward itself. There is no information regarding how much time researcher's spent with each in-patient, or how having a ward recruitment might have affected answers. *Q7: Have ethical issues been taken into consideration?* Yes. All participants gave informed consent, as did parents/carers of participants. Concerns and practicalities surrounding data collection were discussed beforehand. The power differential inherent in child-adult interactions was acknowledged and strategies were employed to minimise it. *Q8: Was the data analysis sufficiently rigorous?* No. In-depth description of data analysis process presented, with a clear description of how codes,

Study details	Participants	Methods	Themes and findings	Limitation
		transcripts along with the field notes. Key quotations were noted, along with notes adding context and initial observations. Initial codes were developed before grouping them together into themes. At each point, any theme that was deemed to be significant was compared to the raw data and emerging themes. An overarching key theme was constructed, producing a common thread throughout the analysis.		themes and sub-themes were developed. Contradictory data is presented and discussed where appropriate. An adequate amount of data was presented to support the reported findings. Pictorial representation used to good effect in this process. However, there was little explanation of the techniques used to mitigate potential bias and influence during analysis. The only mention was the need to ensure that differences in children's experiences on the same ward should be highlighted rather than blended together. There was no critical examination of the researcher's own role in the process, which becomes particularly important as phase 2 was conducted solely through field -work on the ward. Importantly, there is no mention of the number of researcher's who participated in the data analysis. *Q9: Is there a clear statement of findings?* Yes. Good, detailed explanation of findings within the identified themes, with regular referral back to the original research question. However, there is no presentation of possible evidence against the researcher's findings and there is no discussion surrounding the credibility of findings. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* Yes. 1. Yes. Details

Study details	Participants	Methods	Themes and findings	Limitation
				how the study findings fit in with current literature and the UK population, and how they can be used to inform best practice. 2. Can't tell. General in-patient ward population but small sample size. *Overall judgement of quality:* Serious concerns **Other information** None.
Full citation Lowes, L., Eddy, D., Channon, S., McNamara, R., Robling, M., Gregory, J. W., The experience of living with type 1 diabetes and attending clinic from the perception of children, adolescents and carers: analysis of qualitative data from the DEPICTED study, Journal of pediatric nursing, 30, 54-62, 2015 **Ref Id** 1058771	**Sample size** N=518 children and young people completed baseline questionnaires • n=259 baseline intervention • n=259 baseline control N=390 children and young people completed 1 year follow- up questionnaires: • n=185 follow-up intervention • n=205 follow-up control **Characteristics** Not reported.	**Setting** Paediatric diabetes services **Sample selection** Recruited from 26 secondary and tertiary care paediatric services in UK. No further details reported. **Data collection** DEPICTED is a pragmatic cluster randomised controlled trial investigating the effectiveness of a training programme in consultation skills for UK paediatric diabetes teams. DEPICTED study participants completed a questionnaire on quality of life and other self-reported psychosocial outcomes at baseline and 1 year. Questionnaires were age-appropriate (1 for 7-10 year	**Author's themes:** • Communication skills **Findings** Communication skills of health care staff played a huge role in patient and carer experiences, as well as the relationship between families and diabetic team. Good communication by professionals made for a positive, rewarding experience for families. One adolescent mentioned it was helpful to attend clinic with an organised list of questions, which an agenda was setting tool addressed in the DEPICTED intervention. On the other hand, poor communication skills adversely impacted family's experience of attending clinic, limiting the benefits. Participants reported feeling as though they were spoken to rather than listened to. Many respondents felt	**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 methodology used to identify aspect of healthcare young people find helpful or unhelpful. *Q4: Was the recruitment strategy appropriate to the aims of the research?* Can't tell. Sample taken from the DEPICTED study which recruited 693 children aged 4-15 years old with type 1 diabetes from 26 UK specialist paediatric diabetic clinics.

Study details	Participants	Methods	Themes and findings	Limitation
Country/ies where the study was carried out Country-wide, UK **Study type** Mixed methods study Aim of the study To explore experiences of living with and managing Type 1 diabetes in children and adolescents, as well as attending specialist paediatric diabetic services. **Study dates** Not reported. **Source of funding** This study received support from UK National Institute for Health Research Health Technology Assessment Programme and Novo Nordisk UK.	**Inclusion criteria** Participants in DEPICTED trial had to be: • Aged 7-15 years old • Diagnosed with type 1 diabetes for at least 12 months **Exclusion criteria** Not reported.	olds, 1 for 11-15 year olds) and contained 5 free-text boxes on attendance at diabetes clinics, living with diabetes and managing diabetes. **Data analysis** Qualitative descriptive analysis. Responses in the 5 free-text boxes were transcribed verbatim from the returned questionnaires and entered into a database by an independent researcher. Data was labelled as child/adolescent/carer, intervention group/control group, baseline/follow-up and which box it corresponded to. 2 researchers individually analysed these responses before identifying patterns to inform initial codes. These codes were then collated into themes and sub-themes.	as though healthcare staff could not understand what it is like to live with diabetes if they didn't have it themselves, meaning that they tended to oversimplify the impact it has on the lives of adolescents. Children, adolescents and carers tended to prefer consultations with paediatric nurses rather than doctors, as doctors were seen as less patient-centred. Consultations with multiple healthcare professionals present were not always seen as helpful, with some children describing them as overwhelming and intimidating. Some parents mentioned that they would like to be able to consult with their child's doctor without their child present. In some clinics, adolescents were able to consult their healthcare professionals without their parent's present, but this did not always allow them to talk about their concerns and feelings more openly. Parents were especially worried that this might allow their children to withhold important information back if they were not in the consultation.	This is a wide population but there were no further details reported, including any demographic information. *Q5: Were the data collected in a way that addressed the research issue?* Unsure. Use of questionnaires was justified as part of the DEPICTED study. Free-text questions published in article and are accompanied by detailed description of response rates for individual questions. However, no mention of alternative forms of questionnaire (for example, large font). However, it is mentioned that that free-text boxes were not mandatory and so individuals with particularly strong views on certain questions were more likely to use these boxes to elaborate. Additionally, data was collected throughout the DEPICTED trial but not specifically collected to answer this research question. *Q6: Has the relationship between researcher and participants been adequately considered?* Yes. No discussion presented regarding potential bias/influence between researcher and participants but unlikely to be an issue with postal questionnaires. *Q7: Have ethical issues been taken into consideration?* Yes. Study was approved by South East Wales NHS Research Ethics Committee

Study details	Participants	Methods	Themes and findings	Limitation
				(DEPICTED intervention development) and Thames Valley NHS Research Ethics Committee (DEPICTED trial phase) and managing NHS organisations (DEPICTED trial phase). *Q8: Was the data analysis sufficiently rigorous?* Can't tell. Adequate description of data analysis process presented but poor description of how codes, themes and sub-themes were developed. No critical examination of the researcher's own role in the process or techniques used to mitigate potential bias and influence during analysis. However, contradictory data is presented and discussed where appropriate. An adequate amount of data was presented to support the reported findings. *Q9: Is there a clear statement of findings?* Yes. Good, detailed explanation of findings within the identified themes, with regular referral back to the original research question. Good discussion surrounding evidence both for and against the study's findings. Discussion around credibility of findings. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* Yes. 1. Yes. Details how the study findings fit in with current literature and the UK population, and how they can be used

Study details	Participants	Methods	Themes and findings	Limitation
				to inform best practice.2. Can't tell. The initial RCT had a wide sample population but demographic information is not presented. May be generalizable to other chronic diseases. *Overall judgement of quality:* Moderate concerns **Other information** Part of the larger DEPICTED study. Another questionnaire on enablement was administered at the 1st clinic visit since the start of the trial but no qualitative data was reported.
Full citation 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 **Ref Id** 991064 **Country/ies where the study was carried out**	**Sample size** N=3 young people **Characteristics** Age (range): 12-18 years **Inclusion criteria** Participants had to: • Be aged 12-18 years old • Have a diagnosed chronic condition/illness • Be living in rural area **Exclusion criteria**	**Setting** In the community **Sample selection** Participants taking part in 'Stepping into Shoes', a documentary project about the impact of living with a chronic illness in a rural area. No further details given on how these participants were identified or recruited. **Data collection** Semi-structured interviews conducted on camera for a documentary. The interview guide was developed from the current literature, together with input from the 'Stepping into	**Author's themes:** • Experience of healthcare **Findings** All the children interviewed had had significant experience with the healthcare system and were used to seeing an array of healthcare professionals (e.g. consultants, nurses, physiotherapists) in a wide range of settings (e.g. local hospitals, specialist tertiary hospitals, community-based clinics, home-based visits and treatment). Factors that helped create a positive healthcare experience for children were when healthcare staff addressed them as the patients and not just their parents. This allowed the children to feel	**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 methodology used in order to try and gain a fuller understanding of the impact of living with a long-term condition on young people, and place them as an active consumer of healthcare. Royal College of Paediatrics and Child Health research

Study details	Participants	Methods	Themes and findings	Limitation
Cornwall and Devon, UK **Study type** Qualitative **Aim of the study** To explore the impact of chronic health conditions on young people, their lives, their families and their interactions with healthcare services. **Study dates** Not reported. **Source of funding** 'Stepping into Shoes' project received support from Cornwall and the Isles of Scilly Primary Care Trust and the Real Ideas Organisation.	Not reported.	Shoes' team and paediatric clinicians. Open-ended questions were used to explore the impact of a chronic illness on the young person and their experience of healthcare. **Data analysis** Thematic analysis. Interviews were video-recorded and transcribed verbatim. Each transcript was then read several times by the interviewer, who noted initial thoughts, potential themes and summary phrases. These initial themes were extracted and organised into clusters, identifying any potential connections. Initial transcripts were revisited throughout the process to ensure that the developing themes were true to the original quotes and context. Overarching themes were named and organised into a table with supporting themes.	more informed and more in control. Having a good relationship with healthcare professionals was deemed important, as was consistency in seeing the same professionals and a positive attitude of staff to both treatment itself and possible outcomes of treatment. Conversely, lack of suitable equipment, poor communication with or between healthcare staff, time taken for appointments and anxiety prior to appointment was mentioned as factors that adversely affected healthcare experiences.	guidelines specifically mentioned, as they recommend both quantitative and qualitative research methods. *Q4: Was the recruitment strategy appropriate to the aims of the research?* Can't tell. No information given regarding how 'Stepping into Shoes' participants were identified or recruited. *Q5: Were the data collected in a way that addressed the research issue?* Can't tell. Interviews were video-recorded as part of a documentary. Setting for the interview setting and method was well justified throughout the article. However, the interview schedule was not discussed in detail and data saturation was not mentioned. *Q6: Has the relationship between researcher and participants been adequately considered?* No. No description of potential bias/influence between researcher and participants. *Q7: Have ethical issues been taken into consideration?* Can't tell. No information given on ethical approval or discussion on possible ethical considerations given. *Q8: Was the data analysis sufficiently rigorous?* No. Brief description of data analysis process presented, with a

Study details	Participants	Methods	Themes and findings	Limitation
				poor description of how codes, themes and sub-themes were developed. An adequate amount of data was presented to support the reported findings although there is a lack of contradictory data presented. The report mentions that the researcher routinely checked the transcripts to ensure that analysis did not deviate from the original data but there was no critical examination of the researcher's own role in the process. This is important as the first author did all the interviews and analysis. *Q9: Is there a clear statement of findings?* Yes. Good, detailed explanation of findings within the identified themes, with regular referral back to the original research question. Adequate discussion surrounding evidence both for and against the study's findings. Discussion around credibility of findings. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* Can’t tell. 1. Yes. Details how the study findings fit in with current literature and the UK population. Areas for future research are identified. 2. Can’t tell. The sample size is very small and participants were sampled from rural areas in west England. May be generalizable to other chronic diseases.

Study details	Participants	Methods	Themes and findings	Limitation
				Overall judgement of quality: Serious concerns **Other information** None.
Full citation 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 **Ref Id** 958204 **Country/ies where the study was carried out** Multiple countries **Study type** Systematic review **Aim of the study** To explore the current literature and determine the factors affecting	**Sample size** K=68 studies. **Characteristics** Type of study (k): - Qualitative=44 - Quantitative=16 - Mixed-methods=8 ○ This study incorporated all their results (qualitative and quantitative) into a narrative summary, which was then used in the findings of this review. Range of sample size: N=3 to 1388 Marginalised group (k): - Homeless=20 - Living in remote areas=14 - Refugees and migrants=11	**Setting** Not reported **Study selection** A systematic literature search of 5 online databases (Medline, CINAHL, PyscInfo, The University of Sydney Library database and Google Scholar) for qualitative, quantitative and mixed-methods studies (published between Jan 2006 and Feb 2017) identified 1758 articles. Hand searching of reference lists and a grey literature search identified 38 more articles. The search was conducted in 2 phases. First phase involved a generalised search of the literature for terms relating to access, barriers or navigation of healthcare. The second phase specifically searched for 5 marginalised groups of young people (those who are homeless, living in remote areas, refugees and migrants, LGBTQ and part of the indigenous population). While reviewing the literature, 3 more populations were identified (young offenders, low income	**Author's themes:** - Professionals; knowledge, skills and attitudes affect engagement **Findings** Marginalised young people wanted clinicians who are able to take time, facilitate communication, deal with sensitive issues carefully, listen with empathy and be respectful of autonomy. Positive characteristics of professionals included: non-judgmental attitude; welcoming; open-minded, unassuming, supportive and encouraging. Trust was a central theme, building trusting relationships with both providers and services. This ability to develop an ongoing personal connection (involved rapport with service providers), continuity of therapeutic relationships, and having a usual source of care was important to marginalised young people. Being taken seriously and being acknowledged was a pervasive theme, as was discrimination by professionals. Marginalized young people may be treated differently and with disrespect. Culturally	**Limitations (assessed using the CASP checklist for systematic reviews).** *Q1: Did the review address a clearly focused question?* Yes *Q2: Did the authors look for the right type of papers?* Yes *Q3: Do you think all the important, relevant studies were included?* Yes. A wide variety of online databases were used, and the search strategy was devised in collaboration with a librarian from University of Sydney. Reference lists of included studies were checked for relevant studies and a search of the grey literature was conducted. No restrictions were placed on full-text or language of publication. No mention of personal contact with experts. However, only 5 of the 8 marginalised groups of young people were pre-defined before searching and included in the systematic search terms. Young offenders, low income and young people living with a disability were only included after reviewing the identified studies. Authors decided to include studies encompassing these

Study details	Participants	Methods	Themes and findings	Limitation
access to, engagement with, and navigation through healthcare systems for marginalised young people in the digital age. **Study dates** Search dates: January 2006 - February 2017 **Source of funding** None.	• LGBTQ=11 • Indigenous populations=4 • Low income=4 • Young offenders=2 • Living with a disability=2 Study country (k): • United States=24 • Australia=24 • Canada=11 • UK=7 • New Zealand=1 • Portugal=1 Respondents (k): • Young people=61 • Professionals=11 • Parents=7 o Although the study notes that their themes were identified by all the participants in their population (marginalised young people up to age 24 years old, parents and healthcare professionals),	and living with a disability). These terms were subsequently included but were not included in the original systematic search terms. Abstracts were screened, with 2 researchers performing an initial 200 paper pilot and achieving more than 95% inter-rater agreement. Any disagreements were discussed and an agreement reached. Out of 1241 abstracts screen, 235 full texts were read and 68 were included for the final review. **Data collection and analysis** Study characteristics and outcomes were extracted into Microsoft Excel. Data extraction included year, language of publication, country, marginalised group, sample size, age definition, gender distribution, healthcare setting, focus of the study, and key limitations in study protocol. Key findings for access to, engagement with and/or navigation through healthcare systems were recorded through each study. Qualitative thematic synthesis was conducted with all included studies, beginning with free-coding of the extracted themes. These were input into an Excel spreadsheet alongside the other extracted data, forming a matrix. This matrix was then	appropriate services, cultural sensitivity of staff, use of interpreters, and cultural concepts of health, including traditional indigenous therapeutic practices should be provided. Professionals could be better at managing the health issues that young people from marginalized backgrounds may experience e.g. mental health, trauma, and LGBTQ issues.	populations but did not re-do the systematic search to with these terms included. This means that all available papers for these 3 populations may not have been identified and they may be under-represented in the findings. *Q4: Did the review's authors do enough to assess quality of the included studies?* Yes. Quality appraisal of studies was done using both quantitative and qualitative appraisal tools. Qualitative studies received an average CASP checklist score of 7.96/10 (range 3-10). Each criterion was met by 67% of studies, excepting considering the relationship between interviewer and participants (only 25% of studies addressed this). Quantitative studies received an average Glasziou criteria score of 2.88/5 (range 1-5). Participant demographics and ethical review was well scoring among the studies. However, drop-out rates, sampling, use of validate questionnaires and description of outcome measurements were each addressed by 50% of studies or less. *Q5: If the results of the review have been combined, was it reasonable to do so?* Yes. Thematic analysis applied to the data, with good description of the process of combining quantitative and qualitative data.

Study details	Participants	Methods	Themes and findings	Limitation
	views of people > 18 years old, parents and health professionals will also have been included in their results. Our findings have been downgraded for relevance where applicable. Area of healthcare (k): • General=37 • Mental health services=13 • Sexual health services=7 • Substance use services=2 • Emergency departments=2 • Pregnancy-related services=2 • Primary care=2 • Youth services=1 • School health services=1 • Social services=1 **Inclusion criteria**	transferred through to NVivo, allowing grouping of codes and the organisation of higher-level thematic analysis. The method of synthesis involved integrating multiple data components (i.e. qualitative and quantitative) into the analysis, to allow comparisons within and across categories. **Quality appraisal of included papers** Quantitative studies: Glasziou criteria; Qualitative studies: CASP checklist; Mixed-methods: both as appropriate.		*Q6: What are the overall results of the review?* Table presenting the characteristics of included studies is very informative, including details on country, health issue focus, study design, participant characteristics and summary of findings. However, would have liked to see the marginalised group listed in there as well. Very good qualitative description of the 8 general themes identified across the literature, presented in chronological order i.e. help-seeking, access to healthcare services, engagement with healthcare services, navigation through healthcare services, and future directions for increasing access to healthcare (technology). Further discussion surrounding the variation in the themes between marginalised groups of young people, as well as parental and professional views. *Q7: How precise are the results?* Not applicable. *Q8: Can the results be applied to the local population?* Can't tell. The review incorporates data from a wide range of setting and participants. However, only 7 studies were conducted in the UK. 24 were conducted in the USA, which has a very different healthcare system to here, in which cost plays a very large part to access. Convenience sampling used by single services were prevalent within the studies which also affects generalisability.

Study details	Participants	Methods	Themes and findings	Limitation
	Studies had to: • Be focused on marginalised groups (defined as refugees and migrants, homeless, LGBTQ, living in remote areas, part of the indigenous population, young offenders, low income, living with a disability) • Have at least 75% of study participants aged 12-24 years old, their parents or healthcare professionals • Have a study question involving access and barriers to, engagement with, and/or navigation through healthcare services • Be conducted in high-income country • Report original research			*Q9: Were all important outcomes considered?* Not applicable. Themes are driven by data. *Q10: Are the benefits worth the harms and costs?* Not applicable. Literature review. *Overall judgement of quality:* Minor concerns **Other information** None.

Study details	Participants	Methods	Themes and findings	Limitation
	• Be published from Jan 2006 onwards **Exclusion criteria** Not reported.			
Full citation Sharkey, S., Lloyd, C., Tomlinson, R., Thomas, E., Martin, A., Logan, S., Morris, C., Communicating with disabled children when inpatients: barriers and facilitators identified by parents and professionals in a qualitative study, Health expectations : an international journal of public participation in health care and health policy, 19, 738-750, 2016 **Ref Id** 1062015 **Country/ies where the study was carried out** South West England, UK	**Sample size** N=17 parental proxies for children with 'communication difficulties' **Characteristics** Age of children (range): 5-16 years **Inclusion criteria** Parents had to: • Have a disabled child aged 5-16 years old • Have a child had been admitted as an inpatient for more than 24 hours • Have a child admitted for either emergency or elective reasons • Have a child perceived by both healthcare staff and parent to	**Setting** 2 district general hospitals **Sample selection** Convenience sampling. Parents of disabled children who had been admitted to 2 English district general hospitals were identified and given study information by the ward staff. Posters were also displayed on wards and parent rooms. Parents contacted the researchers directly if they wished to be enrolled. NB Purposive sampling was used half-way through the recruitment process to increase number of nurses. However, this population is out of scope for this review and will not affect the risk of bias. **Data collection** Semi-structured, face-to-face interviews with parents. An interview schedule was designed in partnership with parents of disabled children from	**Author's themes:** • Time • Professionals not prioritising communication in their role • Poor information sharing • Learning about the child • Building rapport with the child • Using communication aids **Findings** Time was a very important factor for healthcare professionals, greatly impacting their ability to communicate effectively with patients. Parents linked 'not making time' with poor communication. Parents were aware of staff being busy and how this affected their ability to communicate. Specifically, they felt that a 'non-demanding' disabled child might not be able to make their needs known in a busy setting, with harried staff. Parent's also mentioned that professionals did not prioritise communication with their disabled child and were very aware that healthcare staff often relied upon	**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. The study formed part of a larger research programme into improving communication with disabled children in hospital. The qualitative design was used to gain a better understanding of the needs, barriers and skills that impact on communication with this population, to inform future interventions and training. *Q4: Was the recruitment strategy appropriate to the aims of the research?* No. Convenience sampling was used although the population being sampled is very specific so this might have been a factor. Inclusion criteria well described and matched

Study details	Participants	Methods	Themes and findings	Limitation
Study type Qualitative **Aim of the study** To explore the experiences of healthcare professionals and parents towards communicating with children with 'communication difficulties' whilst on paediatric inpatients wards. Study dates Not reported. **Source of funding** The Peninsula Cerebra Research Unit received support from Cerebra and the National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care of the South West Peninsula.	have a 'communication difficulty'. **Exclusion criteria** Not reported.	the Peninsula Cerebra Research Unit Family Faculty. The guide contained open-ended questions and prompts to explore particular area of interest for the different groups involved in the research i.e. healthcare professionals and parents. For parents, these revolved around their experiences of hospital communication, as well as recommendations to improve communication with children with communication difficulties. **Analysis details** Framework analysis. Interviews were audio-recorded and transcribed verbatim. Data was managed by NVivo software. Parental and professional data was originally analysed separately before being combined at a later time point. After familiarising themselves with the data, 2 researchers individually developed an initial coding framework based on the aim of the research and pre-defined areas of interest. These same researchers then both coded 2 transcripts as a pilot, before discussing and revising the coding framework as needed. Remaining transcripts were indexed independently by the researchers, with any new codes being noted and	them to act as a mediator between them and the child. This made some reluctant to leave the ward. Parents and nurses identified the importance of sharing techniques for communicating with a child. However, parents also mentioned feeling that they were not always asked for advice and that their views are not always sought. Nurses and parents viewed getting to know the child as an aid to communication, including remembering them from previous admittance. Parents felt that it was very important to recognise and utilise their knowledge about the child. Fostering a relationship between a child and healthcare professions was also deemed to aid communication e.g. focusing on the child and using quiet moments. Being experienced in working with children was seen as a positive factor. Parent's felt that experienced staff are more relaxed in communicating with disabled children and are better able to respond appropriately. Parents stressed that professional's having an awareness and empathy for the child's perspective was very	the aim of the study. Written information and posters were only presented in English, although this was rationalised as being because the geographical area where the study was conducted is not ethnically diverse. No demographic information on participants were reported. Mentions that the researchers had difficulty recruiting children directly. *Q5: Were the data collected in a way that addressed the research issue?* Can’t tell. Semi-structured interview setting for data collection was justified as being the most practical for parents. Use of interview guide was mentioned but no further details were reported. Interviews were audio-recorded interviews and transcribed verbatim. Thematic saturation mentioned. However, no information given on whether methods changed during the study. *Q6: Has the relationship between researcher and participants been adequately considered?* No. No description of potential bias/influence between researcher and participants. *Q7: Have ethical issues been taken into consideration?* Yes. Informed consent obtained before participation in interviews or focus groups. 'Stopping interviews' guide was implemented, meaning interviews were ended if participants became

Study details	Participants	Methods	Themes and findings	Limitation
		communicated during the process. Themes and sub-themes were identified, charted and organised into a revised framework. Researchers discussed any differences in analysis, allowing for further synthesis and development of overarching meta-themes. Both professional and parental participants from the Peninsula Cerebra Research Unit Family Faculty steering group were consulted about the themes that emerged from the data analysis.	important for aiding communication, building a rapport with them. Parent's reported how 'quiet talk time' can increase engagement from disabled children. Parent's mentioned communication passports e.g. 'All About Me' booklets, which contain information on the child, how they like to communicate. Other parents mentioned the benefits of the use of hospital environment photos and yes/no cards.	distressed. Study was approved by South West REC and relevant Research and Development committees of hospital sites. *Q8: Was the data analysis sufficiently rigorous?* Yes. Adequate description of data analysis process presented and good description of how codes, themes and sub-themes were developed. There is good discussion about techniques employed throughout the analysis process to increase rigour. These included purposive sampling to increase representation, checking for thematic saturation, multiple researchers, and an audit trail of analytic decisions to track variability between researchers and peer debriefing. Deviant cases were explored using memos taken during interviews and contradictory findings were discussed where appropriate. An adequate amount of data was presented to support the reported findings. *Q9: Is there a clear statement of findings?* No. Good, detailed explanation of findings within the identified themes, with regular referral back to the original research question. However, the article mentions that the study tried to recruit children directly, subsequently interviewing 4 children (results not published). Apparently, the data was substantively different to the views of parents and professionals,

Study details	Participants	Methods	Themes and findings	Limitation
				meaning it was not possible to include their views in the analysis. This leads to some concerns over the reliability of the findings. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* Can't tell. 1. Yes. Details how the study findings fit in with current literature and the UK population, and how they can be used to inform best practice. 2. No. Issues with contradictory children's views limits transferability. *Overall judgement of quality:* Serious concerns **Other information** Also deals with the views of ward staff but this is outside of our protocol so data not extracted where possible.
Full citation Taylor, S., Haase-Casanovas, S., Weaver, T., Kidd, J., Garralda, E. M., Child involvement in the paediatric consultation: a qualitative study of children and carers' views, Child: care, health and development, 36, 678-685, 2010	**Sample size** N=43 children, young people and parents • n=20 children and young people • n=23 parents • Only the views of children and young people included in this review **Characteristics**	**Setting** Paediatric outpatient clinics **Sample selection** Consecutive sampling of families attending participating clinics at 2 paediatric units (1 in North London, 1 in Northampton). Written consent was obtained from the parents and then children. **Data collection**	**Author's themes:** • The view of families about the child's involvement: ideas for enhancing child participation **Findings** The study identified 3 main views regarding enhancing child involvement in consultation and treatment: 1. The doctor is responsible for facilitating child involvement 2. Parents responsible for facilitating child involvement 3. All participants are responsible for facilitating child	**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. No specific justification given for qualitative research. Noted

Study details	Participants	Methods	Themes and findings	Limitation
Ref Id 1062810 **Country/ies where the study was carried out** Northampton and London, UK **Study type** Qualitative **Aim of the study** To explore the views of children and their parents/carers to their involvement in paediatric consultations. **Study dates** Not reported. **Source of funding** This study received support from Imperial College London.	Age [median (range)]: 10 (7-16) years Gender (M/F): 5/15 **Inclusion criteria** Participants had to: • Be aged 6-16 years old • Be fluent in English • Be accompanied by at least 1 parent • No have a learning disability • Be well enough to participate in interview **Exclusion criteria** Not reported.	Semi-structured interviews with parents and children following paediatric consultations. A literature review was used to design an interview guide to study parental and child attitudes towards the child's involvement at various stages of the consultation. Questions were open-ended, with the script allowing for prompts and further exploration of any themes identified. This interview script was refined throughout the study process in response to emerging themes. Children were asked their views first in order to minimise their bias. **Data analysis** Framework analysis. Interviews were audio-recorded and transcribed verbatim. 1 researcher read through all transcripts, immersing themselves in the information, before the interviews were analysed using a thematic coding framework that was informed by the data. While being coded and charted, the range of responses and themes from each interview was noted. Child and parent answers were first analysed separately (to prevent any cross-over of codes) but charted together, allowing a family analysis to take	involvement. For those thinking doctors should be responsible for facilitating communication, children identified the following skills as aiding this: doctors using a shopping list of symptoms; being interested, relaxing and not rushing the child; using rewards and making a child feel important; seeing adolescents alone; increase amount of information given with increased age and understanding of child. For those thinking parents should be responsible for facilitating communication, children identified the following skills as aiding this: parent's presence assists in relaxing the child and assists the child's understanding; parents never stop being involved in important decisions; inform children from an early age about healthy living; a child's responsibility increases with age and parents overseeing their behaviour. For those thinking all parties should be responsible for facilitating communication, children identified the following skills as aiding this: collaborative approach reaching a diagnosis; child to be given a choice of being informed or not; there should be an ongoing discussion about the seriousness of situation treatment and consequences of options. Two other techniques were identified as being helpful: 1.	that there is a lack of research into paediatric communication so gaining a better understanding of the family experience is a logical first step. *Q4: Was the recruitment strategy appropriate to the aims of the research?* Can't tell. Consecutive recruitment of families at paediatric (both in-patient and out-patient) units. Inclusion criteria well described and matched the aim of the study. However, poor information reported for demographic data and no discussion about response rates or non-responders. *Q5: Were the data collected in a way that addressed the research issue?* No. Semi-structured interviews were audio-recorded and transcribed. Data saturation was discussed and reached. However, there are a number of issues with data collection. The setting for data collection was not reported - unsure during reading whether interviews were conducted during the clinic visits or after. Interview guide was used and described as being informed by the literature, but no information given regarding the content. It is noted that the topic guide refined throughout the study but, again, no information was given regarding how. Children were interviewed in the presence of parent/guardian, which may have affected their responses.

Study details	Participants	Methods	Themes and findings	Limitation
		place. All transcripts were read and analysed by 2 researchers, with another validating the methodology.	adolescents being seen privately/separately as well as being seen together with their parents and 2. Training parents in interviewing skills.	*Q6: Has the relationship between researcher and participants been adequately considered?* No. No description of potential bias/influence between researcher and participants. *Q7: Have ethical issues been taken into consideration?* Yes. Informed consent received from parents and child. Paper states that local research ethic committee approval was granted/ *Q8: Was the data analysis sufficiently rigorous?* No. Description of the analysis process is very brief with poor detail of how thematic analysis was utilised. No critical examination of the researcher's own role in the process or techniques used to mitigate potential bias and influence during analysis. Contradictory data is not presented or discussed. However, an adequate amount of data was presented to support the reported findings. *Q9: Is there a clear statement of findings?* Yes. Good, detailed explanation of findings within the identified themes, with regular referral back to the original research question. Good discussion surrounding evidence both for and against the study's findings. Tables are used as a good visual description of the differing perspectives of professionals, parents

Study details	Participants	Methods	Themes and findings	Limitation
				and children throughout the different stages of consultation. Discussion around credibility of findings. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* Yes. 1. Yes. Details how the study findings fit in with current literature and the UK population, and how they can be used to inform best practice. Ideas and directions for future research are identified. 2. Yes. Demographic data show a wide range of participants, increasing transferability. Sample size is a concern, but good size for a qualitative study. *Overall judgement of quality:* Serious concerns **Other information** Views of parents also reported but, due to age of babies, children and young people they are outside of our protocol and therefore not extracted where possible.
Full citation Wood, D., Geoghegan, S., Ramnarayan, P., Davis, P. J., Pappachan, J. V., Goodwin, S., Wray, J., Eliciting the experiences of the adolescent-parent	**Sample size** N=17 young people and parents • n=8 mother-adolescent dyads • n=1 mother ○ Views and experiences of the mothers	**Setting** Intensive care units • n=6 paediatric intensive care unit • n=3 adult intensive care unit **Sample selection** Purposive sampling used with eligible participants/families	**Author's themes:** • Inclusion • Providing explanations • Interpersonal communication • Tailoring communication and interaction style • Respect **Findings**	**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.

Study details	Participants	Methods	Themes and findings	Limitation
dyad following critical care admission: a pilot study, European Journal of Pediatrics, 177, 747-752, 2018 **Ref Id** 994200 **Country/ies where the study was carried out** UK **Study type** Semi-structured interview; qualitative **Aim of the study** To determine whether adolescents and their families can articulate their experiences of their intensive care unit or high dependency unit visit, and to identify the factors that are important to them during such visits.	were included in this review as they were reflecting on a period of time when their child may not have been able to participate in healthcare conversations and decisions while in ICU. **Characteristics** Age of children (years, n): • 14=1 • 15=3 • 16=2 • 17=2 • 19=1 Gender: Not reported. Outcome of visit (n): • Discharged via ward and no ongoing treatment required=2 Discharged via ward and ongoing	contacted by local specialist nurses who were known to them at each participating hospital to seek consent to be contacted and to invite them to interview. Opportunities to discuss participation further provided and consent obtained from participants (parents/carers if aged under 18) prior to interview. Fourteen families satisfied inclusion criteria and agreed to be contacted by researchers. Five families could not be contacted and two families withdrew for logistical or other reasons. **Data collection** All interviews were conducted face-to-face by one researcher (female social scientist with experience interviewing ICU patients/families) in participant's own home or in quiet hospital room. Interviews were 30-90 min and were audio-transcribed verbatim. Topic guides used and participants asked to remember their ICU visit/staff support. Researcher kept contemporaneous notes of interviews and her own reflections, which were also reviewed by other authors. **Data analysis**	Main reported factor determining quality of adolescent's healthcare experience in intensive care unit was quality of interaction with staff, but this was often limited by their awareness (of lack thereof) during their stay. Medical competency and health outcomes were not typically mentioned, and accessibility was not mentioned at all.	*Q3: Was the research design appropriate to address the aims of the research?* Yes. *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. *Q6: Has the relationship between researcher and participants been adequately considered?* Can't tell. Not discussed. *Q7: Have ethical issues been taken into consideration?* Yes. Ethical approval granted from South West-Central Bristol ethics committee (Ref 14/SW/1131). *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, contextualises findings in literature, suggests further research. 2. Can't tell, specific age group and setting make transferability of findings difficult but identified

Study details	Participants	Methods	Themes and findings	Limitation
Study dates Not reported **Source of funding** This study received support from Great Ormond Street Hospital Children's Charity Clinical Research Starter Grant V0015.	treatment required=3 • On-going treatment required 1 • Discharged back to ward and on-going treatment required=2 • On-going contact needed with hospital=1 **Inclusion criteria** Participants had to: • Be aged 10-17 years-old • Be admitted as emergency to adult or paediatric intensive care or high dependency units in 1 of 4 UK hospitals (2 adult and 2 paediatric) for at least 24 hours in previous 12 months • Be at least 2-months post-ICU admission • Be awake for some of their ICU stay • Parents and carers of	Framework analysis used involving: familiarisation, identifying thematic framework, indexing, charting, mapping and interpretation. Two authors and lead researcher independently generated themes/frameworks and agreed on/refined descriptive headings through iterative process. Data from each transcript entered into framework and key themes extracted and relationships between them were explored. Data and findings also discussed with other team members as well as two ICU nurses not directly involved in project to enhance confirmability and credibility of findings.		themes plausibly apply in other situations. *Overall judgement of quality:* No/very minor concerns **Other information** None.

Study details	Participants	Methods	Themes and findings	Limitation
	participants were also invited to join **Exclusion criteria** Not reported			

ADR: Adverse drug reaction; CAMHS: Child and Adolescent Mental Health Service; CASP: Critical Appraisal Skills Programme; F: Female; ICU: Intensive care unit; M: Male; N/n: Number

Appendix E – Forest plots

Forest plots for review question: How should healthcare staff communicate with babies, children and young people, and the parents or carers of babies and young children?

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

Appendix F – GRADE-CERQual tables

GRADE-CERQual tables for review question: How should healthcare staff communicate with babies, children and young people, and the parents or carers of babies and young children?

Table 7: Evidence summary (GRADE-CERQual) for theme 1: Medical information

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**
Sub-theme 1.1: Timing							
1 (Arnott 2012)	Semi-structured interviews	Evidence from 1 study showed that parents/carers of babies and children with suspected adverse drug reactions reported that communication could be poorly timed. For example, some parents remembered receiving detailed information at time when they were preoccupied with a critically ill child. Conversely, at times when they were less anxious and had more time to digest information, communication from healthcare staff was less forthcoming. Ideally, good communication of medical information should be given early and include full details about possible symptoms and next steps. Poor communication of medical information could lead to babies, children and their parents/carers being less involved in decisions surrounding their child's healthcare (for example, continuing to give their child a medication that was exacerbating symptoms).	Moderate concerns[1]	No/very minor concerns	Moderate 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
		'If someone had explained maybe […] the reactions […] we might have thought a bit more about taking it wouldn't we?' (Arnott 2012, page 7, parental proxy)					
Sub-theme 1.2: Co-ordination							
2 (Arnott 2012, McCormack 2010)	Semi-structured interviews	Evidence from 2 studies showed that a lack of co-ordination between medical staff impacts communication between healthcare services and patients, often leading to contradictory advice. For example, one doctor attributing a symptom to a medicine while another doctor attributes it to an underlying medical condition. This uncertainty leads to a lack of clear advice from healthcare staff, with some parents of children with suspected adverse drug reactions reporting that they felt as though they were being lied to. *'The first man said it was herpes […] and then the nice doctor downstairs said, 'No, this is a reaction to Penicillin" (Arnott 2012, page 6, parental proxy)*	Moderate concerns[1]	No/very minor concerns	Moderate concerns[2]	Moderate concerns[4]	VERY LOW
Sub-theme 1.3: Amount							
3 (Gibson 2010, Lowes 2015, Taylor 2010)	Age-appropriate techniques, focus groups, free-text	Evidence from 3 studies showed that the amount of medical information children and young people wanted to be given varies. Older children diagnosed with cancer report not being told enough about their	Minor concerns[5]	No/very minor concerns	No/very minor concerns	Minor concerns[6]	MODERATE

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
	questionnaires and semi-structured interviews	condition and preferred open communication. However, some other adolescents with cancer find medical information to be overwhelming. Allowing children and young people to choose whether to be informed or not was highlighted as a potential tool for enhancing child involvement in medical consultations. *'I think it's better when the doctor tells you everything. . .. It's your body and they are going to do stuff to it and you want to know everything that could happen' (Gibson 2010, page 1402)*					
Sub-theme 1.4: Future							
3 (Arnott 2012, McCormack 2010, Taylor 2010)	Semi-structured interviews	Evidence from 3 studies showed that good communication involves acknowledgment of future possibilities and next steps in a timely manner. Helping babies, children and young people and their families understand their condition and treatment, as well as long-term effects and options going forward, was important for parents of children with suspected adverse drug reactions. Children with chronic conditions mentioned that they wish their healthcare professionals to be positive about their treatment and the outcomes. Additionally, there should be an ongoing discussion about the	Moderate concerns[1]	Moderate concerns[7]	No/very minor concerns	Minor concerns[6]	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
		seriousness of situation treatment and consequences of options. *'I was saying 'well, when she goes home, can I give her paracetamol? Can she never have paracetamol or can she never have a drug that might affect her liver?' And they were going 'well […] it should be fine' but no-one was saying 'well you can, I'll write it down and you can have it' (Arnott 2012, page 7, parental proxy)*					

1 Evidence was downgraded due to moderate concerns about methodological limitations as per CASP qualitative checklist
2 Evidence was downgraded due to moderate concerns about the relevance of evidence as evidence contains views of parental proxies on very specific subject (adverse drug reactions)
3 Evidence was downgraded for adequacy because studies together did not offer rich data
4 Evidence was downgraded for adequacy because studies together offered some rich data
5 Evidence was downgraded due to minor concerns about methodological limitations as per CASP qualitative checklist
6 Evidence was downgraded for adequacy because study offered moderately rich data
7 Evidence was downgraded due to moderate concerns regarding the coherence of findings

Table 8: Evidence summary (GRADE-CERQual) for theme 2: Person not patient

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
Sub-theme 2.1: Creating relationships							
8 (Boyden 2013, Gibson 2010, Law 2020, Livesley 2013, McCormack 2010,	Age-appropriate techniques, focus groups, semi-structured interviews and	Evidence from 7 studies and 1 systematic review showed that multiple groups of children and young people (and parents/carers) mentioned the importance of creating relationships with healthcare professionals in promoting communication. Children enjoyed when healthcare staff made an effort	Minor concerns[1]	No/very minor concerns	No/very minor concerns	No/very minor concerns	HIGH

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
Robards 2018, Sharkey 2016, Wood 2018)	systematic review	to get to know them as an individual, not just their medical diagnosis. Examples ranged from simply chatting about their life or finding a copy of a favourite comic book. Creating a good relationship allows children to feel more informed and in control, building trust with a healthcare service or professional. *'I started to open up cos I trusted Vicky more and more and then everything started like working and like fitting together' (Law 2020, page 470)*					
Sub-theme 2.2: Time							
6 (Heath 2014, Livesley 2013, McCormack 2010, Robards 2018, Sharkey 2016, Taylor 2010)	Age appropriate techniques, focus groups, semi-structured interviews and systematic review	Evidence from 5 studies and 1 systematic review showed that babies, children and young people and their parents/carers report that meaningful communication requires additional time from healthcare staff but that this is a barrier in a busier healthcare setting such as inpatient wards. Busy times may mean that healthcare practitioners do not prioritise communication with children and young people, meaning that they then do not receive appropriate or efficient treatment. This was a particular concern for parents of children with communication difficulties. Conversely, settings such as community clinics present a calmer	Minor concerns[1]	No/very minor concerns	No/very minor concerns	No/very minor concerns	HIGH

<table>
<tr><th colspan="2">Study information</th><th rowspan="2">Description of theme or finding</th><th colspan="5">CERQUAL Quality assessment</th></tr>
<tr><th>No of studies</th><th>Design</th><th>Methodological limitations</th><th>Coherence of findings</th><th>Relevance of evidence</th><th>Adequacy of data</th><th>Overall confidence</th></tr>
<tr><td></td><td></td><td>environment that may be more conducive to longer consultations.

<i>‘I know that they are really difficult as they are busy, but if B was, and I hate using this word, but if B was a ‘normal 14 year old’ child then he would be demanding the Xbox or his food and wanting this and that and they would have to spend their time getting it for him [. . .] He is not getting their time [. . .]’ (Sharkey 2016, page 743, parental proxy)</i></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td colspan="8">Sub-theme 2.3: Importance of nurse involvement</td></tr>
<tr><td>3 (Curtis-Tyler 2012, Gibson 2010, Lowes 2015)</td><td>Age appropriate techniques, focus groups, free-text questionnaires, semi-structured interviews</td><td>Evidence from 3 studies showed that children and young people note the importance of nurses in day-to-day communication, preferring to speak with them about their medical needs instead of doctors. Patients knew nurses better and felt more comfortable with talking to them, describing them as 'kind' and 'helpful'. They also had more of a role in solving practical issues children may experience managing their conditions in their everyday lives. Conversely, doctors were seen to be less patient-centric. This could be due to the fact that they were seen as busier, spent less time on individual wards or concentrated on the physiological side of healthcare issues.</td><td>Moderate concerns[2]</td><td>Minor concerns[3]</td><td>No/very minor concerns</td><td>Minor concerns[4]</td><td>LOW</td></tr>
</table>

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
		'Child: 'The nurses talk to us.' *Interviewer: 'Would you like it if the doctor talked to you?'* *Child: '[No] …he talks like science [laughs], like rocket science!'* *Interviewer: 'What about [Diabetes specialist nurse] does she talk like rocket science?'* *Interviewer: 'She talks like us' (Curtis Tyler 2012, page 1305)*					
Sub-theme 2.4: Insensitivity							
5 (Gibson 2010, Heath 2014, Livesley 2013, Robards 2018, Wood 2018)	Age appropriate techniques, focus groups, semi-structured interviews and systematic review	Evidence from 4 studies and 1 systematic review showed that insensitivity, either perceived or intended, is a barrier to communication with healthcare staff for children and young people. Poor communication was cited as a source of insensitivity, causing annoyance, embarrassment and distress in children. Particularly, marginalised young people may be treated disrespectfully by healthcare staff. In order to minimise potential insensitivity, healthcare staff should be adept at managing the health issues that young people from marginalized backgrounds may experience e.g. mental health, trauma, and sexual minority issues. Culturally appropriate services, cultural sensitivity of staff, use of interpreters, and cultural concepts of health, including traditional	Minor concerns[1]	No/very minor concerns	No/very minor concerns	No/very minor concerns	HIGH

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
		indigenous therapeutic practices should be provided. *'About six doctors come in, in the morning and stand around you and stare at you and you just feel like hitting the lot of them because it's like they don't even need to be there really. I swear they just stand around and stare at you whilst one doctor examines you and you feel like crap and you look like crap. . .I just hated that' (Gibson 2010, page 1403)*					

1 Evidence was downgraded due to minor concerns about methodological limitations as per CASP qualitative checklist and CASP systematic review checklist
2 Evidence was downgraded due to moderate concerns about methodological limitations as per CASP qualitative checklist
3 Evidence was downgraded due to minor concerns regarding the coherence of findings
4 Evidence was downgraded for adequacy because studies together offered some rich data

Table 9: Evidence summary (GRADE-CERQual) for theme 3: Type of communication

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
Sub-theme 3.1: Creative and interactive							
2 (Boyden 2013, Sharkey 2016)	Semi-structured interviews	Evidence from 2 studies showed that children and their parents/carers report that creative and interactive modes help to communicate, especially hard-to-describe concepts such as unacceptable behaviour or a specific feeling. These can include playdough, puppets, games, yes/no cards. *'Participant: 'I used to get angry when the volcano came . . . it*	Serious concerns[1]	No/very minor concerns	No/very minor concerns	Moderate concerns[2]	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
		explodes when you're angry.' Interviewer: 'So when you get stressed you close your eyes and imagine a green field?' Participant: 'Yeah, or imagine being under the sea.'' (Boyden 2013, page 57)					
Sub-theme 3.2: Behavioural							
3 (Boyden 2013, Gibson 2010, Livesley 2013)	Age appropriate techniques, focus groups and semi-structured interviews	Evidence from 3 studies showed that behavioural cues are noticeable by children and young people, both in themselves and others. For example, excessive note taking during consultation means that healthcare staff are not fully concentrating on their patient. Additionally, they believed that healthcare professionals should be better at behavioural cues from children and young people. Examples include making eye contact when patients want to communicate, drawing their curtains when they don't, flinching when frightened and withdrawing when in pain. *'Erm, I didn't like that she writes it quick because I didn't understand very well' (Boyden 2013, page 57)*	Moderate concerns[3]	No/very minor concerns	No/very minor concerns	Minor concerns[4]	MODERATE
Sub-theme 3.3: Talking and listening							
5 (Boyden 2013, Curtis-Tyler 2012, Gibson 2010,	Age appropriate techniques, focus groups, semi-	Evidence from 4 studies and 1 systematic review showed that talking and listening are important factors of communication for children and young people and their parents/carers, although some	Minor concerns[5]	No/very minor concerns	No/very minor concerns	No/very minor concerns	HIGH

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
Robards 2018, Sharkey 2016)	structured interviews and systematic review	children were unable to describe why. The main reason given was that the effort to get to know children and young people as people helps to develop a relationship and a rapport. Using quiet moments and focusing on children and young people was a strong communication factor for parents of children with communication difficulties, possibly by increasing engagement. Barriers to talking to healthcare staff include the fear of being judged, especially for marginalised groups of young people who note the importance of having clinicians listen with empathy, being taken seriously and having views and experiences acknowledged by healthcare staff. *'To use those quiet times to actually gently probe and ask her [. . .] got information that when asked directly on a hospital round that they would not have got.' (Sharkey 2016, page 746)*					
Sub-theme 3.4: Written							
2 (Arnott 2012, Sharkey 2016)	Semi-structured interviews	Evidence from 2 studies showed that parents of babies, children and young people reported that written information would facilitate communication for both patients (for example, simple and reliable information on potential side effects of medication given along with prescription) and for healthcare staff	Moderate concerns[6]	No/very minor concerns	Moderate concerns[7]	Moderate concerns[2]	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**
		(for example, communication passports containing information on how children with communication difficulties like to be communicated with). *'We get sheets from the pharmacy department […] it is something I can refer to and I would much rather that it was given via the treatment centres than looking on the Internet because the Internet can be a horrible place' (Arnott 2012, page 8, parental proxy)*					

1 Evidence was downgraded due to serious concerns about methodological limitations as per CASP qualitative checklist
2 Evidence was downgraded for adequacy because studies together offered some rich data
3 Evidence was downgraded due to moderate concerns about methodological limitations as per CASP qualitative checklist
4 Evidence was downgraded for adequacy because study offered moderately rich data
5 Evidence was downgraded due to minor concerns about methodological limitations as per CASP qualitative checklist and CASP systematic review checklist
6 Evidence was downgraded for methodological limitations as per CASP qualitative checklist
7 Evidence was downgraded due to moderate concerns of the relevance of evidence as evidence contains views of parental proxies only

Table 10: Evidence summary (GRADE-CERQual) for theme 4: Consultations

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**
Sub-theme 4.1: First impressions							
3 (Boyden 2013, Heath 2014, Robards 2018)	Semi-structured interviews and systematic review	Evidence from 2 studies and 1 systematic review showed that a positive first impression of a healthcare practitioner can help to put children and young people at ease and build a better relationship. Positive physical characteristics include handshakes, clothing, high fives, and smiling. Positive	Minor concerns[1]	No/very minor concerns	Minor concerns[2]	No/very minor concerns	MODERATE

		personality characteristics include intuitiveness, humour, welcoming, open-minded and encouraging. *"People should be smiley and polite and nice to me." (Boyden 2013, page 55)*					
Sub-theme 4.2: With and without parents							
2 (Lowes 2015, Taylor 2010)	Free-text questionnaires and semi-structured interviews	Evidence from 2 studies showed that some children and young people wish to see their healthcare professional with their parents, believing that it helps to relax them as well as helping them understand the consultation more clearly. Other adolescents and children want the opportunity to see their healthcare professional by themselves. However, this can be done in addition to seeing their healthcare professional with their parents or carers. No quotes presented for this theme.	Serious concerns[3]	No/very minor concerns	No/ very minor concerns	Moderate concerns[4]	VERY LOW
Sub-theme 4.3: Actively promoting involvement							
4 (Gibson 2010, Heath 2014, Taylor 2010, Wood 2018)	Age appropriate techniques, focus groups and semi-structured interviews	Evidence from 4 studies showed that children and young people would like healthcare staff to involve them more in their consultations, taking a collaborative approach to their interactions. Younger children especially find that asking questions to healthcare staff is challenging for them. Healthcare staff characteristics that may help facilitate this include being non-judgmental, welcoming, open-minded, supportive and encouraging.	Minor concerns[1]	No/very minor concerns	No/very minor concerns	No/very minor concerns	HIGH

		'I'm sorry but even on this ward, I have a conversation with the doctors to know what's going on. I'm just meant to sit there and watch you talk about me' (Wood 2018, page 749)					
Sub-theme 4.4: Open and honest							
2 (Arnott 2012, Gibson 2010)	Age appropriate techniques, focus groups and semi-structured interviews	Evidence from 2 studies showed that older children and young people prefer open and honest communication, as long as the information being given is not overwhelming. Waiting for treatment and long-term consequences or medications were specifically mentioned by children with cancer. Some parents of young children (under 5 years old) with suspected adverse drug reactions reported that any uncertainty surrounding medical information can be unconsciously communicated as deceit by healthcare staff. However, parents of children with cancer reported that their clinicians were very open with the possibility of adverse drug reactions and what to do if they suspect one. This discrepancy might be due to the route of admission to the hospital (chronic condition vs. emergency department). *'they could tell me what was going to happen and when it will happen that would help, they just keep you waiting and they don't tell you why' (Gibson 2010, page 1402)*	Moderate concerns[5]	No/very minor concerns	No/very minor concerns	Moderate concerns[4]	LOW
Sub-theme 4.5: Age-appropriate							

4 (Boyden 2013, Gibson 2010, Taylor 2010, Wood 2018)	Age appropriate techniques, focus groups and semi-structured interviews	Evidence from 4 studies showed that, as children get older, they want to start to be more included in their care and the information that they receive. This should be a gradual process throughout childhood. Language is a part of this migration, with vocabulary evolving with the developmental age of children and young people. Additionally, communication aids should be tailored towards the age of the patient e.g. puppets and playdough for young children, books and drawings for older children. *'They knew that I was quite grown up, mentally, and I knew exactly what was going on, so then they started treating me like an adult, even though I was on a children's ward...I had proper conversations, and we proper talked about treatment as if I were an adult, and I really enjoyed that' (Wood 2018, page 750)*	Minor concerns[6]	No/very minor concerns	No/very minor concerns	No/very minor concerns	HIGH

1 Evidence was downgraded due to minor concerns about methodological limitations as per CASP qualitative checklist and CASP systematic review checklist
3 Evidence was downgraded due to minor concerns of the relevance of evidence as findings contains a systematic review which includes views of children and young people (up to the age of 24 years old), parents and health professionals
3 Evidence was downgraded due to serious concerns about methodological limitations as per CASP qualitative
4 Evidence was downgraded for adequacy because studies offered some rich data
5 Evidence was downgraded due to moderate concerns about methodological limitations as per CASP qualitative checklist
6 Evidence was downgraded due to minor concerns about methodological limitations as per CASP qualitative

Table 11: Evidence summary (GRADE-CERQual) for theme 5: Communication with parents

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**
Sub-theme 5.1: Utilising knowledge of their child							

3 (Arnott 2012, Heath 2014, Sharkey 2016)	Semi-structured interviews	Evidence from 3 studies showed that, for children under 5 and for those with communication difficulties, parents felt as though it was very important for healthcare staff to fully utilise their knowledge of their child and for them to share information on how their child. Some parents felt as though healthcare staff relied too heavily on their knowledge of their children, meaning that they were afraid to leave their children alone without an intermediary. On the other hand, other parents reported that their advice was not sought, or their concerns were dismissed too quickly before fully exploring the reasoning behind them. This led to dissatisfaction with the healthcare experiences. *'Just sit with us first, just sit and talk to us and explain [. . .] How does she show pain? Is this normal? How does she communicate? All those, and just sit down with us' (Sharkey 2016, page 745, parental proxy)*	Moderate concerns[1]	No/very minor concerns	Minor concerns[2]	Minor concerns[3]	LOW
Sub-theme 5.2: Support							
1 (Gibson 2010)	Age appropriate techniques, focus groups and semi-structured interviews	Evidence from 1 study showed that children recognised the stress that parents with a child in hospital may face and suggested that healthcare professionals should make a specific effort to support them emotionally. *"They could say, 'Why don't you hold her hand?' Mummy was just sitting there not knowing what to do" (Gibson 2010, page 1403)*	Moderate concerns[1]	No/very minor concerns	No/very minor concerns	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 relevance of evidence as 2 of the 3 included studies only contains views of parental proxies
3 Evidence was downgraded for adequacy because studies together offered some rich data
4 Evidence was downgraded for adequacy because studies together did not offer rich data

Appendix G – Economic evidence study selection

Economic evidence study selection for review question: How should healthcare staff communicate with babies, children and young people, and the parents or carers of babies and young children?

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

Appendix H – Economic evidence tables

Economic evidence tables for review question: How should healthcare staff communicate with babies, children and young people, and the parents or carers of babies and young children?

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

Appendix I – Economic evidence profiles

Economic evidence profiles for review question: How should healthcare staff communicate with babies, children and young people, and the parents or carers of babies and young children?

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

Appendix J – Economic analysis

Economic evidence analysis for review question: How should healthcare staff communicate with babies, children and young people, and the parents or carers of babies and young children?

No economic analysis was conducted for this review question.

Appendix K – Excluded studies

Excluded studies for review question: How should healthcare staff communicate with babies, children and young people, and the parents or carers of babies and young children?

Clinical studies

Table 12: Excluded studies and reasons for their exclusion

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

Study	Reason for Exclusion
Influence Decisions?, Medical decision making : an international journal of the Society for Medical Decision Making, 34, 567-582, 2014	
Abrines Jaume, N., Hoffman, J., Wolpert, M., Law, D., Wright, E., Shared decision making in child and adolescent mental health services, Neuropsychiatrie de l'Enfance et de l'Adolescence, 1), S294, 2012	Conference abstract
Abu-Rajab, K., Scoular, A., Church, S., Connell, J., Winter, A., Hart, G., Identifying opportunities for sexually transmitted infection prevention: Analysis of critical points in the care pathways of patients with gonorrhoea, International Journal of STD and AIDS, 20, 170-175, 2009	Population not in protocol - Age 15-66 years with data not presented separately for target population.
Achten, J., Parsons, N. R., Edlin, R. P., Griffin, D. R., Costa, M. L., A randomised controlled trial of total hip arthroplasty versus resurfacing arthroplasty in the treatment of young patients with arthritis of the hip joint, BMC musculoskeletal disorders, 11, 8, 2010	Published protocol
Ackner, S., Skeate, A., Patterson, P., Neal, A., Emotional abuse and psychosis: A recent review of the literature, Journal of Aggression, Maltreatment and Trauma, 22, 1032-1049, 2013	Phenomenon of interest not in protocol - Information too specific to child abuse and psychosis to be generalizable.
Actrn,, A randomised controlled trial of a group intervention for family and friends of youth with borderline personality disorder, Http://www.who.int/trialsearch/trial2.aspx?Trialid=actrn12616000304437, 2016	Ongoing trial - still recruitiung
Actrn,, A randomized controlled trial comparing knowledge transfer regarding preoperative information to children and parents: interactive web-based format (Anesthesia Web) vs. conventional brochure information, Http://www.who.int/trialsearch/trial2.aspx?Trialid=actrn12616000528459, 2016	Ongoing trial - still rectruiting
Actrn,, A study of the impact of treating seizures that can be seen and those that can be seen only on a brain monitor in newborn babies, who are having seizures or at high risk of seizures, Http://www.who.int/trialsearch/trial2.aspx?Trialid=actrn12611000327987, 2011	Ongoing trial - still recruiting
Actrn,, Action: pACT. Be Active. Online. A trial to promote physical activity in young people with cystic fibrosis, Http://www.who.int/trialsearch/trial2.aspx?Trialid=actrn12617001009303, 2017	Ongoing trial - still recruiting
Actrn,, HARTI HAUORA TAMARIKI A Randomised Controlled Trial of an Opportunistic, Holistic and Family Centred Approach to Improving Outcomes for Hospitalised Children and their Families, Http://www.who.int/trialsearch/trial2.aspx?Trialid=actrn12618001079235, 2018	Ongoing trial - still recruiting
Actrn,, Mitii ABI: "Move it to improve it": a randomised trial of novel web-based intervention for children with acquired brain injury, Http://www.who.int/trialsearch/trial2.aspx?Trialid=actrn12613000403730, 2013	Ongoing trial - still recruiting
Actrn,, Patient navigators in children with chronic kidney disease, Http://www.who.int/trialsearch/trial2.aspx?Trialid=actrn12618001152213, 2018	Ongoing trial - still recruiting
Adams, C., Lockton, E., Freed, J., Gaile, J., Earl, G., McBean, K., Nash, M., Green, J., Vail, A., Law, J., The Social Communication Intervention Project: a randomized controlled trial of the effectiveness of speech and language therapy for school-age children who have pragmatic and social	Study design not in protocol - No qualitative data.

Study	Reason for Exclusion
communication problems with or without autism spectrum disorder, International journal of language & communication disorders / Royal College of Speech & Language Therapists, 47, 233-244, 2012	
Adams, C., Lockton, E., Gaile, J., Earl, G., Freed, J., Implementation of a manualized communication intervention for school-aged children with pragmatic and social communication needs in a randomized controlled trial: the Social Communication Intervention Project, International journal of language & communication disorders / Royal College of Speech & Language Therapists, 47, 245-256, 2012	Study design not in protocol - No qualitative data.
Adams, N., Churchill, R., Eve, E., Chronic widespread pain in adolescents: A primary care based study, European Journal of Pain Supplements, 5 (1), 146, 2011	Conference abstract
Adewumi, A. D., Hollingworth, S. A., Maravilla, J. C., Connor, J. P., Alati, R., Prescribed Dose of Opioids and Overdose: A Systematic Review and Meta-Analysis of Unintentional Prescription Opioid Overdose, CNS Drugs, 32, 101-116, 2018	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Aebi, M., Kuhn, C., Banaschewski, T., Grimmer, Y., Poustka, L., Steinhausen, H. C., Goodman, R., The contribution of parent and youth information to identify mental health disorders or problems in adolescents, Child and adolescent psychiatry and mental health, 11 (1) (no pagination), 2017	Study design not in protocol - No qualitative data.
Aebi, Marcel, Kuhn, Christine, Metzke, Christa Winkler, Stringaris, Argyris, Goodman, Robert, Steinhausen, Hans-Christoph, The use of the development and well-being assessment (DAWBA) in clinical practice: A randomized trial, European child & adolescent psychiatry, 21, 559-567, 2012	Study design not in protocol - No qualitative data.
Ager, A., Zimmerman, C., Unlu, K., Rinehart, R., Nyberg, B., Zeanah, C., Hunleth, J., Bastiaens, I., Weldy, A., Bachman, G., Blum, A. B., Strottman, K., What strategies are appropriate for monitoring children outside of family care and evaluating the impact of the programs intended to serve them?, Child Abuse & Neglect, 36, 732-42, 2012	Population of included studies not in protocol. Included studies checked for inclusion.
Agnew, T., Shared experience, Nursing Standard, 26, 22-4, 2012	Narrative article, not study results
Agrawal, S., Morris, K., Whitehouse, W. P., Parent's views about drug trials in children with refractory convulsive status epilepticus, Developmental Medicine and Child Neurology, 1), 16, 2009	Conference abstract
Agwu, C. J., Scanlon, J., McCrea, K., Raffeeq, P., Kershaw, M., Broomhead, S., Eminson, J., Peer review: A tool to improve paediatric diabetes services, Hormone Research in Paediatrics, 1), 213, 2013	Conference abstract
Ahmed, M., Boyd, C., Vavilikolanu, R., Rafique, B., Visual symptoms and childhood migraine: Qualitative analysis of duration, location, spread, mobility, colour and pattern, Cephalalgia, 38, 2017-2025, 2018	Study design not in protocol - No qualitative data.
Ahmed, S. A., Arasu, A., Another ethical dilemma in neonatology, Archives of Disease in Childhood, 96, A72, 2011	Conference abstract
Ahmed, S. A., Arasu, A., Ethical dilemma in neonatology, Archives of Disease in Childhood, 97, A300, 2012	Conference abstract
Ahmed, S., Ihe, C., Findings from a pre-clinic questionnaire given prior consultation at an NHS paediatric diabetes outpatient service in England-the patient's perspective: A survey of patient/carer experience of a paediatric diabetes	Conference abstract

Study	Reason for Exclusion
outpatient service, Pediatric Diabetes, 17 (Supplement 24), 127-128, 2016	
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
Ainsworth, S., Raiising awareness of invisible illnesses in schools and education, Annals of the rheumatic diseases, 77 (Supplement 2), 10, 2018	Conference abstract
Akhtar, M. A., Honeyman, C., Aziz, F., Greenough, C., Kalyan, R., Hekal, W., The sky's the limit: Raising the quality and scope of communication for children with scoliosis and their families using digital and social media, British journal of neurosurgery, 30 (2), 177, 2016	Conference abstract
Al Maghaireh, Dua'a Fayiz, Abdullah, Khatijah Lim, Chan, Chong Mei, Piaw, Chua Yan, Al Kawafha, Mariam Mofleh, Systematic review of qualitative studies exploring parental experiences in the Neonatal Intensive Care Unit, Journal of Clinical Nursing, 25, 2745-2756, 2016	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Aladangady, N., Shaw, C., Gallagher, K., Stokoe, E., Marlow, N., Short-Term outcome of treatment limitation discussions for newborn infants, a multicentre prospective observational cohort study, Archives of Disease in Childhood: Fetal and Neonatal Edition, 102, F104-F109, 2017	Study design not in protocol - No qualitative data.
Alan, D., Woolner, A. F., Skinner, R., King, D., Evaluation of infection control advice for patients at risk of chemotherapy-induced neutropaenia in two paediatric oncology centres in south africa and the United Kingdom, Pediatric Blood and Cancer, 57 (5), 846-847, 2011	Conference abstract
Alderson, H., Brown, R., Copello, A., Kaner, E., Tober, G., Lingam, R., McGovern, R., The key therapeutic factors needed to deliver behavioural change interventions to decrease risky substance use (drug and alcohol) for looked after children and care leavers: a qualitative exploration with young people, carers and front line workers, BMC medical research methodology, 19, 38â□□, 2019	Population not in protocol - Age 15-19 years with data not presented separately for target population
Alderson, H., Brown, R., Smart, D., Lingam, R., Dovey-Pearce, G., 'You've come to children that are in care and given us the opportunity to get our voices heard': The journey of looked after children and researchers in developing a Patient and Public Involvement group, Health expectations : an international journal of public participation in health care and health policy., 21, 2019	Phenomenon of interest not in protocol - No themes relating to communication with healthcare staff
Alexakis, C., Davies, G., Stephens, J., Clark, S., Rogers, S., Poullis, A., Perspectives and attitudes of young patients with inflammatory bowel disease: Symptoms, burden of disease and communication with their healthcare professionals, Frontline Gastroenterology, 5, 197-202, 2014	Study design not in protocol - No qualitative data
Alexakis, C., Nash, A., Lloyd, M., Brooks, F., Lindsay, J. O., Poullis, A., Inflammatory bowel disease in young patients: challenges faced by black and minority ethnic communities in the UK, Health & Social Care in the Community, 23, 665-672, 2015	Population and phenomenon of interest not in protocol - No themes relating to communication with healthcare staff in participants < 18 years
Alexander, R., Walter, L. K., Progressive techniques to effectively prepare children for radiotherapy: A supportive framework combining informative films with a miniature working	Conference abstract

Study	Reason for Exclusion
model LINAC, Pediatric Blood and Cancer, 62 (Supplement 4), S209, 2015	
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
Al-Gamal, Ekhlas, Long, Tony, The MM-CGI Cerebral Palsy: Modification and pretesting of an instrument to measure anticipatory grief in parents whose child has cerebral palsy, Journal of clinical nursing, 23, 1810-1819, 2014	Study design not in protocol - No qualitative data.
Al-Harthy, Z. S., Cowling, J. P., Mann, G. K., Salama, M., Medical intervention for children with medical complexity (MICMAC), Archives of disease in childhood, 3), A127-A128, 2015	Conference abstract
Ali, Nasreen, McLachlan, Niel, Kanwar, Shama, Randhawa, Gurch, Pakistani young people's views on barriers to accessing mental health services, International Journal of Culture and Mental Health, 10, 33-43, 2017	Phenomenon of interest not in protocol - No themes relating to communication with healthcare staff
Alifrangis, C., Koizia, L., Rozario, A., Rodney, S., Harrington, M., Somerville, C., Peplow, T., Waxman, J., The experiences of cancer patients, Qjm, 104, 1075-81, 2011	Population not in protocol - People aged ≥ 21 years.
Aljafari, A. K., Scambler, S., Gallagher, J. E., Hosey, M. T., Parental views on delivering preventive advice to children referred for treatment of dental caries under general anaesthesia: A qualitative investigation, Community dental health, 31, 75-79, 2014	Unclear population - Views of parents with no way of discerning age of children.
Allcock, D., Smith, K., Exploring parent views of community matrons, Nursing Times, 110, 21-23, 2014	Unclear population - Questionnaires sent to parents with no way of discerning child age.
Allen, D., Gillen, E., Rixson, L., The Effectiveness of Integrated Care Pathways for Adults and Children in Health Care Settings: A Systematic Review, JBI Library of Systematic Reviewis, 7, 80-129, 2009	Study design not in protocol - No qualitative data.
Allen, D., Scarinci, N., Hickson, L., The Nature of Patient- and Family-Centred Care for Young Adults Living with Chronic Disease and their Family Members: A Systematic Review, International Journal of Integrated Care [Electronic Resource]Int J Integr Care, 18, 14, 2018	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Allen, Kimberly A., Parental decision-making for medically complex infants and children: An integrated literature review, International Journal of Nursing Studies, 51, 1289-1304, 2014	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Almunef, M., Mason, J., Curtis, C., Jalal, Z., Management of chronic illness in young people aged 10-24 years: A systematic review to explore the role of primary care pharmacists, Archives of Disease in Childhood, 104, 2019	Conference abstract
Almunef, M., Mason, J., Curtis, C., Jalal, Z., The role of primary care pharmacist in the management of chronic illnesses in young people aged 10-24 years: A systematic review, International Journal of Pharmacy Practice, 27, 48-49, 2019	Poster abstract
Alvi, S., Priestley, J., Whitehead, A., Walker, J., Mushtaq, T., The impact on families of receiving a diagnosis of congenital hypothyroidism, Hormone Research in Paediatrics, 1), 549, 2015	Conference abstract
Al-Zawaadi, M., Kayyali, R., Kelly, P., Evaluation of a pharmacist-led health intervention in a primary school,	Conference abstract

Study	Reason for Exclusion
International journal of pharmacy practice, 27 (Supplement 1), 8-9, 2019	
Ambrogi, V., Tezenas Du Montcel, S., Collin, E., Coutaux, A., Bourgeois, P., Bourdillon, F., Care-related pain in hospitalized patients: Severity and patient perception of management, European journal of pain (united kingdom), 19, 313-321, 2015	Study design not in protocol - No qualitative data.
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	Phenomenon of interest not in protocol - Information too specific to psychological treatment for depression/anxiety to be generalizable.
Ames, K., Rennick, J., & Baillargeon, S., A qualitative interpretive study exploring parents' perception of the parental role in the paediatric intensive care unit., Intensive & Critical Care Nursing, 27, 143-150, 2011	Population not in protocol - Views of parents of children 0-17 years with data not presented separately for target population.
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	Narrative review
Amsalem, D., Hasson-Ohayon, I., Gothelf, D., Roe, D., Subtle ways of stigmatization among professionals: The subjective experience of consumers and their family members, Psychiatric rehabilitation journal, 41, 163-168, 2018	Unclear population - No way of identifying age of participant
Anderson, C., Lupfer, A., Shattuck, P. T., Barriers to receipt of services for young adults with autism, Pediatrics, 141, S300-S305, 2018	Population not in protocol - Young adults with autism who had left high school in the past 15 years.
Anderson, C., Roy, T., Patient experiences of taking antidepressants for depression: A secondary qualitative analysis, Research in Social and Administrative Pharmacy, 9, 884-902, 2013	Population and study design not in protocol - No qualitative data for under 18s
Anderson, E. S., Ford, J. S., Learning to listen: A patient led innovation to improve student's communication with patient feedback, Medical education, supplement, 2), 118-119, 2011	Conference abstract
Angelopoulou, M. V., Oulis, C. J., Kavvadia, K., School-based oral health-education program using experiential learning or traditional lecturing in adolescents: a clinical trial, International dental journal, 64, 278-284, 2014	Study design not in protocol - No qualitative data.
Angold, A., Erkanli, A., Copeland, W., Goodman, R., Fisher, P. W., Costello, E. J., Psychiatric diagnostic interviews for children and adolescents: A comparative study, Journal of the American Academy of Child and Adolescent Psychiatry, 51, 506-517, 2012	Study design not in protocol - No qualitative data.
Anonymous,, The development and analysis of feedback from a pilot chronic pain group at the Royal Manchester Children's Hospital, Rheumatology (united kingdom), 56 (Supplement 7), vii30, 2017	Conference abstract
Ansmann, L., Kowalski, C., Ernstmann, N., Ommen, O., Pfaff, H., Patients' perceived support from physicians and the role of hospital characteristics, International Journal for Quality in Health Care, 24, 501-8, 2012	Study design not in protocol - No qualitative data.
Antao, V., Evaluation of post-diagnostic support to families and children with autism spectrum disorder, Developmental medicine and child neurology, 4), 69, 2010	Conference abstract

Study	Reason for Exclusion
Anttila, A., Rappaport, D. I., Tijerino, J., Zaman, N., Sharif, I., Interpretation Modalities Used on Family-Centered Rounds: Perspectives of Spanish-Speaking Families, Hospital Pediatrics, 7, 492-498, 2017	Unclear population - Views of parents with age of children not reported.
Arai, L., Bettany-Saltikov, J., Hamilton, S., Findings from a small-scale, exploratory content analysis of information provided to AIS patients and their parents from NHS Scoliosis Hospital Clinics, Scoliosis. Conference: 9th International Conference on Conservative Management of Spinal Deformities SOSORT, 8, 2012	Conference abstract
Archibald, Mandy, Scott, Shannon, Hartling, Lisa, Mapping the waters: A scoping review of the use of visual arts in pediatric populations with health conditions, Arts & Health: An International Journal of Research, Policy and Practice, 6, 5-23, 2014	Scoping review. Included studies checked for inclusion.
Arheiam, A., Albadri, S., Laverty, L., Harris, R., Reasons for low adherence to diet-diaries issued to pediatric dental patients: A collective case study, Patient Preference and Adherence, 12, 1401-1411, 2018	Population and study design not in protocol - No qualitative data for participants under 18 years
Arheiam, A., Brown, S. L., Burnside, G., Higham, S. M., Albadri, S., Harris, R. V., The use of diet diaries in general dental practice in England, Community dental health, 33, 267-273, 2016	Population not in protocol - Views of healthcare professionals only.
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 in protocol - No themes relating to communication with healthcare staff
Armoiry, Xavier, Sturt, Jackie, Phelps, Emma Elizabeth, Walker, Clare-Louise, Court, Rachel, Taggart, Frances, Sutcliffe, Paul, Griffiths, Frances, Atherton, Helen, Digital clinical communication for families and caregivers of children or young people with short- or long-term conditions: Rapid review, Journal of Medical Internet Research Vol 20(1), 2018, ArtID e5, 20, 2018	Population of included studies not in protocol. Included studies checked for inclusion.
Armoogum, J., Cathcart, E., Cazenove, E., Knott, C., Mathambo, N., Tompsitt, L., Vevers, J., Wall, M., Bridging the gap: Giving information to young people undergoing bone marrow transplants using modern media, Bone Marrow Transplantation, 1), S421, 2011	Conference abstract
Arnab, Sylvester, Brown, Katherine, Clarke, Samantha, Dunwell, Ian, Lim, Theodore, Suttie, Neil, Louchart, Sandy, Hendrix, Maurice, de Freitas, Sara, The development approach of a pedagogically-driven serious game to support Relationship and Sex Education (RSE) within a classroom setting, Computers & Education, 69, 15-30, 2013	Description of health education tool development
Arnott, J., Nunn, A. J., Mannix, H., Peak, M., Pirmohamed, M., Smyth, R. L., Turner, M. A., Young, B., Communicating with parents following a suspected adverse drug reaction in a child: Who says what and when?, Archives of disease in childhood, 3), A10-A11, 2015	Conference abstract
Arnott, J., Turner, M. A., Hesselgreave, H., Nunn, A. J., Peak, M., Pirmohamed, M., Smyth, R. L., Young, B., Parents' experiences of adverse drug reations in children: Qualitative study, Pharmacoepidemiology and Drug Safety, 21 (1), 112, 2012	Conference abstract

Study	Reason for Exclusion
Aronson, P. L., Shapiro, E. D., Niccolai, L. M., Fraenkel, L., Shared Decision-Making with Parents of Acutely Ill Children: A Narrative Review, Academic pediatrics, 18, 3-7, 2018	Narrative review. Included studies checked for possible inclusion.
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	Population of included studies not in protocol. Included studies checked for inclusion.
Aslam, A., Children's preference in selecting an emollient of their choice, British journal of dermatology, 1), 116, 2009	Conference abstract
Astbury, R., Shepherd, A., Cheyne, H., Working in partnership: the application of shared decision-making to health visitor practice, Journal of Clinical Nursing, 26, 215-224, 2017	Phenomenon of interest not in protocol - No themes relating to communication with healthcare staff
Aston, Hermione J., Lambert, Nathan, Young people's views about their involvement in decision-making, Educational Psychology in Practice, 26, 41-51, 2010	Setting not in protocol - Shared decision making in education only
Aston, J., Terry, D., Nusgen, U., Champaneri, N., Prescribed antimicrobial therapy: What parents/carers are told and what they would like to know, Archives of Disease in Childhood. Conference: 18th Neonatal and Paediatric Pharmacists Group, NPPG Annual Conference. Liverpool United Kingdom. Conference Publication:, 98, 2013	Conference abstract
Aston, J., Wilson, K. A., Terry, D. R. P., The treatment-related experiences of parents, children and young people with regular prescribed medication, International journal of clinical pharmacy, 41, 113-121, 2019	Unclear population - Views of parents with no way of discerning age of children
Aston, J., Wilson, K., Terry, D., Starting a new medicine study, Archives of disease in childhood, 101 (9), A28, 2016	Conference abstract
Atkins, E., Colville, G., John, M., Finding the way to a 'new normal': Families' recovery in the year after a paediatric intensive care admission, Pediatric critical care medicine, 1), A3-A4, 2011	Conference abstract
Aubugeau-Williams, P., Brierley, J., Consent in paediatric intensive care: A qualitative study of parental & professional views, Archives of Disease in Childhood. Conference: Great Ormond Street Hospital Conference, GOSH, 102, 2017	Conference abstract
Audrey, S., Batista Ferrer, H., Ferrie, J., Evans, K., Bell, M., Yates, J., Roderick, M., Macleod, J., Hickman, M., Impact and acceptability of self-consent procedures for the school-based human papillomavirus vaccine: A mixed-methods study protocol, BMJ open, 8 (3) (no pagination), 2018	Published protocol
Azevedo, Avds, Lanconi, A. C. Junior, Crepaldi, M. A., Nursing team, family and hospitalized child interaction: an integrative review, Ciencia & Saude ColetivaCienc, 22, 3653-3666, 2017	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Azzopardi, L. M., Serracino-Inglott, A., Zarb-Adami, M., Portanier, F. S., Evaluation of patient information leaflets for non-prescription medicines, International journal of pharmacy practice, 2), 81-82, 2010	Conference abstract
Babbage, C., Jackson, G. M., Nixon, E., Desired Features of a Digital Technology Tool for Self-Management of Well-Being in a Nonclinical Sample of Young People: Qualitative Study, JMIR Mental Health, 5, e10067, 2018	Phenomenon of interest not in protocol - No themes relating to communication with healthcare staff
Badri, P., Saltaji, H., Flores-Mir, C., Amin, M., Factors affecting children's adherence to regular dental attendance: a systematic	Population of included studies not in protocol. Included studies checked for inclusion.

Study	Reason for Exclusion
review, Journal of the American Dental Association (1939), 145, 817-828, 2014	
Bailey, J. V., Webster, R., Hunter, R., Freemantle, N., Rait, G., Michie, S., Estcourt, C., Anderson, J., Gerressu, M., Stephenson, J., et al.,, The Men's Safer Sex (MenSS) trial: protocol for a pilot randomised controlled trial of an interactive digital intervention to increase condom use in men, BMJ open, 5, e007552, 2015	Published protocol
Baird, Jennifer, Davies, Betty, Hinds, Pamela S., Baggott, Christina, Rehm, Roberta S., What impact do hospital and unit-based rules have upon patient and family-centered care in the pediatric intensive care unit?, Journal of pediatric nursingJ Pediatr Nurs, 30, 133-142, 2015	Population not in protocol - Age >18 years.
Baker, Erika, Baibazarova, Eugenia, Ktistaki, Georgia, Shelton, Katherine H., van Goozen, Stephanie H., Development of fear and guilt in young children: Stability over time and relations with psychology, Development and psychopathology, 24, 833-845, 2012	Study design not in protocol - No qualitative data.
Balato, N., Megna, M., Di Costanzo, L., Balato, A., Ayala, F., Educational and motivational support service: a pilot study for mobile-phone-based interventions in patients with psoriasis, British journal of dermatology, 168, 201â□□205, 2013	Study design not in protocol - No qualitative data.
Bancroft, V., Ganesan, V., Pistrang, N., Murphy, T., How adolescents and their parents understand and manage paediatric stroke, Developmental Medicine and Child Neurology, 3), 14-15, 2010	Conference abstract
Banks, J., Cramer, H., Sharp, D. J., Shield, J. P., Turner, K. M., Identifying families' reasons for engaging or not engaging with childhood obesity services: a qualitative study, Journal of child health care, 18, 101â□□110, 2014	Population not in protocol - Parental views of children >5 years old. Children present in some interviews but no way of identifying which themes used data from them
Barber, S., Bekker, H., Marti, J., Pavitt, S., Khambay, B., Meads, D., Development of a Discrete-Choice Experiment (DCE) to Elicit Adolescent and Parent Preferences for Hypodontia Treatment, Patient, 12, 137-148, 2019	Description of questionnaire development with no qualitative data presented.
Barber, S., Pavitt, S., Meads, D., Khambay, B., Bekker, H., Assessment of information resources for people with hypodontia, Bdj Open, 4, 18001, 2018	Population not in protocol - Views of healthcare professionals only.
Barber, S., Pavitt, S., Meads, D., Khambay, B., Bekker, H., Can the current hypodontia care pathway promote shared decision-making?, Journal of orthodontics, 46, 126-136, 2019	Phenomenon of interest not in protocol - No themes relating to communication with healthcare staff
Brodsgaard, A., Pedersen, J. T., Larsen, P., Weis, J., Parents' and nurses' experiences of partnership in neonatal intensive care units: A qualitative review and meta-synthesis, Journal of Clinical Nursing, 28, 3117-3139, 2019	Phenomenon of interest not in protocol - No themes relating to communication with healthcare staff
Brown, Freddy Jackson, Guvenir, Jane, The experiences of children with learning disablilities, their carers and staff during a hospital admission, British Journal of Learning Disabilities, 37, 110-115, 2009	Phenomenon of interest not in protocol - No themes relating to communication with healthcare staff
Byron et al, "You learn from each otherâ□□: LGBTIQ Young Peopleâ□™s Mental Health Help-seeking and the RAD Australia Online Directory. , 2016	Country: Australia

Study	Reason for Exclusion
Cameron, M. A., Schleien, C. L., Morris, M. C., Parental presence on pediatric intensive care unit rounds, J Pediatr, 155, 522-8, 2009	Country: USA
Can text messages increase safer sex behaviours in young people? Intervention development and pilot randomized controlled trial, Health technology assessment. 20 (57) (pp 1-81), 2016. Date of publication: august 2016., 2016	Phenomenon of interest not in protocol - No themes relating to communication with healthcare staff
Chaturvedi, Surabhi, Accessing psychological therapies: Homeless young people's views on barriers and facilitators, Counselling and Psychotherapy Research, 16, 54-63, 2016	Population not in protocol - Age 16-25 years with data not presented separately for target population.
Coker, T. R., Sareen, H. G., Chung, P. J., Kennedy, D. P., Weidmer, B. A., Schuster, M. A., Improving access to and utilization of adolescent preventive health care: the perspectives of adolescents and parents, J Adolesc Health, 47, 133-42, 2010	Country: USA
Comp, D., Improving parent satisfaction by sharing the inpatient daily plan of care: an evidence review with implications for practice and research, Pediatric nursing, 37, 237-242, 2011	Population of included studies not in protocol. Included studies checked for inclusion.
Coyne, I., Amory, A., Kiernan, G., Gibson, F., Children's participation in shared decision-making: children, adolescents, parents and healthcare professionals' perspectives and experiences, Eur J Oncol Nurs, 18, 273-80, 2014	Country: Ireland
Coyne, I., Children, parents, and healthcare professional’s perspectives on children’s participation in shared decision making, European Journal of Oncology, 15, 275-276, 2011	Conference abstract
Coyne, I., Gallagher, P., Participation in communication and decision-making: children and young people's experiences in a hospital setting, J Clin Nurs, 20, 2334-43, 2011	Country: Ireland
Coyne, I., Kirwan, L., Ascertaining children's wishes and feelings about hospital life, J Child Health Care, 16, 293-304, 2012	Country: Ireland
Crowley, Making it matter: improving the health of homeless young people., 2012	Population not in protocol - Age 16-25 with data not presented separately for target population.
Daley, A. M., Polifroni, E. C., Sadler, L. S., "Treat Me Like a Normal Person!" A Meta-Ethnography of Adolescents' Expectations of Their Health Care Providers, Journal of pediatric nursing, 36, 70-83, 2017	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Daniels, Karen, Cultural agents creating texts: A collaborative space adventure, Literacy, 48, 103-111, 2014	Phenomenon of interest not in protocol - No themes relating to communication with healthcare staff
Davey, A., Asprey, A., Carter, M., Campbell, J. L., Trust, negotiation, and communication: young adults' experiences of primary care services, BMC family practice, 14, 202, 2013	Population not in protocol - Participants aged 18-25 years.
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.
Davies, E. B., Buchanan, H., An exploratory study investigating children's perceptions of dental behavioural management techniques, International journal of paediatric dentistry, 23, 297-309, 2013	Study design not in protocol - No qualitative data.

Study	Reason for Exclusion
Davies, Karen E., Marshall, Julie, Brown, Laura J., Goldbart, Juliet, Co-working: Parents' conception of roles in supporting their children's speech and language development, Child Language Teaching and Therapy, 33, 171-185, 2017	Phenomenon of interest not in protocol - No themes relating to communication with healthcare staff
Davies-House, A., Ball, N., Balmer, C., Meeting and greeting in the clinical setting - are we doing what patients want?, British dental journal, 222, 457-461, 2017	Study design not in protocol - No qualitative data.
Day, E. R., Jones, L., Langner, R., Stirling, L. C., Hough, R., Bluebond-Langner, M., Teenagers' perspectives on their decisional involvement in the context of interactions with healthcare professionals, Archives of disease in childhood, 102 (Supplement 1), A2, 2017	Conference abstract
Day, Emma, Jones, Louise, Langner, Richard, Bluebond-Langner, Myra, Current understanding of decision-making in adolescents with cancer: A narrative systematic review, Palliative Medicine, 30, 920-934, 2016	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
de Anstiss and Ziaian, Mental health help-seeking and refugee adolescents: Qualitative findings from a mixed-methods investigation, Aust Psychol, 45, 29-37, 2010	Country: Australia
De Vries MC, Bresters D, Kaspers GJL, et al, What constitutes the best interest of a child? Views of parents, children, and physicians in a pediatric oncology setting., AJOB Prim Res, 4, 1-10, 2012	Country: The Netherlands
Dean, L. A., An exploration of the experiences of young people who have been nursed on adult wards, Archives of disease in childhood, 1), A76, 2012	Conference abstract
Dean, L., Black, S., Exploring the experiences of young people nursed on adult wards, British journal of nursing (Mark Allen Publishing), 24, 229-236, 2015	Phenomenon of interest not in protocol - No themes relating to communication with healthcare staff
Deldar, K., Bahaadinbeigy, K., Tara, S. M., Teleconsultation and clinical decision making: A systematic review, Acta Informatica Medica, 24, 286-292, 2016	Population not in protocol - Focus on medical professional views
DeLemos, D., Chen, M., Romer, A., Brydon, K., Kastner, K., Anthony, B., Hoehn, K. S., Building trust through communication in the intensive care unit: HICCC, Pediatric Critical Care Medicine, 11, 378-384, 2010	Unclear population - Population is parents with no way of ascertaining age of child.
Dewlett, S., Polychronakis, T., Ng, G. Y. T., Look who's talking: How well are we communicating with parents in the neonatal unit? A patient survey, Intensive Care Medicine, 37, S419-S420, 2011	Conference abstract
Dhital, R., Whittlesea, C. M., Norman, I. J., Milligan, P., Community pharmacy service users' views and perceptions of alcohol screening and brief intervention, Drug and Alcohol Review, 29, 596-602, 2010	Unclear population - Age of respondents not given.
Diagnosis, assessment, and treatment of childhood eczema in primary care: crosssectional study, BJGP open, 1, 2017	Study design not in protocol - No qualitative data.
Dibley, L., Czuber-Dochan, W., Duncan, J., Artom, M., Burch, J., Wade, T., Verjee, A., Cann, D., Warusavitarne, J., Norton, C., Decision-making about emergency and planned stoma surgery for IBD: A qualitative exploration of patient and clinician perspectives, Journal of Crohn's and Colitis, 11 (Supplement 1), S487-S488, 2017	Conference abstract
Dickens, G., Picchioni, M., A systematic review of the terms used to refer to people who use mental health services: user	Population of included studies not in protocol. Included studies checked for inclusion.

Study	Reason for Exclusion
perspectives, The International journal of social psychiatry, 58, 115-122, 2012	
Dodoo, T., Murhad, Y., Batchelor, H. K., Stirling, H. F., Supporting young people to take their medication, Archives of Disease in Childhood, 102, A51, 2017	Conference abstract
Donnellan, D., Murray, C., Harrison, J., An investigation into adolescents' experience of cognitive behavioural therapy within a child and adolescent mental health service, Clinical Child Psychology and Psychiatry, 18, 199-213, 2013	Phenomenon of interest not in protocol - Information too specific to cognitive behaviour therapy to be generalizable.
Dovey-Pearce, Gail, Price, Christine, Wood, Helen, Scott, Tracy, Cookson, Jennifer, Corbett, Sally, Young people (13 to 21) with disabilities in transition from childhood to adulthood: An exploratory, qualitative study of their developmental experiences and health care needs, Educational and Child Psychology, 29, 86-100, 2012	Population not in protocol - Age 13-21 years (82% over 16) with results not presented separately for target population.
Downing, J., Gleeson, H., Clayton, P. E., Davis, J. R. E., Dimitri, P., Wales, J., Young, B., Callery, P., Communication with young people in paediatric and adult endocrine consultations: an intervention development and feasibility study, BMC Endocrine Disorders, 17, 33, 2017	Phenomenon of interest not in protocol - Information too specific to forensic interview protocol aids to be generalizable.
Drake, E. K., Urquhart, R., The Experiences of Young Adults Living with Metastatic/Advanced Cancer: A Scoping Review, Journal of Adolescent and Young Adult Oncology, 9, 145-156, 2020	Scoping review. Included studies checked for inclusion.
Drewett, O., Hann, G., Price, N., Tipper, C., Devereux, E., A qualitative study to explore the use of the RCPCH epilepsy passport, Archives of disease in childhood, 102 (Supplement 1), A150, 2017	Conference abstract
Duckett, Paul, Kagan, Carolyn, Sixsmith, Judith, Consultation and participation with children in healthy schools: Choice, conflict and context, American Journal of Community Psychology, 46, 167-178, 2010	Phenomenon of interest not in protocol - Educational experiences of children and young adults.
Dugdale, E., Gerrard, G., Priestley, L., Mariappan, L., Choong, E. S., Follow up of low risk thyroid cancer patients by specialist nurse phone consultations rather than via clinic visits, European Thyroid Journal, 1), 165-166, 2014	Conference abstract
Dunne, A., Carolan, R., Swords, L., Fortune, G., Patient and family perspectives of paediatric psychogenic non-epileptic seizures: A systematic review, 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
Edbrooke-Childs, J., Edridge, C., Averill, P., Delane, L., Hollis, C., Craven, M. P., Martin, K., Feltham, A., Jeremy, G., Deighton, J., Wolpert, M., A Feasibility Trial of Power Up: Smartphone App to Support Patient Activation and Shared Decision Making for Mental Health in Young People, JMIR MHealth and UHealth, 7, e11677, 2019	Phenomenon of interest not in protocol - No themes relating to communication with healthcare staff
Edbrooke-Childs, J., Jacob, J., Argent, R., Patalay, P., Deighton, J., Wolpert, M., The relationship between child- and parent-reported shared decision making and child-, parent-, and clinician-reported treatment outcome in routinely collected child mental health services data, Clinical Child Psychology & Psychiatry, 21, 324-38, 2016	Study design not in protocol - No qualitative data.

Study	Reason for Exclusion
Edwards, M., Lawson, C., Rahman, S., Conley, K., Phillips, H., Uings, R., What does quality healthcare look like to adolescents and young adults? Ask the experts!, Clinical Medicine, Journal of the Royal College of Physicians of London, 16, 146-151, 2016	Population not in protocol - Age of participants 17-25 with data not presented separately for target population.
Egbunike, J. N., Shaw, C., Porter, A., Button, L. A., Kinnersley, P., Hood, K., Bowden, S., Bale, S., Snooks, H., Edwards, A., Streamline triage and manage user expectations: lessons from a qualitative study of GP out-of-hours services, British Journal of General Practice, 60, e83-97, 2010	Unclear population - No way of determining age source of data.
El Miedany, Y., Lotfy, H., El Aroussy, N., Mekkawy, D., Nasef, S. I., Hassan, W., El Deriny, G., Farag, Y., Eissa, M., Almedany, S., El Gaafary, M., Facilitating patient centred care: The development of illustrated multidimensional patient reported outcome measure for children with juvenile idiopathic arthritis, Annals of the rheumatic diseases, 77 (Supplement 2), 502, 2018	Conference abstract
Elwell, L., Grogan, S., Coulson, N., Adolescents living with cancer: the role of computer-mediated support groups, Journal of health psychology, 16, 236-248, 2011	Unclear population - Age of study population not reported.
Ely, B., Chen Lim, M., Becker, E., Wilson Jr, B., The pain experience of hospitalized youth: Assessment and management preferences, 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 Spectrum Disorders, Journal of developmental and behavioral pediatrics : JDBP, 37, 53-61, 2016	Phenomenon of interest not in protocol - No themes relating to communication with healthcare staff
Epstein, E. G., Arechiga, J., Dancy, M., Simon, J., Wilson, D., Alhusen, J. L., Integrative Review of Technology to Support Communication With Parents of Infants in the NICU, 46, 357-366, 2017	Duplicate
Epstein, Elizabeth G., Arechiga, Jaqueline, Dancy, Margaret, Simon, Jordan, Wilson, Daniel, Alhusen, Jeanne L., Integrative review of technology to support communication with parents of infants in the NICU, Journal of Obstetric, Gynecologic, & Neonatal Nursing: Clinical Scholarship for the Care of Women, Childbearing Families, & Newborns, 46, 357-366, 2017	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Epstein, Elizabeth Gingell, Sherman, Jessica, Blackman, Amy, Sinkin, Robert A., Testing the feasibility of Skype and FaceTime updates with parents in the neonatal intensive care unit, American Journal of Critical Care, 24, 290-296, 2015	Study design not in protocol - No qualitative data.
Evans, J., Rose, D., Flach, C., Csipke, E., Glossop, H., McCrone, P., Craig, T., Wykes, T., VOICE: developing a new measure of service users' perceptions of inpatient care, using a participatory methodology, Journal of Mental Health, 21, 57-71, 2012	Outcome not in protocol - Validity study of experience measure. No qualitative data presented.
Evans, N., Experiences of a child and adolescent mental health service, Nursing Children and Young People, 29, 41-45, 2017	Phenomenon of interest not in protocol - No themes relating to communication with healthcare staff.
Everley, S., Children's understanding of physical activity and health, Obesity facts, 10 (Supplement 1), 227, 2017	Conference abstract
Fangstrom, Karin, Sarkadi, Anna, Lucas, Steven, Calam, Rachel, Eriksson, Maria, "And they gave me a shot, it really hurt"-Evaluative content in investigative interviews with young	Phenomenon of interest not in protocol - Information too specific to forensic interview protocol aids to be generalizable.

Study	Reason for Exclusion
children, Children and Youth Services Review, 82, 434-443, 2017	
Fawcett, R., Porritt, K., Stern, C., Carson-Chahhoud, K., Experiences of parents and carers in managing asthma in children: A qualitative systematic review, JBI Database of Systematic Reviews and Implementation Reports, 17, 793-984, 2019	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Fazel, M., Garcia, J., Stein, A., The right location? Experiences of refugee adolescents seen by school-based mental health services, Clinical Child Psychology and Psychiatry, 21, 368-380, 2016	Phenomenon of interest not in protocol - No themes relating to communication with healthcare staff
Flett, A. M., Hall, M., McCarthy, C., Marshman, Z., Benson, P. E., Does the British Orthodontic Society orthognathic DVD aid a prospective patient's decision making? A qualitative study, Journal of orthodontics, 41, 88-97, 2014	Phenomenon of interest not in protocol - No themes relating to communication with healthcare staff
Flynn,D., Knoedler,M.A., Hess,E.P., Murad,M.H., Erwin,P.J., Montori,V.M., Thomson,R.G., Engaging patients in health care decisions in the emergency department through shared decision-making: A systematic review, Academic Emergency Medicine, 19, 959-967, 2012	Study design of included studies not in protocol. Included studies checked for inclusion.
Fortier, M. A., Chorney, J. M., Rony, R. Y. Z., Perret-Karimi, D., Rinehart, J. B., Camilon, F. S., Kain, Z. N., Children's desire for perioperative information, Anesthesia and Analgesia, 109, 1085-1090, 2009	Phenomenon of interest not in protocol - No themes relating to communication with healthcare staff
Foster, M. J., Whitehead, L., Maybee, P., Cullens, V., The parents', hospitalized child's, and health care providers' perceptions and experiences of family centered care within a pediatric critical care setting: a metasynthesis of qualitative research, Journal of Family Nursing, 19, 431-468, 2013	Population of included studies not in protocol. Included studies checked for inclusion.
Foster, Mandie Jane, Whitehead, Lisa, Maybee, Patricia, Cullens, Victoria, The parents', hospitalized child's, and health care providers' perceptions and experiences of family centered care within a pediatric critical care setting: A metasynthesis of qualitative research, Journal of Family Nursing, 19, 431-468, 2013	Population of included studies not in protocol. Included studies checked for inclusion.
Franck, L. S., Oulton, K., Bruce, E., Parental involvement in neonatal pain management: an empirical and conceptual update, J Nurs Scholarsh, 44, 45-54, 2012	Phenomenon of interest not in protocol - No themes relating to communication with healthcare staff
Franck, L. S., Oulton, K., Nderitu, S., Lim, M., Fang, S., Kaiser, A., Parent involvement in pain management for NICU infants: A randomized controlled trial, PediatricsPediatrics, 128, 510-518, 2011	Study design not in protocol - No qualitative data.
Freer, Y., McIntosh, N., Teunisse, S., Anand, K. J., Boyle, E. M., More information, less understanding: a randomized study on consent issues in neonatal research, Pediatrics, 123, 1301â□□1305, 2009	Study design not in protocol - No qualitative data.
Gates, M., Shulhan-Kilroy, J., Featherstone, R., MacGregor, T., Scott, S. D., Hartling, L., Parent experiences and information needs related to bronchiolitis: A mixed studies systematic review, Patient Education and Counseling, 102, 864-878, 2019	Population of included studies not in protocol. Included studies checked for inclusion.
Giambra, B. K., Stiffler, D., Broome, M. E., An integrative review of communication between parents and nurses of hospitalized technology-dependent children, Worldviews on evidence-based nursing / Sigma Theta Tau International, Honor Society of Nursing, 11, 369-375, 2014	Population of included studies not in protocol. Included studies checked for inclusion.

Study	Reason for Exclusion
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.
Graham, R., Pemstein, D., & Curley, M. , Experiencing the pediatric intensive care unit: Perspective from parents of children with severe antecedent disabilities. , Critical Care Medicine, 37, 2064-2070, 2009	Country: USA
Grainger, H., Joyce, C., Beuschel, S., Davies, A., Shreeve, K., Super blood! development of a child patient information leaflet, Transfusion Medicine, 2), 45, 2014	Conference abstract
Grealish, A., Tai, S., Hunter, A., Morrison, A. P., Qualitative exploration of empowerment from the perspective of young people with psychosis, Clinical Psychology & Psychotherapy, 20, 136-148, 2013	Phenomenon of interest not in protocol - No themes relating to communication with healthcare staff
Gregory, J. W., UK: Communication in patient-centered care, Pediatric diabetes, 18), 8, 2013	Conference abstract
Grist, Rebecca, Porter, Joanna, Stallard, Paul, Mental health mobile apps for preadolescents and adolescents: A systematic review, Journal of medical internet research, 19, 153-166, 2017	Study design not in protocol - No qualitative data.
Guest, J., Cheal, H., Welcome to Ward 3 at the Great North children's hospital-a fun guide to your first two days with us (DVD format patient family information), Bone Marrow Transplantation, 1), S519, 2016	Conference abstract
Gund A, Sjoqvist BA, Wigert H, Hentz E, Lindecrantz K, Bry K, A randomized controlled study about the use of eHealth in the home health care of premature infants, Neonatal Intensive Care, 26, 42-50, 2013	Country: Sweden
Gurung, G., Richardson, A., Wyeth, E., Edmonds, L., Derrett, S., Child/youth, family and public engagement in paediatric services in high-income countries: A systematic scoping review, Health expectations : an international journal of public participation in health care and health policy, 23, 261-273, 2020	Scoping review. Included studies checked for inclusion.
Gutman, T., Hanson, C. S., Bernays, S., Craig, J. C., Sinha, A., Dart, A., Eddy, A. A., Gipson, D. S., Bockenhauer, D., Yap, H. K., Groothoff, J., Zappitelli, M., Webb, N. J. A., Alexander, S. I., Goldstein, S. L., Furth, S., Samuel, S., Blydt-Hansen, T., Dionne, J., Michael, M., Wenderfer, S. E., Winkelmayer, W. C., Currier, H., McTaggart, S., Walker, A., Ralph, A. F., Ju, A., James, L. J., Carter, S., Tong, A., Child and Parental Perspectives on Communication and Decision Making in Pediatric CKD: A Focus Group Study, American Journal of Kidney Diseases, 72, 547-559, 2018	Countries: Australia, Canada and USA
Hajivassiliou, E. C., Hajivassiliou, C. A., Informed consent in primary dental care: patients' understanding and satisfaction with the consent process, British dental journal, 219, 221-224, 2015	Population not in protocol - Adults with capacity.
Hamama, Liat, Ronen, Tammie, Children's drawings as a self-report measurement, Child & Family Social Work, 14, 90-102, 2009	Country: Israel
Hamann, J., Kohl, S., McCabe, R., Buhner, M., Mendel, R., Albus, M., Bernd, J., What can patients do to facilitate shared decision making? A qualitative study of patients with depression or schizophrenia and psychiatrists, Social psychiatry and psychiatric epidemiology, 51, 617-625, 2016	Population not in protocol - Adult population only aged 18-65 years.

Study	Reason for Exclusion
Harper, B., Dickson, J. M., Bramwell, R., Experiences of young people in a 16-18 Mental Health Service, Child and Adolescent Mental Health, 19, 90-96, 2014	Phenomenon of interest not in protocol - No themes relating to communication with healthcare staff
Harper, Ben, Dickson, Joanne M., Bramwell, Ros, Experiences of young people in a 16-□“18 Mental Health Service, Child and Adolescent Mental Health, 19, 90-96, 2014	Duplicate
Hartling, L., Scott, S., Pandya, R., Johnson, D., Bishop, T., Klassen, T. P., Storytelling as a communication tool for health consumers: development of an intervention for parents of children with croup. Stories to communicate health information, BMC pediatrics, 10, 64, 2010	Narrative description of intervention development.
Harvey, M. E., Redshaw, M. E., Analysis of audio-recordings of discussions between parents and clinicians regarding scanning results, Archives of Disease in Childhood: Fetal and Neonatal Edition, 99, A57, 2014	Conference abstract
Heinemann, A. B., Hellstrom-Westas, L., Hedberg Nyqvist, K., Factors affecting parents' presence with their extremely preterm infants in a neonatal intensive care room, Acta Paediatr, 102, 695-702, 2013	Country: Sweden
Hemsley, B., Bastock, K., Baladin, S., Davidson, B., Scarinci, N., Worrall, L., Communication during hospitalization: The path to better healthcare for children and adults with cerebral palsy, Developmental Medicine and Child Neurology, 54, 31-32, 2012	Conference abstract
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	Population of included studies not in protocol. Included studies checked for inclusion.
Hill, J., Masding, M. G., The development of an innovative mobile phone App for Type 1 diabetes alcohol education, Diabetic medicine, 1), 112, 2013	Conference abstract
Hinton, D., Kirk, S., Paediatric multiple sclerosis: A qualitative study of families' diagnosis experiences, Archives of disease in childhood, 100, 623-629, 2015	Phenomenon of interest not in protocol - No themes relating to communication with healthcare staff
Hughes, B., O'Brien, M. R., Flynn, A., Knighting, K., The engagement of young people in their own advance care planning process: A systematic narrative synthesis, Palliative Medicine, 32, 1147-1166, 2018	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Hughes, V. C., Phillips, S., Exploring the pre-hospitalisation needs of parents of children with cystic fibrosis, Journal of Cystic Fibrosis, 13, S115, 2014	Conference abstract
Hunt, A., Brown, E., Coad, J., Staniszewska, S., Hacking, S., Chesworth, B., Chambers, L., 'Why does it happen like this?' Consulting with users and providers prior to an evaluation of services for children with life limiting conditions and their families, Journal of child health care : for professionals working with children in the hospital and community, 19, 320-333, 2015	Phenomenon of interest not in protocol - No themes relating to communication with healthcare staff
Ignatowicz, Agnieszka, Slowther, Anne-Marie, Elder, Patrick, Bryce, Carol, Hamilton, Kathryn, Huxley, Caroline, Forjaz, Vera, Sturt, Jackie, Griffiths, Frances, Ethical implications of digital communication for the patient-clinician relationship: Analysis of interviews with clinicians and young adults with long term conditions (the LYNC study), BMC Medical Ethics Vol 19 2018, ArtID 11, 19, 2018	Population not in protocol - Clinicians and patients (aged 16-24 years) with data not presented separately for target population.

Study	Reason for Exclusion
Ion, R., Cropper, J., Walters, H., Involving young people in decision making about sequential cochlear implantation, Cochlear Implants International, 14, S44-S47, 2013	Study design not in protocol - No qualitative data.
Jacob, J., Edbrooke-Childs, J., Holley, S., Law, D., Wolpert, M., Horses for courses? A qualitative exploration of goals formulated in mental health settings by young people, parents, and clinicians, Clinical child psychology and psychiatry, 21, 208-223, 2016	Phenomenon of interest not in protocol - Information too specific to individual goal examples to be generalizable.
Jacob, J., Edbrooke-Childs, J., Law, D., Wolpert, M., Measuring what matters to patients: Using goal content to inform measure choice and development, Clinical Child Psychology and Psychiatry, 22, 170-186, 2017	Study design not in protocol - No qualitative data.
Jansen, R., Reid, M., Caregivers of adolescents with mental health issues using communication technology: a systematic review, JMIR mHealth and uHealth, 2020	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Jefferies, K., Haest, J., Edge, J., Admission pack for newly diagnosed diabetes: Help or hindrance?, Archives of disease in childhood, 1), A120, 2012	Conference abstract
Jenkins, Peter, Having confidence in therapeutic work with young people: Constraints and challenges to confidentiality, British Journal of Guidance & Counselling, 38, 263-274, 2010	Narrative review. Included studies checked for inclusion.
Joanne, C., Deepa, P., Emily, W., Vanessa, M., An evaluation of the views of adolescent patients with a learning disability and their carers on a medicines information leaflet, Archives of Disease in Childhood. Conference: 22nd Annual Conference of the Neonatal and Paediatric Pharmacists Group. United Kingdom, 103, 2018	Conference abstract
Jobbins, A., Baily, C., Wilkinson, G., Menzies, J., Mildner, R., Adolescents in PICU: Are we meeting their needs?, Pediatric critical care medicine, 1), A37-A38, 2011	Conference abstract
Kean, S., Children and young people visiting an adult intensive care unit, Journal of advanced nursing, 66, 868-877, 2010	Phenomenon of interest not in protocol - Reports experiences of children visiting family members in intensive care.
Kerri, O., Byron, P., Improving strategies to better support adolescents with cancer: The creation of an "adolescent-friendly oncology ward", Pediatric Blood and Cancer, 53 (5), 751-752, 2009	Conference abstract
Kew, K. M., Malik, P., Aniruddhan, K., Normansell, R., Shared decision-□□making for people with asthma, Cochrane Database of Systematic Reviews, 2017	Duplicate paper
Kew, K. M., Malik, P., Aniruddhan, K., Normansell, R., Shared decision-making for people with asthma, Cochrane Database of Systematic Reviews, 2017 (10) (no pagination), 2017	Study design not in protocol - No qualitative data.
Latour, Jos M., van Goudoever, Johannes B., Schuurman, Beatrix Elink, Albers, Marcel J. I. J., van Dam, Nicolette A. M., Dullaart, Eugenie, van Heerde, Marc, Verlaat, Carin W. M., van Vught, Elise M., Hazelzet, Jan A., A qualitative study exploring the experiences of parents of children admitted to seven Dutch pediatric intensive care units, Intensive care medicineIntensive Care Med, 37, 319-325, 2011	Country: The Netherlands
Lawrence, M., Young adults' experience of stroke: a qualitative review of the literature, British journal of nursing (Mark Allen Publishing), 19, 241-248, 2010	Population not in protocol - Adults 18-65 years

Study	Reason for Exclusion
Lawton, J., Waugh, N., Noyes, K., Barnard, K., Harden, J., Bath, L., Stephen, J., Rankin, D., Improving communication and recall of information in paediatric diabetes consultations: A qualitative study of parents' experiences and views, BMC pediatrics, 15 (1) (no pagination), 2015	Unclear population - Parents of children with Type 1 diabetes with no way of discerning age of children.
Lea, S., Martins, A., Morgan, S., Cargill, J., Taylor, R. M., Fern, L. A., Online information and support needs of young people with cancer: A participatory action research study, Adolescent Health, Medicine and Therapeutics, 9, 121-135, 2018	Population not protocol - Ages 13-24 years with data not presented separately for target population.
Lerch, Matthew F., Thrane, Susan E., Arnett, Babler Baucom Bishay Borus Dashiff Gaston Heath Hilliard Kayle King Knopf Miller Polfuss Sanders Sawicki Seiffge-Krenke Skinner Stevens Vygotsky Williams, Adolescents with chronic illness and the transition to self-management: A systematic review, Journal of Adolescence, 72, 152-161, 2019	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Levin, A. B., Fisher, K. R., Cato, K. D., Zurca, A. D., October, T. W., An Evaluation of Family-Centered Rounds in the PICU: Room for Improvement Suggested by Families and Providers, Pediatric critical care medicine : a journal of the Society of Critical Care Medicine and the World Federation of Pediatric Intensive and Critical Care SocietiesPediatr Crit Care Med, 16, 801-7, 2015	Country: USA
LGBT Youth Scotland et al, Life in Scotland for LGBT young people: Health Report, 2013	Grey literature survey
Lindberg, Birgitta, Axelsson, Karin, Öhrling, Kerstin, Taking care of their baby at home but with nursing staff as support: The use of videoconferencing in providing neonatal support to parents of preterm infants, Journal of Neonatal Nursing, 15, 47-55, 2009	Country: Sweden
Lion, K. C., Kieran, K., Desai, A., Hencz, P., Ebel, B. E., Adem, A., Forbes, S., Kraus, J., Gutman, C., Horn, I., Audio-Recorded Discharge Instructions for Limited English Proficient Parents: A Pilot Study, Joint Commission Journal on Quality and Patient Safety, 45, 98-107, 2019	Study design not in protocol - No qualitative data.
Liossi, C., Noble, G., Franck, L. S., How parents make sense of their young children's expressions of everyday pain: A qualitative analysis, European journal of pain (united kingdom), 16, 1166-1175, 2012	Phenomenon of interest not in protocol - No themes relating to communication with healthcare staff
Lipstein, E. A., Brinkman, W. B., Britto, M. T., What is known about parents' treatment decisions? A narrative review of pediatric decision making, Medical decision making : an international journal of the Society for Medical Decision Making, 32, 246-258, 2012	Narrative review. Included studies checked for possible inclusion.
Little, P., White, P., Kelly, J., Everitt, H., Gashi, S., Bikker, A., Mercer, S., Verbal and non-verbal behaviour and patient perception of communication in primary care: An observational study, British journal of general practice, 65, e357-e365, 2015	Study design not in protocol - No qualitative data.
Loewenstein, K., Barroso, J., Phillips, S., The Experiences of Parents in the Neonatal Intensive Care Unit: An Integrative Review of Qualitative Studies Within the Transactional Model of Stress and Coping, The Journal of perinatal & neonatal nursing, 33, 340-349, 2019	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Macdonald, M. E., Liben, S., Carnevale, F. A., Cohen, S. R., An office or a bedroom? Challenges for family-centered care in the pediatric intensive care unit, J Child Health Care, 16, 237-49, 2012	Country: Canada

Study	Reason for Exclusion
Martin-Kerry, J. M., Knapp, P., Atkin, K., Bower, P., Watt, I., Stones, C., Higgins, S., Sheridan, R., Preston, J., Horton Taylor, D., Baines, P., Young, B., Supporting children and young people when making decisions about joining clinical trials: Qualitative study to inform multimedia website development, BMJ open, 9 (1) (no pagination), 2019	Population not in protocol - Age 6-19 years with data not presented separately for target population.
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.
Mc Manus, V., Savage, E., Cultural perspectives of interventions for managing diabetes and asthma in children and adolescents from ethnic minority groups, Child: Care, Health and Development, 36, 612-622, 2010	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
McKenna, K., Collier, J., Hewitt, M., Blake, H., Parental involvement in paediatric cancer treatment decisions, Eur J Cancer Care (Engl), 19, 621-30, 2010	Study design not in protocol - No qualitative data.
McMillan, S. S., Wilson, B., Stapleton, H., Wheeler, A. J., Young people's experiences with mental health medication: A narrative review of the qualitative literature, Journal of Mental Health, 2020	Narrative review. Included studies checked for inclusion.
McPherson, G., Jefferson, R., Kissoon, N., Kwong, L., Rasmussen, K., Toward the inclusion of parents on pediatric critical care unit rounds, Pediatric critical care medicine : a journal of the Society of Critical Care Medicine and the World Federation of Pediatric Intensive and Critical Care SocietiesPediatr Crit Care Med, 12, e255-61, 2011	Country: Canada
Miller, V. A., Parent-child collaborative decision making for the management of chronic illness: a qualitative analysis, Fam Syst Health, 27, 249-66, 2009	Country: USA
Mimmo, L., Harrison, R., Taking time to care: Meta narrative review of the experience of parents with a child with intellectual disability in hospital, Journal of Intellectual Disability Research, 63, 812, 2019	Conference abstract
Mimmo, L., Woolfenden, S., Travaglia, J., Harrison, R., Partnerships for safe care: A meta-narrative of the experience for the parent of a child with Intellectual Disability in hospital, Health Expectations, 22, 1199-1212, 2019	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Mitchell, Wendy, Parents' accounts: Factors considered when deciding how far to involve their son/daughter with learning disabilities in choice-making, Children and Youth Services Review, 34, 1560-1569, 2012	Phenomenon of interest not in protocol - No themes relating to communication with healthcare staff
Nair, T., Savulescu, J., Everett, J., Tonkens, R., Wilkinson, D., Settling for second best: when should doctors agree to parental demands for suboptimal medical treatment?, Journal of medical ethics, 43, 831-840, 2017	Study design not in protocol - Empirical and ethical analyses only
Neill, S. J., Jones, C. H., Lakhanpaul, M., Roland, D. T., Thompson, M. J., Parents' help-seeking behaviours during acute childhood illness at home: A contribution to explanatory theory, Journal of child health care : for professionals working with children in the hospital and community, 20, 77-86, 2016	Phenomenon of interest not in protocol - No themes relating to communication with healthcare staff
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	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.

Study	Reason for Exclusion
participation in health care and health policy, 18, 3044-3056, 2015	
Neill, S., Roland, D., Jones, C. H. D., Thompson, M., Lakhanpaul, M., Information resources to aid parental decision-making on when to seek medical care for their acutely sick child: A narrative systematic review, BMJ open, 5 (12) (no pagination), 2015	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Nelson, P. A., Kirk, S. A., Parents' perspectives of cleft lip and/or palate services: A qualitative interview, Cleft Palate-Craniofacial Journal, 50, 275-285, 2013	Phenomenon of interest not in protocol - Information too specific to cleft lip palate and/or services to be generalizable.
Ngo-Metzger, Q., Hayes, G. R., Yunan, Chen, Cygan, R., Garfield, C. F., Improving communication between patients and providers using health information technology and other quality improvement strategies: focus on low-income children, Medical Care Research & ReviewMed Care Res Rev, 67, 246S-267S, 2010	Population of included studies not in protocol. Included studies checked for inclusion.
Nicholls, S. G., Southern, K. W., Parental selection and use of information when learning about newborn bloodspot screening, Pediatric Pulmonology, 46, 427, 2011	Conference abstract
Nik-Hussin, N. M. H., Saleem, Y., Sivayoham, E., Rothera, M. P., A survey of parent's attitudes towards viewing intraoperative photographs used as an educational tool, International journal of pediatric otorhinolaryngology, 73, 585-588, 2009	Study design not in protocol - No qualitative data.
Obeysekera, M., Tanney, K., Picture books to improve the quality of communication in newborn intensive care, Archives of Disease in Childhood, 102, A88, 2017	Conference abstract
Ochieng, B. M., Black African migrants: the barriers with accessing and utilizing health promotion services in the UK, European Journal of Public Health, 23, 265-269, 2013	Population not in protocol - >18 years old.
October, Tessie W., Fisher, Kiondra R., Feudtner, Chris, Hinds, Pamela S., The parent perspective: "being a good parent" when making critical decisions in the PICU, Pediatric critical care medicine : a journal of the Society of Critical Care Medicine and the World Federation of Pediatric Intensive and Critical Care SocietiesPediatr Crit Care Med, 15, 291-298, 2014	Country: USA
O'Hare, L., Santin, O., Winter, K., McGuinness, C., The reliability and validity of a Child and Adolescent Participation in Decision-Making Questionnaire, Child: care, health and development, 42, 692-698, 2016	Study design not in protocol - No qualitative data.
O'Reilly, M., Karim, K., Taylor, H., Dogra, N., Parent and child views on anonymity: ‘I’ve got nothing to hide’, International Journal of Social Research Methodology: Theory & Practice, 15, 211-223, 2012	Phenomenon of interest not in protocol - No themes relating to communication with healthcare staff
Oulton, K., Wray, J., Carr, L., Hassiotis, A., Jewitt, C., Kerry, S., Tuffrey-Wijne, I., Gibson, F., Pay More Attention: a national mixed methods study to identify the barriers and facilitators to ensuring equal access to high-quality hospital care and services for children and young people with and without learning disabilities and their families, BMJ open, 6, 2016	Published protocol with no experimental data
Page, C. J., Dunkley, L., Edgerton, J., Hawley, D., Tattersall, R. S., Don't lose your HEADSS in the adolescent clinic: An evaluation of how an adolescent rheumatology service counsels young people's issues, Rheumatology (United Kingdom), 3), iii6, 2014	Conference abstract

Study	Reason for Exclusion
Palatability of hypoallergenic formulas for cow's milk allergy and healthcare professional recommendation, Pediatric allergy and immunology, 29, 857â□□862, 2018	Population not in protocol - Views of healthcare providers only
Pallotta-Chiarolli, Maria, Martin, Erik, â□œWhich Sexuality? Which Service?â□□: Bisexual Young People's Experiences with Youth, Queer and Mental Health Services in Australia, Journal of LGBT Youth, 6, 199-222, 2009	Country: Australia
Pellerin-Leblanc, A. A., Derynck, M., Dow, K., Improving communication in the NICU: Parental perceptions and knowledge about resident physicians, Paediatrics and Child Health (Canada), 23 (Supplement 1), e47-e48, 2018	Conference abstract
Pepper,D., Rempel,G., Austin,W., Ceci,C., Hendson,L., More than information: a qualitative study of parents' perspectives on neonatal intensive care at the extremes of prematurity, Advances in Neonatal Care, 12, 303-309, 2012	Country: Canada
Petrie, K., McArdle, A., Cookson, J., Powell, E., Poblete, X., 'Let us speak'-children's opinions of doctors, Archives of Disease in Childhood, 102 (Supplement 1), A200-A201, 2017	Conference abstract
Pini, S., Education mentoring for teenagers and young adults with cancer, British journal of nursing (Mark Allen Publishing), 18, 1316-1319, 2009	Phenomenon of interest not in protocol - No themes relating to communication with healthcare staff
Pyke-Grimm, Kimberly A., Franck, Linda S., Kelly, Katherine Patterson, Halpern-Felsher, Bonnie, Goldsby, Robert E., Kleiman, Ari, Rehm, Roberta S., Albritton, Alsous Barakat Bhatia Bhatia Bleyer Bluebond-Langner Britto Britto Broome Broome Butow Coccia Coyne Coyne Coyne Coyne Day de Vries Dunsmore Ellis Hinds Jacobs Joffe Kelly Knopf Lyon Martenson Masera Miller Miller Miller Miller Moher Noblit Pace Pearce Pluye Read Ruhe Ruhe Smith Snethen Spinetta Stegenga Stewart Tenniglo Unguru Unguru Weaver Whittemore Young Zwaanswijk Zwaanswijk, Treatment decision-making involvement in adolescents and young adults with cancer, Oncology Nursing Forum, 46, E22-E37, 2019	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Pyke-Grimm, Kimberly A., Franck, Linda S., Kelly, Katherine Patterson, Halpern-Felsher, Bonnie, Goldsby, Robert E., Kleiman, Ari, Rehm, Roberta S., Treatment decision-making involvement in adolescents and young adults with cancer, Oncology Nursing Forum, 46, E22-E37, 2019	Duplicate record - Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Read, N., Schofield, A., Autism: are mental health services failing children and parents?, The journal of family health care, 20, 120-124, 2010	Population and study design not in protocol - No qualitative data for under 18s.
Redley, M., Prince, E., Bateman, N., Pennington, M., Wood, N., Croudace, T., Ring, H., The involvement of parents in healthcare decisions where adult children are at risk of lacking decision-making capacity: A qualitative study of treatment decisions in epilepsy, Journal of intellectual disability research, 57, 531-538, 2013	Population not in protocol - Parents' views with no way of discerning age of child
Rennick, J., Lambert, S., Childerhose, J., Campbell-Yeo, M., Filion, F., & Johnston, C. , Mothers' experiences of a touch and talk nursing intervention to optimize pain management in the PICU: A qualitative descriptive study. , Intensive & Critical Care Nursing, 27, 151-157, 2011	Country: Canada
Richards, C. A., Starks, H., O'Connor, M. R., Doorenbos, A. Z., Elements of Family-Centered Care in the Pediatric Intensive Care Unit: An Integrative Review, Journal of hospice and	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.

Study	Reason for Exclusion
palliative nursing : JHPN : the official journal of the Hospice and Palliative Nurses Association, 19, 238-246, 2017	
Richardson, C., Paslakis, G., Men's experiences of eating disorder treatment: A qualitative systematic review of men-only studies, Journal of psychiatric and mental health nursing, 2020	Population of included studies not in protocol. Included studies checked for inclusion.
Riddell, R., Lewis, A., Tuthill, D., PN for children-information leaflet, Archives of disease in childhood, 101 (9), A13, 2016	Conference abstract
Robert, Marie, Leblanc, Line, Boyer, Thierry, When satisfaction is not directly related to the support services received: Understanding parents' varied experiences with specialised services for children with developmental disabilities, British Journal of Learning Disabilities, 43, 168-177, 2015	Country: Canada
Robertson, A. O., Tadic, V., Rahi, J. S., Transition from paediatric to adult ophthalmology services: what matters most to young people with visual impairment, Eye, 32, 406-414, 2018	Phenomenon of interest not in protocol - Child to adult healthcare transition.
Rosenthal, S. A., Nolan, M. T., A Meta-Ethnography and Theory of Parental Ethical Decision Making in the Neonatal Intensive Care Unit, Jognn-Journal of Obstetric Gynecologic and Neonatal Nursing, 42, 492-502, 2013	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Rubin,S.E., McKee,M.D., Campos,G., O'Sullivan,L.F., Delivery of confidential care to adolescent males, Journal of the American Board of Family Medicine: JABFM, 23, 728-735, 2010	Country: USA
Russell, G., Sawyer, A., Rabe, H., Abbott, J., Gyte, G., Duley, L., Ayers, S., Parents' views on care of their very premature babies in neonatal intensive care units: a qualitative study, BMC Pediatrics, 14, 230, 2014	Phenomenon of interest not in protocol - Experiences focus strongly on parent's views only. Not a good proxy for unders 5s.
Saaltink, R., MacKinnon, G., Owen, F., Tardif-Williams, C., Protection, participation and protection through participation: young people with intellectual disabilities and decision making in the family context, J Intellect Disabil Res, 56, 1076-86, 2012	Country: Canada
Sanders, C., Pritchard, E., Bray, L., McKenna, J., Exploring young people's expectations and experiences of discussing sexual and relationship health with professionals in a children's hospital, Journal of clinical nursing, 20, 1705-1712, 2011	Study design not in protocol - No qualitative data.
Sayal, Kapil, Mills, Jonathan, White, Kate, Merrell, Christine, Tymms, Peter, Predictors of and barriers to service use for children at risk of ADHD: Longitudinal study, European child & adolescent psychiatry, 24, 545-552, 2015	Study design not in protocol - No qualitative data.
Schaeuble, K., Haglund, K., Vukovich, M., Adolescents' preferences for primary care provider interactions, J Spec Pediatr Nurs, 15, 202-10, 2010	Country: USA
Scholefield, B., Gosney, J., Callens, C., Duncan, H., Morris, K., Draper, H., Consultation with children regarding deferred consent in emergency care research, Pediatric critical care medicine, 1), A44, 2011	Conference abstract
Sherratt, F. C., Beasant, L., Crawley, E. M., Hall, N. J., Young, B., Enhancing communication, informed consent and recruitment in a paediatric urgent care surgical trial: A qualitative study, BMC Pediatrics, 20, 140, 2020	Phenomenon of interest not in protocol - No themes relating to communication with healthcare staff
Sime, D., 'I think that Polish doctors are better': Newly arrived migrant children and their parents' experiences and views of health services in Scotland, Health and Place, 30, 86-93, 2014	Phenomenon of interest not in protocol - No themes relating to communication with healthcare staff

Study	Reason for Exclusion
Sisson, Helen, Jones, Catriona, Williams, Rhona, Lachanudis, Lisa, Metaethnographic synthesis of fathers' experiences of the neonatal intensive care unit environment during hospitalization of their premature infants, Journal of Obstetric, Gynecologic, & Neonatal Nursing: Clinical Scholarship for the Care of Women, Childbearing Families, & Newborns, 44, 471-480, 2015	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Smith, L. A. M., Critoph, D. J., Hatcher, H. M., How Can Health Care Professionals Communicate Effectively with Adolescent and Young Adults Who Have Completed Cancer Treatment? A Systematic Review, Journal of Adolescent and Young Adult Oncology, 2020	Population of included studies not in protocol. Included studies checked for inclusion.
Stafford, V., Hutchby, I., Karim, K., O'Reilly, M., "Why are you here?" Seeking children's accounts of their presentation to Child and Adolescent Mental Health Service (CAMHS), Clinical child psychology and psychiatry, 21, 3-18, 2016	Phenomenon of interest not in protocol - No themes relating to communication with healthcare staff
Starkman, Harold, Fisher, Kathleen, Pilek, Nicole L., Lopez-Henriquez, Gloria, Lynch, Laura, Bilkins-Morgis, Briana L., Listening to adolescents with uncontrolled diabetes, their parents and medical team, Families, systems & health : the journal of collaborative family healthcare, 37, 30-37, 2019	Country not in protocol: USA
Stenberg, U., Haaland-Overby, M., Koricho, A. T., Trollvik, A., Kristoffersen, L. G. R., Dybvig, S., Vagan, A., How can we support children, adolescents and young adults in managing chronic health challenges? A scoping review on the effects of patient education interventions, Health expectations : an international journal of public participation in health care and health policy, 2019	Scoping review. Included studies checked for inclusion.
Stickney, C. A., Ziniel, S. I., Brett, M. S., Truog, R. D., Family participation during intensive care unit rounds: goals and expectations of parents and health care providers in a tertiary pediatric intensive care unit, J Pediatr, 165, 1245-1251.e1, 2014	Country: USA
Sullivan, V., de Sa, J., Hamlyn, E., Baraitser, P. How can we facilitate online disclosure of safeguarding concerns in under 18s to support transition from online to face-to-face care?, International journal of STD & AIDS, 31(6), 553-559, 2020.	Phenomenon of interest not in protocol - No themes relating to communication with healthcare staff
Sunderland, E., Wood, K., Barwick, S., What do looked after young people think about the specialist health services they use?, Archives of disease in childhood, 3), A184, 2015	Conference abstract
Sutcliffe, P., Martin, S., Sturt, J., Powell, J., Griffiths, F., Adams, A., Dale, J., Systematic review of communication technologies to promote access and engagement of young people with diabetes into healthcare, BMC endocrine disorders, 11 (no pagination), 2011	Study design not in protocol - No qualitative data.
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 themes relating to communication with healthcare staff
Templeton, Lorna, Novak, Claire, Wall, Sarah, Young people's views on services to help them deal with parental substance misuse, Drugs: Education, Prevention & Policy, 18, 172-178, 2011	Phenomenon of interest not in protocol - No themes relating to communication with healthcare staff
Ulph, F., Cullinan, T., Qureshi, N., Kai, J., Informing children of their newborn screening carrier result for sickle cell or cystic fibrosis: qualitative study of parents' intentions, views and support needs, Journal of Genetic Counseling, 23, 409-20, 2014	Phenomenon of interest not in protocol - No themes relating to communication with healthcare staff

Study	Reason for Exclusion
Van Cleave, A., Roosen-Runge, M., Miller, A., Karkazis, K., Magnus, D., Quality of communication in interpreted versus non-interpreted pediatric ICU family meetings, Critical Care Medicine, 1), A177, 2013	Conference abstract
Van De Vijver, M., Bertaud, S., Nailor, S., Marais, G., Baby diaries: A tool to improve parental communication in the neonatal unit, Archives of Disease in Childhood, 99, A81-A82, 2014	Conference abstract
van de Vijver, M., Evans, M., A tool to improve communication in the neonatal unit, BMJ Quality Improvement ReportsBMJ qual, 4, 2015	Study design not in protocol - Close ended, yes/no questionnaire
Waite-Jones, J. M., Majeed-Ariss, R., Smith, J., Stones, S. R., Van Rooyen, V., Swallow, V., Young People's, Parents', and Professionals' Views on Required Components of Mobile Apps to Support Self-Management of Juvenile Arthritis: Qualitative Study, JMIR MHealth and UHealth, 6, e25, 2018	Phenomenon of interest not in protocol - No themes relating to communication with healthcare staff
Wales, Jackie, Brewin, Nicola, Raghavan, Raghu, Arcelus, Jon, Exploring barriers to South Asian help-seeking for eating disorders, Mental Health Review Journal, 22, 40-50, 2017	Population not in protocol - >18 years old
Walsh, J., Scaife, V., Notley, C., Dodsworth, J., Schofield, G., Perception of need and barriers to access: The mental health needs of young people attending a Youth Offending Team in the UK, Health and Social Care in the Community, 19, 420-428, 2011	Phenomenon of interest not in protocol - No themes relating to communication with healthcare staff
Watts, R., Zhou, H., Shields, L., Taylor, M., Munns, A., Ngune, I., Family-centered care for hospitalized children aged 0-12 years: A systematic review of qualitative studies, JBI Database of Systematic Reviews and Implementation Reports, 12, 204-283, 2014	Phenomenon of interest not in protocol - No themes relating to communication with healthcare staff
White, B., Tuschl, K., Walker, J., Segal, T., Viner, R. M., Confidentiality, consent and privacy: A challenge even in a specialist young person unit, Archives of disease in childhood, 1), A65, 2010	Conference abstract
Whittingham,Koa, Boyd,Roslyn N., Sanders,Matthew R., Colditz,Paul, Parenting and prematurity: Understanding parent experience and preferences for support, Journal of Child and Family Studies, 23, 1050-1061, 2014	Country: Australia
Wiering, B. M., Noordman, J., Tates, K., Zwaanswijk, M., Elwyn, G., De Bont, E. S. J. M., Beishuizen, A., Hoogerbrugge, P. M., Van Dulmen, S., Sharing decisions during diagnostic consultations; an observational study in pediatric oncology, Patient Education and Counseling, 99, 61-67, 2016	Study design not in protocol - No qualitative data.
Wong et al, Risk discourse and sexual stigma: Barriers to STI testing, treatment and care among young heterosexual women in disadvantaged neighbourhoods in Toronto, Can J Hum Sex, 21, 75-89, 2012	Country: Canada
Wyatt, K. D., Prutsky Lopez, G., Domecq Garces, J. P., Erwin, P., Brinkman, W. B., Montori, V. M., LeBlanc, A., Study protocol: a systematic review of pediatric shared decision making, Systematic reviews, 2, 48, 2013	Published protocol for quantitative systematic review.
Yamaji, Noyuri, Suto, Maiko, Takemoto, Yo, Suzuki, Daichi, Lopes, Katharina da Silva, Ota, Erika, Supporting the Decision Making of Children With Cancer: A Meta-synthesis, Journal of pediatric oncology nursing : official journal of the Association of Pediatric Oncology Nurses, 1043454220919711, 2020	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.

Study	Reason for Exclusion
Ye, Jiali, Rust, George, Fry-Johnson, Yvonne, Strothers, Harry, E-mail in patient-provider communication: A systematic review, Patient Education and Counseling, 80, 266-273, 2010	Population of included studies not in protocol. Included studies checked for inclusion.

Economic studies

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

Appendix L – Research recommendations

Research recommendations for review question: How should healthcare staff communicate with babies, children and young people, and the parents or carers of babies and young children?

No research recommendations were made for this review question.

Appendix M – Evidence from reference groups and focus groups

Reference group and focus group evidence for review question: How should healthcare staff communicate with babies, children and young people, and the parents or carers of babies and young children?

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 13: Evidence from reference groups and focus groups

Age < 7 years	Age 7-11 Years	Age 11-14 years	Overall quality of the evidence
• I like it when doctors are friendly –all agreed (18/18) • I like it if the doctor/dentist/nurse listens to me when I talk to them: ○ Agree (27/31) - ‘I like it when they are nice’ - ‘I like it when they listen to me’ - ‘I like telling them about my holidays’ - ‘I agree because they are very kind’ - ‘I agree because they respect my zone and are kind to me and respect my zone’ - ‘Because they are always nice to you by saying that it might not hurt’ - ‘If it does hurt, you can tell them and they will listen’ ○ Disagree (4/31) - ‘I don’t like the doctors, I don’t want the injection and I have to have it anyway’ - ‘They don’t listen’	• ‘Say hello’ • ‘I like it when doctors are friendly and good at their job’ • ‘Doctors who have a big, friendly smile’ • ‘Doctors who make you feel relaxed’ • ‘Not be rude’ • ‘Doctors notice when you have been brave and haven’t screamed’ • ‘Doctors and nurses not be too busy’ • ‘Listen to how you are feeling’ • ‘Doctors ask what you like and what you don’t like’ • ‘Doctors treat us nicely, be a nice doctor’ • ‘Doctor’s not being rude – swift 2 seconds and you need to get out now, she should take her time’ • ‘Smart – how they talk, but lots of long words can be confusing ‘normal common words, please.’	• ‘Listening’ (MH services) x 2 • ‘You can make jokes with the same people without being mixed up’ (MH services) • ‘Good people friendly’ (MH services) • ‘Doctors and nurses are friendly and welcoming’ (MH services) • ‘Go with the flow’ (MH services) • ‘Not short-tempered, grumpy • ‘Pay attention’ • ‘Make eye contact’ • ‘Friendly’ x2 • ‘Not time-limited’ • ‘Communication’ • ‘Don’t just read from pages’ • ‘Welcoming’ • ‘Face to face support’ • ‘Tell us things’	• Low

Age < 7 years	**Age 7-11 Years**	**Age 11-14 years**	**Overall quality of the evidence**
• Doctors care about what I think and say: • Agree (8/16) - ‘Because they always take care of us’ ○ Disagree (5/16) - ‘Because they gave me [an injection] once and I said ow and they didn’t listen’ • I like it when doctors talk to me: ○ Agree (13/22) - ‘Because the doctor who I see is really nice and my mummy and little sister like her and know her’ - ‘Because it might be important’ - ‘Because they can see what is the matter’ - ‘Because they tell me I’m big and strong’ - ‘They are kind’ ○ Disagree (7/22) - ‘Because they are weird’ - ‘Because they hurt’ - ‘I don’t like it when they don’t give me a sticker’ • How would the world’s best doctor or the world’s best nurse talk to you? ○ ‘Be kind, be nice’ ○ ‘Helps me understand’ • How would the world’s worst doctor or the world’s worst nurse talk to you? ○ ‘Mean’ x3 ○ ‘Asks ‘Why did you fall over?’’ x2 ○ ‘Shouts at me’ x2 ○ ‘Bossy’ x2	• ‘Being friendly is the most important – if they’re not friendly, they might ask you ‘how have you been feeling today’ [cross voice] and it won’t help you answer but if they’re friendly they might say ‘how have you been feeling today’ [kind voice] and you’ll answer – so they link together’ • ‘When doctors say something… it’s like, I don’t know what this means. So if you ask a question you don’t know what they mean’ • ‘If they use the complicated words I prefer if they [health professionals] talk to mum and dad but if they use words I understand I prefer them talking to me’ • ‘Doctors should ask: ‘What do you want to ask?’’ • ‘Doctors should use clear words’ • ‘Doctors can use words you understand’	• ‘Kind staff –explanations, so know what is happening’	

Age < 7 years	Age 7-11 Years	Age 11-14 years	Overall quality of the evidence
○ Shouts ‘You have to do this, and you have to do that.’’ ○ o ‘Cross – says ‘You should have been more careful’’ ○ ‘Frustrated’ ○ ‘Rude’ ○ ‘Ignoring me’ ○ ‘Says ‘Get out now!’ when you might have fallen and broken your leg’ • Doctors and nurses should use words I understand: ○ Agree (17/18) - ‘If they use words I don’t understand, I don’t know what is happening’ - ‘I never know what it means’ - ‘I don’t know the words that a doctor is going to use’ - ‘Don’t know what the instrument is and when I don’t know what it is and then they use it on me, it feels a bit strange and scary’ - ‘It makes me feel scared when I don’t understand’			

Appendix N – Evidence from national surveys

Evidence from national surveys for review question: How should healthcare staff communicate with babies, children and young people, and the parents or carers of babies and young children?

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

Table 14: 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	HOSPITAL STAFF: • 87% 12-15 year olds said staff talked to them about their care; for 8-11 year olds this was 83% UNDERSTANDING: • 70% children and young people understood what staff said ASKING QUESTIONS: • 95% 8-15 year olds felt able to ask questions and 92% said their questions were answered.	• Low
Child Outcomes Research Consortium. Child- and Parent-reported Outcomes and Experience from Child and Young People's Mental Health Services 2011-2015	LISTENING: • 84.6% children and young people said they were listened to • 70.8% said the staff were easy to talk to	• Moderate
Health and Social Care Information Centre. Children's Dental Health Survey 2013. (Country specific report for England, published 2015)	• No relevant findings were identified for this question	• N/A

Survey	Findings	Overall quality of the evidence
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	COMMUNICATION BY DOCTORS: • Children and young people aged 12-19 years reported 'doctors don't explain things and they speak to your parents, the language they use is confusing'. COMMUNICATION WITH DISABLED YOUNG PEOPLE: Disabled young people aged 15-21 recommended that there should be an NHS e-learning module on communicating with young people with learning difficulties and communication impairments, resources in hospitals to address communication with disabled young people, and systems for setting up appointments which would support preparation for the consultation.	• Moderate
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	UNDERSTANDING (EMERGENCY DEPARTMENT): • 70% children and young people aged 8-16 said doctors and nurses explained what was wrong in a way they could understand • 27% children and young people aged 8-16 said doctors and nurses did not talk to them about their questions or worries LISTENING (OUTPATIENTS): • 76% children and young people aged 8-16 years thought they were listened to by hospital staff	• Low

Survey	Findings	Overall quality of the evidence
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).*	COMMUNICATION WITH STAFF ON NEONATAL UNIT: • When you visited the unit did the staff caring for your baby introduce themselves to you? Score = 79 • Were you told which nurse was responsible for your baby's care each day he/she was in the neonatal unit? Score = 90 • Were you able to talk to staff on the unit about your worries and concerns? Score = 88 • Were you able to speak to a doctor about your baby as much as you wanted? Score = 66 • Were the nurses on the unit sensitive to your emotions and feelings? Score = 85 • Were the doctors on the unit sensitive to your emotions and feelings? Score = 83 • Did staff refer to your baby by his/her first name? Score = 90	• Moderate
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	BEING INFORMED ABOUT TREATMENT: • Young people aged 13 to 17 reported a good experience of how the diagnosis and treatment plan was communicated and discussed with them and none felt excluded from this process. All felt that the manner in which doctors had spoken with them (and with their parents at the same time) had been unproblematic. None felt that that medical staff had spoken about them but not to them, nor that they were made to feel that their views were not important. Quotes: 'When they were deciding the treatment, I felt I was fully involved. I was always asked before they were doing anything. They always had me and my parents there and they talked to us all, explaining it all to me and them.' (M16) 'I've always been told that they would never do anything without talking to me first. They said I'm old enough to make my own decisions and I have been heard at all times. They have always talked to me and my mum and dad at the same time. I've never felt excluded.' (F13) 'Everything I asked, I got an answer to. I was definitely listened to. And that was true the whole way through. With the surgeon, I wanted to see the CT scans and she was fine about it.	• Low

Survey	Findings	Overall quality of the evidence
	At every shift change the nurse would come in and introduce themselves and say, 'just push the buzzer if you want anything'. The diagnosis was as positive as it can be. First and foremost, they were talking to me. My mum was there too. But it was at the point where I could make my own decisions, so they were talking to me.' (M16) 'They listened to me most of the time and my voice was heard. There weren't any times when I was treated in ways that were bad. I was diagnosed and the doctor explained things quite well. I felt that they were speaking to me. They always asked me if I had any questions or needed anything. My oncologist would always ask me if I had any questions.' (F15)	

N/A: not applicable