National Institute for Health and Care Excellence

FINAL

Babies, children and young people's experiences of healthcare

[G] Support from healthcare staff

NICE guideline NG204

Evidence reviews underpinning recommendations 1.1.4 to 1.1.7 and 1.5.7 to 1.5.13 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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How do children and young people want healthcare staff to support them?

Introduction

Children and young people will interact with a variety of healthcare professionals while accessing and using healthcare. Needing to use healthcare services can be challenging for children and young people and the ability of healthcare professionals to build trust and engage directly with children and young people and to support them in the way that they need will have a significant impact on the overall quality of their healthcare experience.

The aim of this review is to determine how children and young people would like healthcare staff to deliver support and engagement throughout healthcare experiences.

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
	  o The baby or child of the parent or carer is under 5 years-old, or
	  o There is a clear rationale provided as to why the study is using parents' or carers' views on and experiences of healthcare as proxies for their child.

Phenomenon of interest	Experience of healthcare, in particular of being supported by healthcare staff (or not) to be actively involved in, and making decisions about, their own healthcare.
Primary 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): • Accessing or using developmentally-appropriate health literature • Adapting support throughout child's or young person's health journey • Advocacy for child or young person's interests and rights in their role as healthcare professional • Be sensitive to, have knowledge of and understand child or young person's circumstances • Creating a safe environment • Listening to and discussing concerns of child or young person • Provide advice on the individual healthcare needs of child or young person • Respect and protect privacy and dignity of children and young people • Represent child's or young person's interests and rights • Signposting child or young person to appropriate local services

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:

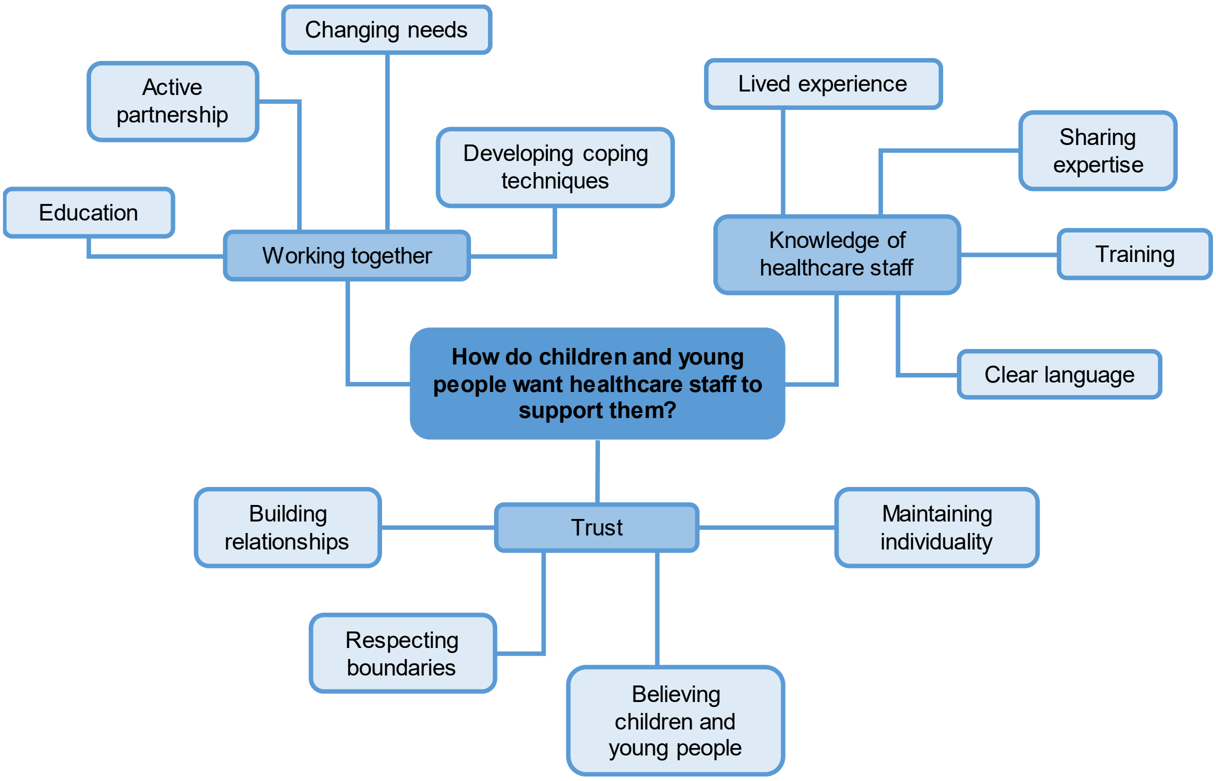
- Understanding how children and young people want healthcare staff to support them to be involved in making decisions about their healthcare.

A systematic review of the literature was conducted using a combined search. Nine studies were included for this review: 8 were qualitative studies (Alderson 2019, Astbury 2017, Davies 2017, Grealish 2013, Harper 2014, Holley 2018, Taylor 2010 and Walsh 2011) and 1 was a mixed-methods study (Davison 2017). Data collection methods included focus groups (Alderson 2019, Holley 2018), face-to-face interviews (Astbury 2017, Davies 2017, Grealish 2013, Harper 2014, Holley 2018, Taylor 2010, Walsh 2011) or a combination of these (Holley 2018). One study also used free-text questionnaires alongside interviews (Davison 2017) while the remaining study used observation of a consultation between parents and healthcare visitors as well as interviews (Astbury 2017). All studies were conducted in the UK.

The included studies are summarised in Table 2.

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

Figure 1: Theme map



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

Excluded studies

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

Summary of studies included in the evidence review

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

Table 2: Summary of included studies

Study	Population	Methods	Themes
Alderson 2019 **Study design** Focus group **Aim of the study** To explore the experiences and views of members of a PPI group for LAC set in the context of an ongoing health service intervention trial. North-East England, UK	N=11 young people **Characteristics** Age range: 15-19 years Gender (M/F): 6/5	**Recruitment** Volunteer sampling of looked after children involved in an established Children in Care Council **Data collection** Focus groups **Analysis** Iterative constant comparative method	• Knowledge of healthcare staff: Sharing expertise • Trust: Maintaining individuality • Trust: Building relationships • Trust: Respecting boundaries • Working together: Active partnership
Astbury 2017 **Study design** Observation and semi-structured interview **Aim of the study** To explore the processes that support shared decision-making when health visitors and parents are creating plans to improve the well-being of babies and children in context of Getting It Right For Every Child policy context Scotland, UK	N=22 • n=11 health visitors • n=11 parental proxies ○ n=2 parental proxies, Phase 1 ○ n=9 parental proxies, Phase 2 • Only the views of the parental proxies are included in this review. **Characteristics** Not reported but health visitors are a national service for parents of children aged 0-5 years old.	**Recruitment** Parents recruited for Phase 1 of study from current caseload of healthcare visitors from 2 Scottish health board areas; Parents recruited for Phase 2 of study from the caseload of last 6 months of healthcare visitors **Data collection** Audio recordings of 2 health visitor-parent consultations in Phase 1 of study, followed by 18 semi-structured interviews (9 with parents and 9 with healthcare visitors) in Phase 2. **Analysis** Thematic framework analysis using NViVo	• Knowledge of healthcare staff: Clear language • Working together: Education

Study	Population	Methods	Themes
Davies 2017 **Study design** Semi-structured interviews **Aim of the study** To examine how parents think about their own role and that of speech and language therapists during a speech and language therapy intervention. England, UK	N=14 parental proxies of pre-school children **Characteristics** Not reported but pre-school age in England is 3-4 years old.	**Recruitment** Purposive sampling from 4 NHS sites in England, used to identify parents of pre-school children attending their initial speech and language therapy assessment until data saturation reached **Data collection** Three semi-structured interviews conducted for each parent whilst their child is receiving typical care **Analysis** Thematic network analysis of 1st round of interviews, followed by thematic (framework) analysis of longitudinal data for each participant and between participants from 1st, 2nd and 3rd interview rounds	• Knowledge of healthcare staff: Sharing expertise • Trust: Respecting boundaries • Working together: Developing coping techniques • Working together: Education
Davison 2017 **Study design** Free-text questionnaires and semi-structured interviews **Aim of the study** To explore young people's experience of using local CAMHS North-East England, UK	N=34 young people • n=34 completed questionnaire • n=17 completed semi-structured interview **Characteristics** Mean age: 15 (SD 0.93) years Gender (M/F): • Questionnaire: 9/25 • Semi-structured interviews: 6/11	**Recruitment** Purposive sampling from a secondary school within a multi-site Foundation Special School which teaches 11-16 year-olds referred from CAMHS **Data collection** CHI ESQ Questionnaire, which includes 3 open-ended questions, followed by semi-structured interviews with subset of participants **Analysis** Thematic analysis	• Knowledge of healthcare staff: Lived experience • Trust: Building relationships • Working together: Active partnership
Grealish 2013 **Study design** Semi-structured interviews **Aim of the study**	N=9 young people **Characteristics** Mean age: 16.4 (range 14-18) years Gender (M/F): 5/4	**Recruitment** No details reported **Data collection** Semi-structured interviews	• Knowledge of healthcare staff: Clear language • Trust: Maintaining individuality • Trust: Believing babies, children and young people

Study	Population	Methods	Themes
To examine how young people with psychosis think about the concept of empowerment. UK (No further specification)		**Analysis** Interpretative phenomenological analysis	• Trust: Building relationships • Working together: Active partnership • Working together: Developing coping techniques • Working together: Education
Harper 2014 **Study design** Semi-structured interviews **Aim of the study** To examine young people's experience of mental health services North-West England, UK	N=10 young people **Characteristics** Age (years): • 16 (n) = 1 • 17 (n) = 5 • 18 (n) = 4 Gender (M/F): 3/7	**Recruitment** Purposive sampling by key workers at 2 NHS 16-18 mental health service sites **Data collection** Semi-structured interviews **Analysis** Interpretative phenomenological analysis	• Knowledge of healthcare staff: Training • Trust: Building relationships • Working together: Active partnership • Working together: Changing needs • Working together: Developing coping techniques
Holley 2018 **Study design** Semi-structured focus group and semi-structured interview **Aim of the study** To explore the views of young people with asthma, their parents and related healthcare professionals, regarding barriers and facilitators to self-management. Southampton and Isle of Wight, UK	N=54 • n=14 healthcare professionals • n=12 parents • n=28 young people (only the views of the young people are included in this review) **Characteristics** Age range: 12-18 years • 12-13 (n)=9 • 14-15 (n)=7 • 16-18 (n)=12 Gender of young people (M/F): 14/14	**Recruitment** Purposive sampling of patient lists from GP surgeries and hospital paediatric outpatient wards **Data collection** Semi-structured focus groups at hospital for each group or if unable to participate in these, structured interviews in home/hospital as preferred by participants **Analysis** Inductive thematic analysis	• Knowledge of healthcare staff: Clear language • Trust: Building relationships • Working together: Active partnership • Working together: Education
Taylor 2010 **Study design** Semi-structured interviews	N=43 from 20 families • n=17 mothers • n=5 fathers • n=1 brother (who acted as an interpreter)	**Recruitment** Consecutive sampling of families attending 1 of 2 paediatric in- and out-patient clinics	• Trust: Building relationships • Working together: Active partnership • Working together: Education

Study	Population	Methods	Themes
Aim of the study To explore the views of children and their parents/carers regarding their involvement in paediatric consultations. Northampton and London, UK	- n=20 children and young people (only the views of the children and young people are included in this review) **Characteristics** Median age: 10 (range 7-16) years Gender (M/F): 5/15	**Data collection** Semi-structured interviews informed by literature review. **Analysis** Thematic framework analysis	
Walsh 2011 **Study design** Semi-structured interviews **Aim of the study** To explore young offenders' views of their mental health needs, their history of support and preferences for future support, and their opinions as to what the barriers are in accessing services effectively. Suffolk, UK	N=44 young people - Only the views of n=6 young people who participated in semi-structured interviews included in this review. **Characteristics** Age (range): 13-17 years Gender (M/F): 4/2	**Recruitment** Purposive sampling of mental health services in Suffolk. **Data collection** Semi-structured interviews informed by earlier questionnaires. **Analysis** Practical thematic analysis.	- Trust: Building relationships - Trust: Maintaining individuality

CAMHS: Child and Adolescent Mental Health Service; F: Female; GP: General practitioner; LAC; looked after children; M: Male; MHS: Mental health service; N: Number; NHS: National Health Service; PPI: patient and public involvement; SD: standard deviation; SLT: speech and language therapy

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

Quality assessment of studies included in the evidence review

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

Main theme 1: Knowledge of healthcare staff

- Sub-theme 1.1: Clear language. The overall confidence in this sub-theme was judged to be moderate.
- Sub-theme 1.2: Sharing expertise. The overall confidence in this sub-theme was judged to be moderate.
- Sub-theme 1.3: Training. The overall confidence in this sub-theme was judged to be low.

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

Main theme 2: Trust

- Sub-theme 2.1: Maintaining individuality. The overall confidence in this sub-theme was judged to be low.
- Sub-theme 2.2: Believing children or young people. The overall confidence in this sub-theme was judged to be very low.
- Sub-theme 2.3: Building relationships. The overall confidence in this sub-theme was judged to be high.
- Sub-theme 2.4: Respecting boundaries. The overall confidence in this sub-theme was judged to be moderate.

Main theme 3: Working together

- Sub-theme 3.1: Active partnership. The overall confidence in this sub-theme was judged to be high.
- Sub-theme 3.2: Changing needs. The overall confidence in this sub-theme was judged to be moderate.
- Sub-theme 3.3: Developing coping techniques. The overall confidence in this sub-theme was judged to be moderate.
- Sub-theme 3.4: Education. The overall confidence in this sub-theme was judged to be high.

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

Evidence from reference groups and focus groups

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

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

Age groups	• <7 years • 7-11 years • 11-14 years
Areas covered	• Healthcare staff qualities • Support from healthcare staff
Illustrative quotes	• 'Let you be asleep if something bad is going to happen' • 'Get a toy if you have been good' • 'Need to be really friendly – so you feel you have known them for a long time so you can trust them more' • 'Especially if they talked about what things they liked so you get to know them better, so you can know who they are' • 'Someone to explain what happens next – looks at lots of options, in advance' • What might influence if you feel able to ask a healthcare professional a question: ○ 'Privacy' ○ '1 on 1' ○ 'Smaller room'

See the full evidence summary in appendix M.

Evidence from national surveys

The grey literature review of national surveys provided additional evidence for this review. A summary of the evidence 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 Outcome Research Consortium. Child- and Parent- reported Outcomes and Experience from Child's and Young People's Mental health services 2011-2015 • National Children's Bureau. Listening to children's views on health provision 2012 • Opinion Matters. Declare your care survey 2018 • Pincker Institute/NHS England/ BLISS. Neonatal survey 2014
Areas covered	• Emotional support • Views and worries • Being taken seriously • Lack of respect • Emotional support • Trust
Key findings	• Most children and young people felt they received adequate emotional support and that their views and worries were taken seriously by healthcare staff • However, young people with disabilities felt that their concerns were not always taken seriously, and recommended performance assessments for staff working with people with long-term conditions • Most of the complaints raised by young people were due to lack of respect from staff or poor patient care • Some parents and carers of babies in the neonatal unit felt that they were offered emotional support, and most of them reported having confidence and trust in the staff caring for their baby

See the full evidence summary in appendix N.

Economic evidence

Included studies

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

Excluded studies

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

Summary of studies included in the economic evidence review

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

Economic model

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

The committee's discussion of the evidence

Interpreting the evidence

The outcomes that matter most

This review focused on understanding how babies, children and young people want healthcare staff to support them regarding their healthcare. The most suitable design to address this was determined to be a qualitative systematic review. Therefore, the committee could not specify in advance the data that would be located. Instead, they identified the following main themes to guide the review:

- Accessing or using developmentally-appropriate health literature
- Adapting support throughout child's or young person's health journey
- Advocacy for child or young person's interests and rights in their role as healthcare professional
- Be sensitive to, have knowledge of and understand child or young person's circumstances
- Creating a safe environment
- Listening to and discussing concerns of child or young person
- Provide advice on the individual healthcare needs of child or young person
- Respect and protect privacy and dignity of children and young people
- Represent child's or young person's interests and rights
- Signposting child or young person to appropriate local services

Not all of these themes were identified in the literature (for example creating a safe environment). Additional sub-themes were identified relating to specialist training, healthcare professionals sharing lived experience and active partnership.

The quality of the evidence

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

Confidence in the review findings ranged from very low to high. Evidence was mainly downgraded due to concerns over the methodological limitations of the included studies. Examples of these are where there was a lack of information regarding recruitment methods or lack of reflexivity in data analysis. Sub-themes were downgraded for coherence in the study findings. For example, the evidence for certain sub-themes were closely interlinked and may have lost some nuances in the synthesis and separation. Some sub-themes were also downgraded due to relevance, where evidence was from very specific populations that might not be generalizable to other babies, children and young people. The evidence was also downgraded due to concerns about the adequacy of data, as some themes included only small amounts of evidence from the included studies.

Benefits and harms

The committee discussed that children and young people have rights relating to the provision of healthcare (as well as other aspects of their lives) and that these are enshrined in the United Nations Convention on the Rights of the Child (UNCRC). The committee discussed that healthcare staff should provide support in line with these rights.

The committee discussed the evidence from the review. They noted that the evidence from the sub-theme on maintaining individuality showed that children and young people have differing needs and preferences for support from healthcare professionals, and that these may vary depending on factors such as personal history and experiences and different ways of coping. The committee therefore recommended that support should be personalised, for example some children may need more support than others and that this support may change over time. The committee agreed that it should be explained to children and young people what support is available and they should be asked how they want to be supported and their preferences about support. The committee noted that this was reinforced by the evidence on respecting boundaries, which indicated that healthcare professionals should respect how much children and young people want them to be involved. There was also evidence that this support might need to be adapted as age and emotional needs evolve, and the committee were aware from their own knowledge and experience that children and young people's need for support would vary depending on what was happening to them, and even from day to day. The committee therefore made a recommendation to state this.

Evidence from a number of sub-themes informed the recommendation on building healthcare relationships with children and young people. By building strong, trusting relationships, children feel more comfortable with healthcare staff, leading to a more truthful and better therapeutic partnership. There was also evidence that children and young people like to be listened to and believed. Based on their own experience and knowledge, the committee discussed that healthcare professionals need to take children and young people's views and concerns seriously, and act on them. They should also ensure that they provide calm and positive emotional support and encouragement when doing this. The committee also agreed that in some situations, healthcare professionals needed to advocate for children, and to support them to speak up for themselves, or to speak on their behalf, including when they feel as though another healthcare professional, or their parent or carer is not listening to these views and concerns.

There was evidence that children and young people valued healthcare professionals helping them to use or develop coping techniques, and sharing coping techniques that they thought would be useful. Finally, the sub-theme on education provided evidence that children and young people liked to be offered education on their diagnosis and possible treatment as part of the support they received from healthcare professionals. They also appreciated information on other support available which could further empower them to make healthcare decisions.

There was evidence from this review which the committee did not use to make recommendations. There was evidence that children and young people wanted support from healthcare professionals in the form of communication and information that was clear, consistent and accurate but the committee agreed that they had already made recommendations in the information and communication sections of the guideline stating this and that they did not need to duplicate them. There was also evidence that children and young people wanted to be supported by healthcare professionals who had specific knowledge about their condition, or preferably lived experience of their condition. The committee agreed that they could not recommend healthcare staff should have lived experience as it would very hard to implement. The committee agreed that healthcare professionals should have specific knowledge about the conditions they were treating, but that recommending the level of specialist knowledge required by healthcare staff was outside the remit of this guideline.

The committee discussed the potential harms from the evidence and recommendations. Evidence from the sub-theme on active partnership suggested that when children and young people are involved in healthcare discussions and decisions, they feel more engaged in their healthcare. However, the committee agreed that there is a risk that involvement in discussions may be implemented in a 'tokenistic' fashion, which can lead to inappropriate healthcare decisions and poorer engagement with treatment. The committee also discussed that if healthcare professionals had had bad healthcare experiences themselves, this may lead them to frame discussions negatively.

The committee reviewed the evidence from the children and young people's focus and reference groups and from the grey literature review of national surveys to help make their recommendations. Evidence from the reference groups showed there was a wide range of suggestions of how healthcare staff can support children and young people. These ranged from building relationships, which was a strong message across all age groups, caring about their feelings, being friendly, and reassuring them, to practical or fun support such as stickers (this was mainly for the 4-7 year olds), toys, support animals to stroke or cuddly toys. They also wanted healthcare professionals to introduce themselves. Several of the national surveys provided additional evidence regarding the importance of healthcare professionals taking children and young people's views seriously, providing emotional support and building relationships with children and young people. The committee decided that these findings were already reflected in their recommendations.

Evidence on believing children and young people, taking their concerns seriously and advocating for their healthcare was included in national surveys of disabled young people and mental health services for young people. Again, the committee felt that this evidence supported the systematic review findings and were already reflected in their recommendations.

The committee highlighted the lack of evidence from children aged 6-11 years old from the systematic review. This population may have differing needs and preferences that are not represented in the themes. However, the evidence from focus groups and grey literature publications is from this age group, and is coherent with the review findings.

Cost effectiveness and resource use

There was no existing economic evidence for this review. The committee noted that there may be some resource implications in terms of healthcare professionals' time required to implement recommendations in this area. In practice, this may require longer consultation times to advise children and young people about how they can be supported, encourage them to express their preferences, facilitating access to support etc. However, the overall view was that the recommendations in this area reflect current practice for most services and would have only modest resource implications, if any, which are justifiable as such care is likely to lead to improvements in children's and young people's experience of healthcare and potentially their quality of life.

Recommendations supported by this evidence review

This evidence review supports recommendations 1.1.4to 1.1.7 and 1.5.7 to 1.5.13 in the NICE guideline.

References

Alderson 2019

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

Astbury 2017

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

Davies 2017

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

Davison 2017

Davison, Jo, Zamperoni, Victoria, Stain, Helen J., Vulnerable young people's experiences of child and adolescent mental health services, Mental Health Review Journal, 22, 95-110, 2017

Grealish 2013

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

Harper 2014

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

Holley 2018

Holley, S., Walker, D., Knibb, R., Latter, S., Liossi, C., Mitchell, F., Radley, R., Roberts, G., Barriers and facilitators to self-management of asthma in adolescents: An interview study to inform development of a novel intervention, Clinical and Experimental Allergy, 48, 944-956, 2018

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, 36, 678-685, 2010

Walsh 2011

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

Appendices

Appendix A – Review protocol

Review protocol for review question: How do children and young people want healthcare staff to support them?

Table 5: Review protocol

Field	Content
PROSPERO registration number	CRD42019152558
Review title	Support from healthcare staff
Review question	How do children and young people want healthcare staff to support them?
Objective	To establish how children and young people want healthcare staff to support them to be involved in, and making decisions about, their own healthcare.
Searches	The following databases will be searched: • CCTR • CDSR • Embase • MEDLINE • MEDLINE IN-Process • PsycINFO One broad, guideline-wide, search will be conducted for qualitative questions, capturing the population and the settings. A UK filter will be applied to identify relevant UK studies and a systematic review filter will be applied to the remainder of the results to identify relevant reviews that include evidence from non-UK high-income countries. If no systematic reviews of this type are identified, then a more focused search may be conducted to identify studies conducted in the following high-income countries: Australia, Austria, Belgium, Canada Denmark, Finland, France, Germany, Greece, Iceland, Ireland, Italy, Liechtenstein, Luxembourg, Malta, Monaco, Netherlands, New Zealand, Norway, Portugal, Spain, Sweden, Switzerland, and USA. Searches will be restricted by: • Date: 2009 • Language of publication: English language only • Publication status: Conference abstracts will be excluded because these do not typically provide sufficient information to fully assess risk of bias

Field	Content
	• Standard exclusions filter (animal studies/low level publication types) will be applied • For each search (including economic searches), the principal database search strategy is quality assured by a second information specialist using an adaption of the PRESS 2015 Guideline Evidence-Based Checklist
Condition or domain being studied	• Babies, children's and young people's experience of healthcare
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.
Intervention/Exposure/Test	Experience of healthcare, in particular of being supported by healthcare staff (or not) to be actively involved in, and making decisions about, their own healthcare.
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 countries not listed in the search strategy 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: • Non-NHS commissioned health promotion interventions

Field	Content
	• Support from staff providing or delivering non-NHS commissioned health promotion interventions • Support from healthcare staff in disease- or condition- specific services (e.g. accessing chemotherapy services), if not applicable to healthcare staff generally • Views and experiences of healthcare professionals and service managers regarding support from healthcare staff 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: ○ Child abuse and neglect (NG76) ○ Child maltreatment: when to suspect maltreatment in under 18s (CG89) • Drug misuse in children and young people: ○ Alcohol: school-based interventions (PH7) ○ Alcohol-use disorders: diagnosis, assessment and management of harmful drinking and alcohol dependence (CG115) ○ Alcohol-use disorders: prevention (PH24) ○ 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: ○ Maternal and child nutrition (PH11) ○ Obesity prevention (CG43) ○ Physical activity for children and young people (PH17) ○ Weight management: lifestyle services for overweight or obese children and young people (PH47) • Pregnancy, including routine antenatal, intrapartum or postnatal care: ○ Antenatal and postnatal mental health: clinical management and service guidance (CG192) ○ Antenatal care for uncomplicated pregnancies (CG62) ○ Intrapartum care for healthy women and babies (CG190) ○ Intrapartum care for women with existing medical conditions or obstetric complications and their babies (NG121) ○ Multiple pregnancy: antenatal care for twin and triplet pregnancies (CG129) ○ Postnatal care up to 8 weeks after birth (CG37)

Field	Content
	○ Pregnancy and complex social factors: a model for service provision for pregnant women with complex social factors (CG110) • Self-harm: ○ Self-harm in over 8s: long-term management (CG133) ○ Self-harm in over 8s: short-term management and prevention of recurrence (CG16) • Sexual health and contraception ○ Contraceptive services for under 25s (PH51) ○ Sexually transmitted infections and under-18 conceptions: prevention (PH3) ○ Harmful sexual behaviour among children and young people (NG55) • Smoking prevention: ○ Smoking: preventing uptake in children and young people (PH14) ○ Smoking prevention in schools (PH23) ○ Stop smoking interventions and services (NG92) • Transition from children's to adults services for young people using health or social care services (NG43)
Context	UK studies from 2009 onwards will be prioritised for decision making by the committee as those conducted in other countries may not be representative of current expectations about either services or current attitudes and behaviours of healthcare professionals. The committee presumes that due to their development, particular circumstances and/or condition, there are some topics that babies, children and young people may not be in a position to pronounce on, and that in these circumstances, it may be necessary to treat the 'indirect' views of their parents or carers as proxies for their own views on and experiences of healthcare in order to make recommendations. The guideline committee will be consulted on whether a study should be included if it is unclear why parents' or carer's views are being reported instead of their child or charge, and reasons for exclusion if appropriate will be documented. The topic about which the children or young people are talking about should be generalizable to the wider healthcare context (e.g. a study on the views on and experience of communication with healthcare professionals whilst receiving chemotherapy would be included, whilst a study on experience of chemotherapy would be too narrow and not generalizable to wider healthcare context and therefore excluded). Recommendations will apply to those receiving care in all settings where NHS- or local authority- commissioned healthcare is provided (including home, school, community, hospital, specialist and transport settings). Specific recommendations for groups listed in the Equality Considerations section of the scope may be also be made as appropriate.
Primary outcomes (critical outcomes)	Themes 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): • Accessing or using developmentally-appropriate health literature • Adapting support throughout child's or young person's health journey (e.g. integrating children or young people more into decision making process as they mature) • Advocacy for child or young person's interests and rights in their role as healthcare professional

Field	Content
	• Be sensitive to, have knowledge of and understand child or young person's circumstances • Creating a safe environment • Listening to and discussing concerns of child or young person • Provide advice on the individual healthcare needs of child or young person • Respect and protect privacy and dignity of children and young people • Represent child's or young person's interests and rights (• Signposting child or young person to appropriate local services (e.g. sexual health, drug and alcohol services, sport and leisure) The following themes will not be covered in this review despite relating to empowering children to advocate for themselves in healthcare: • Babies, children and young people's communication with healthcare staff (reviewed in RQ 1.2) • Consent and privacy (reviewed in RQ 1.3) • Support to participate in usual activities (reviewed in RQ 7.1) • Factors promoting continuity and co-ordination of care (reviewed in RQ 8.2)
Secondary outcomes (important outcomes)	Not applicable
Data extraction (selection and coding)	All references identified by the searches and from other sources will be uploaded into STAR and de-duplicated. Titles and abstracts of the retrieved citations will be screened to identify studies that potentially meet the inclusion criteria outlined in the review protocol. Duplicate screening will not be undertaken for this question. 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 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.
Strategy for data synthesis	• Extracted second-order study themes and related first-order quotes will be synthesised by the reviewer into third-order themes and related sub-themes. • The GRADE-CERQual (Confidence in the Evidence from Reviews of Qualitative research; Lewin 2015) approach will be used to summarise the confidence in the third-order themes or sub-themes synthesized from

Field	Content		
	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.		
Analysis of sub-groups	If there is sufficient data, views and experiences will be analysed separately by the following age ranges: • <1 year-old (i.e. 364 days-old or less) • ≥1 to <12 years-old (i.e. 365 days-old to 11 years and 364 days-old • ≥12 to <18 years-old (i.e. 12 years and 0 days-old to 17 years and 364 days-old) The committee are aware that children can experience substantial cognitive and developmental change during the ages of 1 and 12, and that there may be (though not necessarily) substantive differences between children in this group depending on the topic about which they are being asked. The committee will therefore be consulted regarding whether data regarding further subgroups within this age range (e.g. 1-5, 6-11) should be used. Subgroup analysis according to any of the groups listed in the Equality Considerations section of the scope will be conducted if there is sufficient data.		
Type and method of review	☐	Intervention	
	☐	Diagnostic	
	☐	Prognostic	
	☒	Qualitative	
	☐	Epidemiologic	
	☐	Service Delivery	
	☐	Other (please specify)	
Language	English		
Country	England		
Anticipated or actual start date	25 September 2019		
Anticipated completion date	07 April 2021		
Stage of review at time of this submission	Review stage	Started	Completed
	Preliminary searches		☒

Field	Content		
	Piloting of the study selection process		☒
	Formal screening of search results against eligibility criteria		☒
	Data extraction		☒
	Risk of bias (quality) assessment		☒
	Data analysis		☒
Named contact	**5a. Named contact** National Guideline Alliance **5b. Named contact e-mail** infant&younghealth@nice.org.uk **5c. Organisational affiliation of the review** National Institute for Health and Care Excellence (NICE) and National Guideline Alliance		
Review team members	NGA Technical Team		
Funding sources/sponsor	This systematic review is being completed by the National Guideline Alliance, which receives funding from NICE.		
Conflicts of interest	All guideline committee members and anyone who has direct input into NICE guidelines (including the evidence review team and expert witnesses) must declare any potential conflicts of interest in line with NICE's code of practice for declaring and dealing with conflicts of interest. Any relevant interests, or changes to interests, will also be declared publicly at the start of each guideline committee meeting. Before each meeting, any potential conflicts of interest will be considered by the guideline committee Chair and a senior member of the development team. Any decisions to exclude a person from all or part of a meeting will be documented. Any changes to a member's declaration of interests will be recorded in the minutes of the meeting. Declarations of interests will be published with the final guideline.		
Collaborators	Development of this systematic review will be overseen by an advisory committee who will use the review to inform the development of evidence-based recommendations in line with section 3 of Developing NICE guidelines: the manual. Members of the guideline committee are available on the NICE website: https://www.nice.org.uk/guidance/indevelopment/gid-ng10119/documents		
Other registration details			
Reference/URL for published protocol	https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42019152558		
Dissemination plans	NICE may use a range of different methods to raise awareness of the guideline. These include standard approaches such as:		

Field	Content	
	- 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	Children; decision; decision making; experience; healthcare; healthcare professional; healthcare staff; infant; qualitative; rights; support; views; young people.	
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		
Details of final publication	www.nice.org.uk	

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

Appendix B – Literature search strategies

Literature search strategies for review question: How do children and young people want healthcare staff to support them?

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.
26	"speech and language therap*".tw.

#	Searches
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/
75	(national health service* or nhs*).ti,ab,in,ad,cq.

#	Searches
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
112	102 not 111

#	Searches
113	animals/ not humans/ use ppez
114	animal/ not human/ use emez
115	nonhuman/ use emez
116	"primates (nonhuman)"/
117	exp Animals, Laboratory/ use ppez
118	exp Animal Experimentation/ use ppez
119	exp Animal Experiment/ use emez
120	exp Experimental Animal/ use emez
121	animal research/ use psyh
122	exp Models, Animal/ use ppez
123	animal model/ use emez
124	animal models/ use psyh
125	exp Rodentia/ use ppez
126	exp Rodent/ use emez
127	rodents/ use psyh
128	(rat or rats or mouse or mice).ti.
129	or/112-128
130	87 not 129
131	meta-analysis/
132	meta-analysis as topic/
133	systematic review/
134	meta-analysis/
135	(meta analy* or metanaly* or metaanaly*).ti,ab.
136	((systematic or evidence) adj2 (review* or overview*)).ti,ab.
137	((systematic* or evidence*) adj2 (review* or overview*)).ti,ab.
138	(reference list* or bibliograph* or hand search* or manual search* or relevant journals).ab.
139	(search strategy or search criteria or systematic search or study selection or data extraction).ab.
140	(search* adj4 literature).ab.
141	(medline or pubmed or cochrane or embase or psychlit or psyclit or psychinfo or psycinfo or cinahl or science citation index or bids or cancerlit).ab.
142	cochrane.jw.
143	((pool* or combined) adj2 (data or trials or studies or results)).ab.
144	((comprehensive* or integrative or systematic*) adj3 (bibliographic* or review* or literature)).ti,ab,id.
145	(meta-analy* or metaanaly* or "research synthesis").ti,ab,id.
146	(((information or data) adj3 synthesis) or (data adj2 extract*)).ti,ab,id.
147	(review adj5 (rationale or evidence)).ti,ab,id. and "Literature Review".md.
148	(cinahl or (cochrane adj3 trial*) or embase or medline or psyclit or pubmed or scopus or "sociological abstracts" or "web of science").ab.
149	("systematic review" or "meta analysis").md.
150	(or/131-132,135,137-142) use ppez
151	(or/133-136,138-143) use emez
152	(or/144-149) use psyh
153	150 or 151 or 152
154	73 and 153
155	154 not 130
156	155 not 129

Database: Cochrane Library

Date searched: 29/07/2020

#	Search
1	MeSH descriptor: [Adolescent] this term only
2	MeSH descriptor: [Minors] this term only
3	(adolescen* or teen* or youth* or young or juvenile* or minors or highschool*):ti,ab,kw

#	Search
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
57	(hospital* or inpatient* or outpatient*):ti,ab,kw

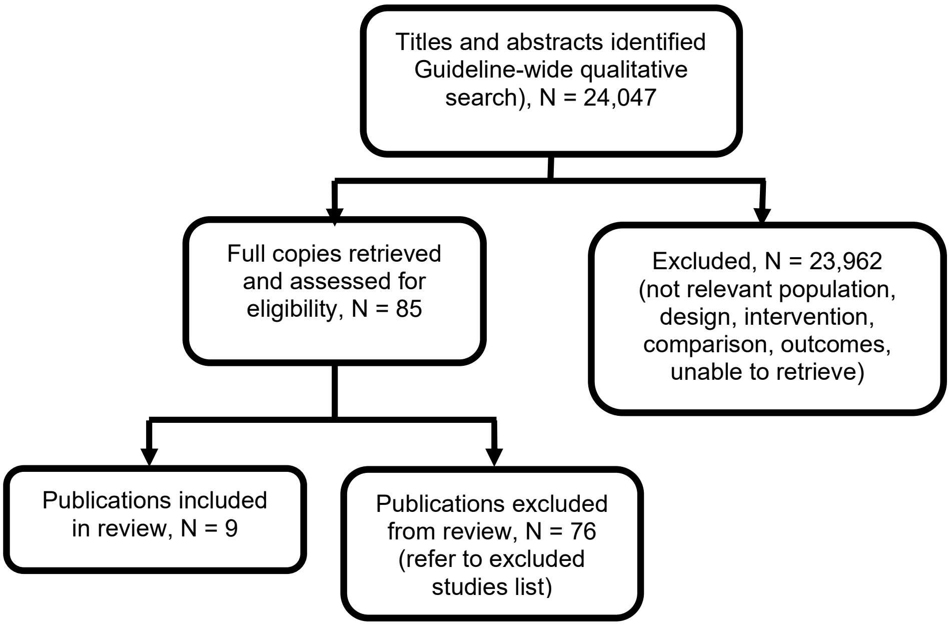
#	Search
58	(health* near/3 (care or center* or centre* or clinic* or facility or facilities or service* or setting* or specialist*)):ti,ab,kw
59	((dental or communit* or emergency or hospital* or home or intensive or high-dependen* or mental* or primary or secondary or tertiary) near/3 (care or health*)):ti,ab,kw
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
104	(grounded near (theor* or study or studies or research or analys*s)):ti,ab,kw

#	Search
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 do children and young people want healthcare staff to support them?

Figure 2: Study selection flow chart



Appendix D – Clinical evidence tables

Evidence tables for review question: How do children and young people want healthcare staff to support them?

Table 6: Evidence tables

Study details	Participants	Methods	Outcomes and Results	Limitations
Full citation 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 **Ref Id** 1052635 **Country/ies where the study was carried out**	**Sample size** N=11 young people • n=7, Phase 1 • n=4, Phase 2 • Only information from Phase 1 was extracted – see other considerations) **Characteristics** Age range:15-19 years Gender (M/F): 6/5 All white British All living in North-East England in • Foster placements • Residential children home • Independent living **Inclusion criteria** Not reported. **Exclusion criteria**	**Setting** North-East England Children in Care Council (CICC) meeting, CICC is an organisation designed to allow looked after children (LAC) and care leavers to have an input in how councils should run their Children's Services. **Sample selection** Researchers contacted the CICC Participation Officer to arrange to attend a CICC meeting. LAC volunteered their interest with the Participation Officer (no information given on how they were informed of the patient and public involvement (PPI) group initially), who then arranged mutually convenient times for researchers and LAC to meet. **Data collection** 9 sessions held over 18 months. Semi-structured focus groups exploring LAC's views to research and how they could contribute to PPI project and their expectations and feelings about working with researchers.	**Results summarised under the following themes:** • Knowledge of healthcare staff: Sharing expertise • Trust: Maintaining individuality • Trust: Building relationships • Trust: Respecting boundaries • Working together: Active partnership **Findings** Face-to-face interaction with researchers was essential in engaging participants. Doing this over a long period of time allowed young people to become comfortable in the situation, allowing a relaxed rapport building. Due to the perceived vulnerability of LAC by society, they routinely miss out on opportunities to be involved in healthcare research. Authors tried to engage LAC on an 'equal' footing, encouraging participants to lead discussions and directing the content of the video aid. Despite this, not all	**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. *Q4: Was the recruitment strategy appropriate to the aims of the research?* Yes - Convenience sampling was used to recruit case interested children and young peoples. However, incentives could have created bias. Looked after children and care leavers were given a £10 voucher for each session they engaged which may have led to bias. *Q5: Were the data collected in a way that addressed the research issue?* Yes - LAC were identified

Study details	Participants	Methods	Outcomes and Results	Limitations
North-East England, UK **Study type** Qualitative **Aim of the study** To explore the experiences and views of members of a PPI group for LAC set in the context of an ongoing health service intervention trial. **Study dates** Not reported. **Source of funding** This study received funding from the Catherine Cookson Foundation and National Institute for Health Research.	Not reported.	Sessions were in 2 parts – the first involved a broad discussion about academic research and they different ways it can be conducted. Second part of the sessions was used to record the group taking part in activities and mock focus groups to be used in final video production The final video was shown in the last sessions, produce top tips of running a PPI session and provide certificate of attendance to all LAC. Interviews were audio-recorded and transcribed verbatim. **Data analysis** Thematic analysis using iterative constant comparative method.	participants were comfortable taking this active role and preferred traditional teacher-student dynamics. Sessions should be interactive. This not only engages LAC but tailors them to the differing literacy and behavioural needs of participants. A familiar person helps LAC to maintain contact with the research programme. This can be support in person (for example during sessions) or via technology (for example by sending reminder text messages). LAC wanted session researchers that had experience and were therefore aware of the challenges encountered in the care system. Researchers should be empathetic, non-judgement and sensitive.	using appropriate channel and data was audio-recorded and transcribed verbatim. *Q6: Has the relationship between researcher and participants been adequately considered?* Can't tell – Researchers involved in the PPI project were interviewed twice by an independent researcher. However, details of the impact of this interviews were not provided. *Q7: Have ethical issues been taken into consideration?* Yes - Informed consent received (and from guardians for under 16s) and ethical approval obtained from Newcastle and North Tyneside NRES. *Q8: Was the data analysis sufficiently rigorous?* Yes - Themes were developed in an iterative manner to in cooperate evolving ideas during the semi-structured interviews and allow for input from an independent researcher to ensure rigour. *Q9: Is there a clear statement of findings?* Yes - The authors discuss findings for supporting LACs within research; supported this within contrary evidence from literature.

Study details	Participants	Methods	Outcomes and Results	Limitations
				Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability) Yes. 1. Yes - Detailed recommendations for PPI, LAC or groups of under-represented young people were provided that are applicable to the UK and future research linked to policy making. 2. Yes - Findings are generalizable to other situations but may require tailoring to non-research contexts within the UK. *Overall judgement of quality:* Minor concerns. **Other information** Study was carried out in 2 phases. Phase 1 involved interviews with LAC and phase 2 involved interviews with researchers, designed to investigate researcher's previous experiences of being involved in PPI work. However, these participants are outside of protocol population so data not extracted.
Full citation Astbury, R., Shepherd, A., Cheyne, H., Working in partnership: the application of shared	**Sample size** N=22 health visitors and parents • n=11 health visitors • n=11 parental proxies for children	**Setting** Parent's home. **Sample selection** Parents were recruited by health visitors from their current case	**Results summarised under the following themes:** • Knowledge of healthcare staff: Clear language • Working together: Education	**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	Outcomes and Results	Limitations
decision-making to health visitor practice, Journal of Clinical Nursing, 26, 215-224, 2017 **Ref Id** 693901 **Country/ies where the study was carried out** Scotland, UK **Study type** Qualitative **Aim of the study** To explore ways to support shared-decision making between health visitors and parents when developing healthcare plans for children under 5. **Study dates** Not reported. **Source of funding** This study received funding from the General Nursing Council for Scotland.	○ n=2 parental proxies, Phase 1 ○ n=9 parental proxies, Phase 2 • Only the views of the parental proxies are included in this review. **Characteristics** Not reported but health visitors are a national service for parents of children aged 0-5 years old. **Inclusion criteria** *Phase 1* Parents had to: • Be in the process of making a decision with health visitor • Give informed consent *Phase 2* Parents had to: • Have made a decision about the healthcare of their child in conjunction with their health visitor in the last 6 months • Give informed consent	load (phase 1) or from within the last 6 months (phase 2). **Data collection** *Phase 1* Audio-recording of 2 health visitor consultations with parents where shared-decision making for child was discussed. These conversations did not have a researcher present. All 4 participants (assuming that parents were treated as dyads but not stated) were asked to complete a questionnaire regarding their experiences of the consultation. *Phase 2* Individual semi-structured interviews where participants were asked to recall an experience of shared-decision making for their child. Separate topic guides were created for healthcare visitors and parents, both based on validated shared decision-making framework. **Data analysis** Framework analysis. 2 recordings from Phase 1 and 18 from Phase 2 were audio-recorded and transcribed verbatim, before adding the responses from the questionnaires. Data was loaded into NVivo resulting in 267 codes and 12 themes. These themes were used to create a framework.	**Findings** Shared decision-making is enhanced by clearly defining the healthcare issues being discussed (either by the health visitor or the parent) and relating it back to the child. If this does not happen, either agreement of the healthcare issue or agreement of the importance of the healthcare issues may be decreased. Parents valued being given information before health visits.	*Q2: Was a qualitative methodology appropriate?* Yes. *Q3: Was the research design appropriate to address the aims of the research?* Yes. Qualitative design used and justified in light of limited understanding of the social constructs that govern interactions between parents and health visitors. *Q4: Was the recruitment strategy appropriate to the aims of the research?* No. Parents were recruited by health visitors themselves which potentially introduces strong sampling bias. *Q5: Were the data collected in a way that addressed the research issue?* Phase 1: Can't tell. The questionnaire used to collect experiences of consultation is validated to establish the extent of shared decision-making. However, in this study it was used to collect the participants' interpretation of the consultation. Participants were aware of the purpose of the study. Phase 2: Can't tell. Shared-decision making could have occurred any time in the last 6 months, introducing recall bias.

Study details	Participants	Methods	Outcomes and Results	Limitations
	Exclusion criteria Not reported.			Participants were aware of the purpose of 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. Study received ethical approval from University of Stirling, School of Health Sciences, Ethics Committee and the NHS Research Ethics Service. Consent obtained from participating parents. *Q8: Was the data analysis sufficiently rigorous?* No. Poor description of analytic process. Contradictory data not presented. No critical examination of the researcher's own role in the process or description of any techniques used to mitigate potential bias and influence during analysis e.g. number of analysts. No description of how data presented was selected but adequate supporting quotes are presented. *Q9: Is there a clear statement of findings?* Can't tell. Good,

Study details	Participants	Methods	Outcomes and Results	Limitations
				detailed explanation of findings within the identified themes, with regular referral back to the original research question. No discussion surrounding evidence for/against findings or credibility. *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. No discussion of future research. 2. Can't tell. Lack of demographic data provided combined with the specific population participants were sampled from limits transferability. *Overall judgement of quality:* Serious concerns. **Other information** Healthcare visitors also interviewed but outside of protocol population so data not extracted.
Full citation Davies, Karen E., Marshall, Julie, Brown, Laura J., Goldbart, Juliet, Co-working: Parents' conception of	**Sample size** N=14 parental proxies for pre-school children **Characteristics**	**Setting** After initial SLT assessments in clinics, children's centres or homes. **Sample selection**	**Results summarised under the following themes:** • Knowledge of healthcare staff: Sharing expertise • Trust: Respecting boundaries	**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	Outcomes and Results	Limitations
roles in supporting their children's speech and language development, Child Language Teaching and Therapy, 33, 171-185, 2017 **Ref Id** 1054856 **Country/ies where the study was carried out** England, UK **Study type** Qualitative **Aim of the study** To explore parental views on their role and healthcare provider's role during their child's SLT and how these change during an SLT intervention. **Study dates** January 2011 - March 2013 **Source of funding** This study received funding from National Institute for Health	Not reported but pre-school age in England is 3-4 years old. **Inclusion criteria** Parents had to: • Have a child referred for SLT primary needs assessment • Have a child between 2 years to 5 years 11 months **Exclusion criteria** • Parents of children with neuro-developmental difficulties • Parents of children with marked social need	Purposive sampling used to collect information from a range of services in a range of demographics. SLT managers from 4 NHS sites in England were used to identify 12 SLTs working with pre-school aged children. These SLTs then invited parents of children who were attending their initial assessment. **Data collection** 3x 20-30 minute semi-structured interviews with each parent scheduled over 30 weeks while their child received care. Each interview had a separate interview schedule, designed and piloted with a parent reference group. The first interview consisted of 9 open-ended questions (focusing on their child's progress in SLT and views on their role in SLT) in a face-to-face setting, with the next 2 interviews (focusing on support, decision-making and expectations) either face-to-face or telephone. **Data analysis** Interviews were audio-recorded, transcribed verbatim and loaded into NVivo. Field notes were kept for each interview. Stage 1: Thematic Network Analysis used to analyse themes from first set of interviews. Each	• Working together: Developing coping techniques • Working together: Education **Findings** Parents wanted SLTs to give them an informed assessment of their child, including how they compared to others. Parents felt that they were unable to form an unbiased opinion of their child. The role of SLTs includes planning and providing techniques to help babies, children and young people develop. Parent's reported differing levels of involvement in this process: some felt as though they were being led by the SLT while some wanted to be involved in the planning. Parents wanted SLTs to educate them in new and alternative ways to help their child develop	*Q2: Was a qualitative methodology appropriate?* Yes. *Q3: Was the research design appropriate to address the aims of the research?* Yes. Qualitative design used and justified. *Q4: Was the recruitment strategy appropriate to the aims of the research?* Yes. Purposive sampling used to ensure a wide variety of demographics captured and due to the specific characteristics of the participants (first-time assessments). However, parents were identified using SLT managers as gate-keepers. *Q5: Were the data collected in a way that addressed the research issue?* Yes. Data collected using recorded semi-structured interviews with justification given. Topic guide was piloted with a small focus group. Saturation of data achieved. *Q6: Has the relationship between researcher and participants been adequately considered?* Yes. Researcher bias was mitigated by using transparency of research design,

Study details	Participants	Methods	Outcomes and Results	Limitations
Research for Programme Grant.		transcript was analysed as soon as it was completed, with 1 researcher completing the coding. Codes were categorised into themes which were then organised into larger framework of global themes. Stage 2: Framework Analysis used to analyse longitudinal data from the sequence of interviews, using themes defined in stage 1. Changes were compared between individuals and within individuals.		contemporaneous field notes, reflexive analysis and input from an advisory group. *Q7: Have ethical issues been taken into consideration?* Yes. Study received ethical approval Manchester Metropolitan University Ethics Committee and NHS Research Authority. Informed consent obtained from all participants before interviews. *Q8: Was the data analysis sufficiently rigorous?* Can't tell. Adequate description of analysis process (both cross-sectional and longitudinal) and how they interacted. Sufficient data presented alongside the findings. Some risk of biases in the study design was discussed, although researcher's own bias was not mentioned. Additionally, only 5 parents out of the 14 completed the 3rd interview with no discussion on how that might affect the reliability of the findings. *Q9: Is there a clear statement of findings?* Yes. Detailed explanation of findings within the identified themes, with regular referral back to the original research question. However, would have liked to see more

Study details	Participants	Methods	Outcomes and Results	Limitations
				discussion around how views changed over time. Adequate discussion surrounding evidence both for and against the study's findings, as well as the 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 how they can be used to inform best practice. Directions for future research not discussed. 2. Yes. Purposive sampling used to ensure variety of socio-economic factors but no other characteristics considered. *Overall judgement of quality:* Minor concerns. **Other information** None.
Full citation Davison, Jo, Zamperoni, Victoria, Stain, Helen J., Vulnerable young people's experiences of child and adolescent mental health services, Mental Health Review Journal, 22, 95-110, 2017	**Sample size** N=34 young people • n=34 completed questionnaire • n=17 completed semi-structured interview **Characteristics**	**Setting** Secondary school in North-East England **Sample selection** Purposive sampling from a secondary school which teaches 11-16 year olds referred from CAMHS. Students have a history of school refusal because of poor attendance at mainstream	**Results summarised under the following themes:** • Knowledge of healthcare staff: Lived experiences • Trust: Building relationships • Working together: Active partnership **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	Outcomes and Results	Limitations
Ref Id 1054883 **Country/ies where the study was carried out** North-East England, UK **Study type** Mixed methods **Aim of the study** To explore the experiences of a group of vulnerable young people using CAMHS in North-East England in order to produce guidance for services wanting to improve user experience. A secondary aim was to validate an experience measure (Commission for Health Improvement Experience of Service Questionnaire) for future use in this population. **Study dates** Not reported.	For total study sample (N=34) Mean age: 15 (SD 0.93) years Gender (M/F): • Questionnaire: 9/25 • Semi-structured interviews: 6/11 All white British **Inclusion criteria** Participants had to: • Be aged 12-18 years old • Currently attending the study school • Current or prior experience of CAMHS • Able to consent **Exclusion criteria** Not reported.	schools, particularly during transition from primary to secondary education. **Data collection** 3 free-text questions were included in the in the CHI-ESQ. A subset of participants undertook 10-25 minute individual semi-structured interviews, conducted on-site at the study school. The interview guide was designed using a selective literature search and available study data from previous CHI-ESQ answers. The interview schedule explores what young people value in their CAMHS care, and the service in general. The questions were piloted with a sample of 2 young people to ensure relevance and ease of understanding. This resulted in only minor amendments to question wording, and so data was included in the final sample. **Analysis** Thematic analysis. Interviews were digitally recorded and transcribed verbatim before transcripts were re-read, highlighting key concepts and quotations to form initial descriptive codes. Data with similar codes were collated together into themes and sub-themes. Themes were	The experiences and views of participants should be respected and valued by healthcare professionals. They should be listened to in a friendly, non-judgemental way. Children reported that feeling listened to improved their mental healthcare experience. Conversely, participants who felt that they were not listened to reported feeling misunderstood and distressed, or decisions being made about their healthcare that were not appropriate. Healthcare staff should be able to understand and relate to young people using mental health services in order for them to feel supported (for example, having staff with experience of mental health disorders). Trust is built by frequent and dedicated contact with young people, especially at the beginning of a relationship. Inconsistent contact with key workers, tardy staff and cancelled appointments were all cited as reasons people did not feel supported by CAMHS.	*Q3: Was the research design appropriate to address the aims of the research?* Yes. Mixed-methods design used to answer the dual research aims of this study - exploring the experiences of vulnerable patients accessing CAMHS and to measure the acceptability of a routine service measurement (CHI-ESQ). *Q4: Was the recruitment strategy appropriate to the aims of the research?* Can't tell. Purposive sampling used to ensure recruitment of vulnerable young people. However, study school is a very specific population (multi-site Foundation Special School in North-East England providing education for adolescents referred from CAMHS). There is a statement saying there is no difference between responders and non-responders but unsure whether this is referring to students who did not want to be tested or those who did not wish to be interviewed. *Q5: Were the data collected in a way that addressed the research issue?* Can't tell. Topic guide for interviews were developed using previous literature and available CHI-ESQ data, reported in the article and was piloted with 2 initial participants. The guide was

Study details	Participants	Methods	Outcomes and Results	Limitations
Source of funding This study was conducted by the Child Outcome Research Consortium and received no external funding.		independently reviewed by another researcher and differences were solved through consensus, before finalising themes.		applied flexibly to allow participants to introduce novel views and experiences. However, no mention of data saturation. Additionally, there is no information provided on the open-ended questions that were included in the thematic analysis. *Q6: Has the relationship between researcher and participants been adequately considered?* Can't tell. Mentions that some of the longer interviews showed much more negative comments, but that this appears to be also due to participant's anxiety in not being able to communicate their views. No further discussion surrounding potential influence from researcher and participants. *Q7: Have ethical issues been taken into consideration?* Yes. Study received ethical approval from Durham University and the study school. Informed consent obtained from students before interviews. *Q8: Was the data analysis sufficiently rigorous?* No. Very brief description of analysis process and how themes very developed from transcripts. No explanation of how raw data presented was selected from the original sample although

Study details	Participants	Methods	Outcomes and Results	Limitations
				adequate data is presented for each theme. Contradictory data not presented. No critical examination of the researcher's own role in the process or description of any techniques used to mitigate potential bias and influence during analysis e.g. number of analysts. No independent coding. *Q9: Is there a clear statement of findings?* No. Very brief description of analysis process and how themes very developed from transcripts. No explanation of how raw data presented was selected from the original sample although adequate data is presented for each theme. Contradictory data not presented. No critical examination of the researcher's own role in the process or description of any techniques used to mitigate potential bias and influence during analysis e.g. number of analysts. *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

Study details	Participants	Methods	Outcomes and Results	Limitations
				presented. 2. Can't tell. Lack of demographic data provided combined with the specific population participants were sampled from limits transferability. *Overall judgement of quality:* Serious concerns. **Other information** None.
Full citation 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 **Ref Id** 989228 **Country/ies where the study was carried out** UK (No further specification) **Study type** Qualitative	**Sample size** N=9 young people **Characteristics** Mean age (years): 16.4 • Range: 14-18 years Gender (M/F): 5/4 Ethnicity (N): • White British=8 • Asian=1 Mean duration of symptoms 5 years (range 3-8 years) **Inclusion criteria** Not specifically reported but paper states that participants were:	**Setting** Not reported. **Sample selection** Not reported. **Data collection** Semi-structured interviews with young people, lasting 60-90 minutes. A choice was given to have parents involved in the interview process - all chose to have their guardians present. Interviews began with a discussion surrounding the concept of empowerment. The interview schedule was designed to use open-ended, neutral questions to prompt a flowing narrative from the participants with minimal input from researchers. **Analysis**	**Results summarised under the following themes:** • Knowledge of healthcare staff: Clear language • Trust: Maintaining individuality • Trust: Believing babies, children and young people • Trust: Building relationships • Working together: Active partnership • Working together: Developing coping techniques • Working together: Education **Findings** Young people reported that they found it empowering to have freedom and flexibility in using their own personal coping mechanisms for psychosis symptoms. These could include going for walks of listening to music.	**Limitations (assessed using the CASP checklist for qualitative studies).** *Q1: Was there a clear statement of the aims of the research?* Yes. To examine how the concept of empowerment applies to young people with psychosis. *Q2: Was a qualitative methodology appropriate?* Yes. Semi-structured interviews. *Q3 Was the research design appropriate to address the aims of the research?* Yes. Qualitative design using interviews were used to explore their experiences. *Q4: Was the recruitment strategy appropriate to the aims of the research?* Can't tell. Participants were purposely selected from

Study details	Participants	Methods	Outcomes and Results	Limitations
Aim of the study To explore the understanding and experience of empowerment in young people with a diagnosis of a psychotic disorder. **Study dates** Not reported. **Source of funding** Not reported.	• In recovery (defined as a period where young people were coping with psychiatric symptoms) • Ongoing contact with CAMHS for a minimum of 6 months at recruitment • Able to provide informed consent as determined by consultant psychiatrist **Exclusion criteria** Not reported.	Interpretative phenomenological analysis (designed to produce a rich idiographic analysis). Data was transcribed verbatim and read/re-read a minimum of 5 times by 1 researcher who was experienced in mental health nursing. Initial ideas and common themes were noted on transcripts, which were then grouped and condensed into a master list for each interview. These were then compared between participants, creating sub-themes and higher-order categories. Themes were checked by 2 other authors and modified if needed. The final findings were presented to a 4th researcher who confirmed the reliability of the analysis.	Young inpatients reported feeling frustrated when their lifestyle choices were impacted by the rules and regulations within institutions. They called staff patronising and inflexible in their enforcement of these rules. Healthcare professionals should use simple language in a non-patronising way to communicate with young people. Participants had less confidence in their treatment if they felt as though they were not being listened to. Participants highlighted the importance of being able to talk about their experience and the feeling of being believed in increasing their empowerment. Being patronised, not being believed and having their stories cut short decreased empowerment. Healthcare professionals should be giving consistent, clear and accurate information to participants. This information should be regarding treatment, symptoms and how to best access and engage relevant services.	only one NHS clinical environment. While there was no dropout, the nature of the recruitment - using links with attending consultant - may have led to coercion. *Q5: Were the data collected in a way that addressed the research issue?* Yes. Authors provide a detailed description of the ethical approval with adequate time before consent. Participants were interviewed in with parents and offered lone interviews. Semi-structured interviews were used, developed using current literature and flexible to allow for the natural evolution of evidence. *Q6: Has the relationship between the researcher and participants been adequately considered?* Can't tell. The influence of the researcher on the data was mentioned but not adequately addressed. *Q7: Have ethical issues been taken into consideration?* Yes. Consent was obtained before the interview and described within the methods, and ethical approval was sought from the local research ethics committee.

Study details	Participants	Methods	Outcomes and Results	Limitations
			Lack of collaboration in treatment decisions, coupled with no explanation of healthcare decisions, increases the risk of young people disengaging from treatment. By talking and discussing symptoms of psychosis, young people were able to increase their understanding of their diagnosis (leading to decreased anxiety and fear) and increase their help-seeking behaviour. Participants commented that lack of education in mental health had a huge impact on their ability to seek help, especially with primary care services acting as gatekeepers to specialist services. Issues included healthcare professionals not listening and not believing symptoms. Young people said that it was important to them that clinicians worked with them to develop their existing coping mechanisms and teach potential new coping mechanisms. This made them feel more confident in utilising the techniques and increasing the possibility of achieving symptom reduction. Of the 2, it was especially important that clinicians respected the coping	*Q8: Was the data analysis sufficiently rigorous?* Yes. Themes were developed iteratively to incorporate contrary ideas and input from a research team to ensure rigour as well as triangulation. *Q9: Is there a clear statement of findings?* Yes. The authors discuss of findings of the experience of empowerment among patients with psychosis, identifying gaps in research grounded in the relevant literature and using broader UK evidence to support their findings as well as recommendations for future research. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* Yes. 1. Details how the study findings fit in with current literature and the UK population were provided, and how they can be used to inform best practice. Ideas and directions for future research presented. 2. Probably. Good mixed of population (children, young people and parents), size for qualitative study and data collection processes; but perhaps less generalizable to other clinical populations.

Study details	Participants	Methods	Outcomes and Results	Limitations
			mechanisms that participants had developed themselves. Empowerment was increased when clinicians assisted inpatients (and their families) in structured activates. Face-to-face contact with clinicians was important for young people, as well as clear discussion of healthcare options. When they were not able to meet with clinicians, participants felt as though they were policing them rather than helping them. Emotional support is paramount in empowering young people. This is enhanced when clinicians are approachable, friendly and funny.	*Overall judgement of quality:* Minor concerns **Other information** None.
Full citation Harper, B., Dickson, J. M., Bramwell, R., Experiences of young people in a 16-18 Mental Health Service, Child and Adolescent Mental Health, 19, 90-96, 2014 **Ref Id** 989439	**Sample size** N=10 young people **Characteristics** Age (years) [N]: • 16 (n)=1 • 17 (n)=5 • 18 (n)=4 Gender (M/F): 3/7 All White-British	**Setting** 2 specialist NHS 16-18 mental health service sites **Sample selection** Purposive sampling. Potential participants were identified by key workers at 2 NHS 16-18 MHS. The study wanted to recruit a small, homogeneous sample in order to obtain rich data source. **Data collection**	**Results summarised under the following themes:** • Knowledge of healthcare staff: Training • Trust: Building relationships • Working together: Active partnership • Working together: Changing needs • Working together: Developing coping techniques **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. *Q3: Was the research design appropriate to address the aims*

Study details	Participants	Methods	Outcomes and Results	Limitations
Country/ies where the study was carried out North-West England, UK **Study type** Qualitative **Aim of the study** To explore young people's experiences of the newly-established 16-18 mental health services. **Study dates** Not reported. **Source of funding** First author received support from the NHS as part of their Clinical Psychology training. No other funding reported.	**Inclusion criteria** Participants had to: • Prior experience of CAMHS • Suitable current mental health status • Be available to participate • Mental capacity to consent **Exclusion criteria** Not reported.	Individual semi-structured interviews lasting an average of 45 minutes (ranged from 25-80 minutes). The interview schedule was designed according to prior literature on young people's experiences of MHS, and modified from another study that investigated transition from childhood to adulthood. Questions focused on encouraging young people to reflect on their experiences of using MHS and the schedule was used flexibly to allow the young people to talk about areas that were important to them. Researchers used limited prompts in an effort to expand views and experiences. The schedule was piloted with 2 study participants to ensure relevance and ease of understanding. After reviewing, data from these interviews was included with the final results. **Analysis** Interpretative phenomenological analysis (designed to produce a rich idiographic analysis). Data was transcribed and researchers were familiarised with the data by reading and re-reading. During this process, preliminary analytical findings were noted before line-by-line coding occurred to summarise findings	Participants commented that they experienced an evolution of mental health issues as they aged. They preferred to see specialist healthcare professionals that they felt were trained to cope with more complex conditions, such as self-harm. One reason given for this was a view that adults were unable to control their emotions and were likely to panic in new scenarios. Young people reported that they felt disempowered and unable to challenge healthcare professionals due to uneven power dynamics. CAMHS were seen as blaming participants for their mental health issues, which served it invalidate their experiences. Collaboration was agreed to be very important to increase independence of young people. Participants gradually develop tools for self-expression throughout adolescences, as well as learning new therapies and techniques. Relationships with therapists were highly valued by young people, involving a large emotional attachment from participants, but reported that	*of the research?* Yes. Interpretive phenomenological analysis used in order to deeply explore participants' personal experiences and views of a particular event. This approach does not make objective statements about analysed data. *Q4: Was the recruitment strategy appropriate to the aims of the research?* Yes. Researchers wanted to recruit a small number of homogenous participants. Key workers from 2 NHS 16-18 MHS identified potential participants. Reasons for non-participation given. *Q5: Were the data collected in a way that addressed the research issue?* Yes. Data collected via semi-structured interviews. Topic guide developed using previous literature and was piloted with 2 initial participants. Examples of questions are provided. The guide was applied flexibly to allow participants to introduce novel views and experiences. However, no mention of data saturation. *Q6: Has the relationship between researcher and participants been adequately considered?* No. No description of potential

Study details	Participants	Methods	Outcomes and Results	Limitations
		and higher-order codes were identified. Emergent themes were used to determine emergent cluster themes for each participant. Throughout this process, original quotes from transcripts were identified. After themes had been determined for each participant, superordinate themes were identified across all participant interviews whilst continually being checked for coherence against the evolving analysis.	these relationships were often ended before they were ready (either due to service protocols or staffing changes). Re-telling stories with new therapists was unhelpful and a source of anxiety for some.	bias/influence between researcher and participants. *Q7: Have ethical issues been taken into consideration?* Yes. Study received ethical approval from NRES. Informed consent obtained before interviews with a 2 week cooling off period to change their mind. *Q8: Was the data analysis sufficiently rigorous?* Yes. Very detailed description of analysis and how themes were derived from the raw transcripts. Section detailing the techniques used to mitigate bias in the analysis, including group discussion of themes, independent researcher conducted an analysis audit at each stage. Contradictory data is presented and discussed where appropriate and a good amount of data is presented to support the reported findings. However, no explanation of how the data presented were chosen from the original sample. *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

Study details	Participants	Methods	Outcomes and Results	Limitations
				findings, as well as the 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 presented. 2. No. Interpretative phenomenological analysis is designed to produce rich data on a homogeneous sample. It is not designed to be generalizable. *Overall judgement of quality:* Minor concerns. **Other information** None.
Full citation Holley, S., Walker, D., Knibb, R., Latter, S., Liossi, C., Mitchell, F., Radley, R., Roberts, G., Barriers and facilitators to self-management of asthma in adolescents: An interview study to inform development of a novel intervention,	**Sample size** N=54 • n=14 healthcare professionals • n=12 parents • n=28 young people (only the views of the young people are included in this review)	**Setting** • Focus groups: Hospital • Semi-structured interviews: Participant's home or hospital **Sample selection** Purposive sampling of GP surgeries and hospital paediatric outpatients lists. Potential participants were contacted by a letter from 1 of their usual	**Results summarised under the following themes:** • Knowledge of healthcare staff: Clear language • Trust: Building relationships • Working together: Active partnership • Working together: Education **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	Outcomes and Results	Limitations
Clinical and experimental allergy, 48, 944-956, 2018 **Ref Id** 989694 **Country/ies where the study was carried out** Southampton and Isle of Wight, UK **Study type** Qualitative **Aim of the study** To address these issues by utilizing robust, contemporary qualitative research methods to gain a broader insight into self-reported barriers and facilitators to adolescent asthma self-management, not just adherence to treatment. **Study dates** October 2014 - March 2015 **Source of funding**	**Characteristics** Age range: 12-18 years • 12-13 (n)=9 • 14-15 (n)=7 • 16-18 (n)=12 Gender of child (M/F): 14/14 **Inclusion criteria** Participants had to: • Be aged 12-18 years • Attend paediatric outpatient clinic for adolescents with doctor-diagnosed asthma • Be prescribed regular prophylactic medication for asthma • Have no other significant long-term medical condition **Exclusion criteria** Not reported.	healthcare professionals. A range of ages, genders and asthma severity were targeted. **Data collection** Individual semi-structured interviews were conducted with participants under 16 years old. Participants aged 16-18 years were given a choice of individual semi-structured interviews or focus groups. Topic guide was developed using a literature review and expert advice. The interview guide was piloted in the first interview. No changes were needed and data were therefore included in this analysis. **Analysis** Inductive thematic analysis with independent interim analysis was performed to ascertain data saturation. Adolescent transcripts were analysed with 2 investigators meeting to discuss the initial codes and review the transcripts developed in NVivo. The same procedure was conducted with the parent and healthcare professional transcripts. Triangulation, multiple perspectives and reflexivity were employed to increase rigour.	Young people discussed how being confused about diagnosis and treatments, not understanding how medications worked and different healthcare professionals issuing conflicting information were barriers to self-management. The amount of information ranged from too much to too little, with both being problematic. Healthcare professionals were negatively described as rude, condescending, poor listeners and officious. babies, children and young people said that they gave incorrect information, contradicting information or not enough information. Young people did not feel as though they were able to ask questions to their healthcare workers. They did not feel comfortable being honest with healthcare professionals regarding their symptoms or medication regimes, or avoided answering questions. However, when a good relationship was established, healthcare professionals were described as nice and supportive, using language that they could understand and gave out understandable information.	*Q3: Was the research design appropriate to address the aims of the research?* Yes. Qualitative design using interviews were used to explore their experiences. *Q4: Was the recruitment strategy appropriate to the aims of the research?* Yes. Participants were purposely selected from GP surgeries and hospital paediatric outpatients. *Q5: Were the data collected in a way that addressed the research issue?* Yes. Semi-structured interviews were used, developed using current literature and flexible to allow new themes to emerge. Interim analysis concluded that saturation had been reached but further interviews were conducted to ensure an even spread of ages and asthma severity. *Q6: Has the relationship between researcher and participants been adequately considered?* Yes. A description of the influence of the researcher on the data was provided. *Q7: Have ethical issues been taken into consideration?* Yes. Written informed consent was

Study details	Participants	Methods	Outcomes and Results	Limitations
This study received funding from the Asthma UK—Joanna Martin Project.				sought from all participants and parents/guardians. Ethical approval was obtained from East of England National Research Ethics Committee. *Q8: Was the data analysis sufficiently rigorous?* Yes. Themes were developed in an iterative manner to in cooperate contrary ideas and input from a research team to ensure rigour. *Q9: Is there a clear statement of findings?* Yes. The authors discuss of findings on self-managing asthma among children and young peoples using broader UK evidence to support their 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 were provided, and how they can be used to inform best practice. Ideas and directions for future research presented. 2. Yes. Good population size for qualitative study and data collection processes. *Overall judgement of quality:* No/very minor concerns.

Study details	Participants	Methods	Outcomes and Results	Limitations
				Other information Study involved parents and healthcare professionals. However, these participants are outside the protocol population and data not extracted.
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 **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	**Sample size** N=43 from 20 families • n=17 mothers • n=5 fathers • n=1 brother (who acted as an interpreter) • n=20 children and young people (only the views of the children and young people are included in this review) **Characteristics** *Characteristics reported for children and young people only* Median age: 10 (range 7-16) years Gender (M/F): 5/15 **Inclusion criteria** Participants had to: • Be aged 6-16 • Be fluent in English	**Setting** 2 paediatric units (1 in North London, 1 in Northampton). **Sample selection** Consecutive sampling of families attending participating clinics at 2 paediatric units. Written consent was obtained from the parents and then children. **Data collection** Semi-structured interviews with parents and children following paediatric consultations. A literature review was used to design an interview guide to study parental and child attitudes towards the child's involvement at various stages of the consultation. 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.	**Results summarised under the following themes:** • Trust: Building relationships • Working together: Active partnership • Working together: Education **Findings** Children need to feel at ease in order to be involved in the consultation. Doctors should increase child participation by being interested, relaxing and not rushing child, using rewards and making child feel important. They should offer to see babies, children and young people alone (although this does not have to be at the exclusion of seeing babies, children and young people with their parents). Healthcare professionals should attempt to increase the amount of information given with increasing age and understanding of babies, children and young people. A collaborative approach should be	**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?* Can't tell. No specific justification given for qualitative research. Noted that there is a lack of research into paediatric communication so gaining a better understanding of the family experience is a logical first step. *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

Study details	Participants	Methods	Outcomes and Results	Limitations
parents/carers to their involvement in paediatric consultations. **Study dates** Not reported. **Source of funding** This study received support from Imperial College London.	- Be accompanied by at least 1 parent - Not have a learning disability - Be well enough to participate in interview **Exclusion criteria** Not reported.	**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 place. All transcripts were read and analysed by 2 researchers, with another validating the methodology.	taken when reaching a diagnosis and treatment plan.	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?* Can't tell. 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. *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	Outcomes and Results	Limitations
				Q7: Have ethical issues been taken into consideration? Can't tell. Informed consent received from parents and child. Paper states that local research ethic committee approval was granted but no further information. *Q8: Was the data analysis sufficiently rigorous?* Can't tell. 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 and children throughout the different

Study details	Participants	Methods	Outcomes and Results	Limitations
				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** None.
Full citation 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	**Sample size** N=44 young people • Only the views of n=6 young people who participated in semi-structured interviews included in this review. **Characteristics**	**Setting** Mental health services in Suffolk, East of England. **Sample selection** Target sample size of 66 participants with wide age-range was targeted to maximise the sample size and gain a representative distribution of views. Participants were recruited	**Results summarised under the following themes:** • Trust: Building relationships • Trust: Maintaining individuality **Findings** Social workers were typically blamed for young people's problems (for example, causing family problems).	**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*

Study details	Participants	Methods	Outcomes and Results	Limitations
Community, 19, 420-428, 2011 **Ref Id** 910269 **Country/ies where the study was carried out** Suffolk, UK **Study type** Qualitative **Aim of the study** To explore young offenders' views of their mental health needs, their history of support and preferences for future support, and their opinions as to what the barriers are in accessing services effectively. **Study dates** Summer of 2008 **Source of funding** Grant from the Suffolk Youth Offending Service	Age (range): 13-17 years Gender (M/F): 4/2 **Inclusion criteria** Participants had to: • Have completed questionnaire **Exclusion criteria** Not reported	from the whole of the Suffolk geographical area. **Data collection** All interview participants were aged between 13- and 17-years old. Interviews lasted 30–45 minutes and were structured around the responses the young people had given to their questionnaires. Interviews were tape-recorded. **Analysis** Data were qualitatively analysed using a practical thematic analysis method.	Communication via telephone was not liked due to lack of face-to-face contact and scepticism regarding degree of engagement of support worker on other end of line. Young people were concerned about transitory rather than long-term nature of relationship. This lack of continuity of relationship with service professional discourages them from seeking support from healthcare professionals for mental health disorders or emotional difficulties. Young people are generally concerned about confidentiality (for example, when meeting GP with parents) and how others perceive them. This appears to be regardless of who is providing support.	*of the research?* Yes. Qualitative design using interviews were used to explore who young people sought help from in the past in relation to any mental health or emotional difficulties, which they would be most likely to seek advice from if problems were experienced in the future, what the barriers might be, and what they understood about mental health problems. Q4: *Was the recruitment strategy appropriate to the aims of the research?* No. Details on recruitment strategy was not provided, suitable volunteers were identified and approached by caseworkers, suggesting selection bias. Caseload members targeted were screened by workers and considered not to be at risk of harm by participation. 44 young people completed and returned questionnaires, and 6 young people agreed to participate in a follow-up interview. Q5: *Were the data collected in a way that addressed the research issue?* Yes. Semi-structured interviews were used, but no detailed information on interview guides

Study details	Participants	Methods	Outcomes and Results	Limitations
				Q6: *Has the relationship between the researcher and participants been adequately considered?* No. Descriptions of potential bias/influence between researcher and participants were not described. Q7: *Have ethical issues been taken into consideration?* Yes. A Local University Ethics Committee granted ethical approval for the study. Legal guardian consent was obtained for each participant below 18 years. Q8: *Was the data analysis sufficiently rigorous?* Yes. Independent researchers developed themes and categories using an iterative approach; disagreements were resolved with consensus, and contrary statements were incorporated in the findings. Q9: *Is there a clear statement of findings?* Yes. The authors provide a clear discussion of results on structural barriers, poor communication and collaboration; supported by literature on broader UK mental health services.

Study details	Participants	Methods	Outcomes and Results	Limitations
				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 presented. 2. Probably. Good population size for qualitative study and sample had a wide age range. *Overall judgement of quality:* Moderate concerns. **Other information** None.

CAMHS: Children and Adolescent Mental Health service; CASP: Critical Skills Appraisal Programme; CHI-ESQ: Commission for health improvement experience of service questionnaire; CICC: Children in care council; GP: General practitioner; HCP: Healthcare professional; K: Number of studies; LAC: looked after children; MHS: Mental health service; N: number; NHS: National Health Service; NRES: National Research Ethics Service; PPI: Patient and public involvement; SLT: Speech and language therapy/therapist

Appendix E – Forest plots

Forest plots for review question: How do children and young people want healthcare staff to support them?

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

Appendix F – GRADE-CERQual tables

GRADE-CERQual tables for review question: How do children and young people want healthcare staff to support them?

Table 7: Evidence summary (GRADE-CERQual) for theme 1: Knowledge of healthcare staff

Study information		Description of theme or finding	CERQUAL Quality assessment				
No of studies	**Design**		**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
Sub-theme 1.1: Clear language							
3 (Astbury 2017, Grealish 2013 and Holley 2018)	Observations of consultations, semi-structured interviews and focus groups.	Data from 3 studies showed that healthcare professionals should use clear and simple language in order to convey consistent and accurate healthcare information to children and young people. This decreases confusion surrounding diagnoses and treatment, which increases the likelihood of babies, children and young people engaging in conversations and decisions. Professionals may have to work with individual babies, children and young people to understand the best way to explain information to them specifically. *'They were so good at explaining things, they'd keep explaining things until I understood them and they didn't use big words'. (Grealish 2013, page 141)*	Moderate concerns[1]	No/very minor concerns	No/very minor concerns	Minor concerns[2]	MODERATE
Sub-theme 1.2: Sharing expertise							
2 (Alderson 2019,	Semi-structured interviews	Data from 2 studies showed that sharing expertise on communication techniques, or	Minor concerns[3]	No/very minor concerns	Minor concerns[4]	Moderate concerns[5]	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
Davies 2017)	and focus groups.	coping mechanisms that might not be learnt through traditional education, can support children and young people in their healthcare journey. *'Sometimes as a parent you don't know what strategy to follow and what's going to work and obviously they're more experienced, and sort of feel they can advise you.' (Davies 2017, page 180, parental proxy)*					
Sub-theme 1.3: Training							
1 (Harper 2014)	Semi-structured interviews	Data from 1 study showed that children and young people feel more supported when they know professionals have received specialist training in their particular healthcare issue. *'…they (CAMHS Staff) didn't seem to get my self-harm and seemed to panic, (they) need to know that and be trained for those different aspects,' (Harper 2014, page 92)*	Minor concerns[6]	No/very minor concerns	No/very minor concerns	Serious concerns[7]	LOW
Sub-theme 1.4: Lived experience							
1 (Davison 2017)	Semi-structured interviews	Data from 1 study showed that, in order to completely understand their experiences, children and young people wanted healthcare staff to have a personal connection to their condition.	Serious concerns[8]	No/very minor concerns	No/very minor concerns	Serious concerns[7]	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**
		'Someone who can relate to them [young people] […] someone who's been through it themselves and someone that can actually talk to them with past experience' *(Davison 2017, page 101)*					

1 Evidence was downgraded due to moderate concerns about methodological limitations as per CASP qualitative checklist
2 Evidence was downgraded for adequacy because studies together offered moderately rich data
3 Evidence was downgraded due to minor concerns about methodological limitations as per CASP qualitative checklist
4 Evidence was downgraded for relevance of evidence as the finding contains the experiences of children and young people when developing a Patient and Public Involvement group, rather than direct experiences with healthcare services
5 Evidence was downgraded for adequacy because studies together offered some rich data
6 Evidence was downgraded due to minor concerns about methodological limitations as per CASP qualitative checklist
7 Evidence was downgraded for adequacy because studies together did not offer rich data
8 Evidence was downgraded due to serious concerns about methodological limitations as per CASP qualitative checklist

Table 8: Evidence summary (GRADE-CERQual) for theme 2: Trust

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: Maintaining individuality							
2 (Alderson 2019 and Grealish 2013)	Semi-structured interviews and focus groups	Data from 2 studies showed that recognising that different young people have differing needs helps healthcare professionals to support them better. Not every child has the same communication level, personal demographics or history. Healthcare staff should not adhere to the 'one size fits all' motif. *'Because I had the freedom to go anywhere like when I was hearing the voices and stuff I had the freedom to use my ways of coping*	Moderate concerns[1]	Minor concerns[2]	Minor concerns[3]	Moderate concerns[4]	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**
		(pointing to the chart) I didn't have to ask anyone could I go to my room things like that (5 sec pause) and I was able to chill out as well whenever I wanted and this relaxed me.' (Grealish 2013, page 140)					
Sub-theme 2.2: Believing children or young people							
1 (Grealish 2013)	Semi-structured interviews	Data from 1 study showed that, in order to support young people, healthcare professionals should listen to young people and believe their experiences. This is important in accessing appropriate services, particularly considering the gatekeeping role primary healthcare providers have. *'He (the doctor) said I was just doing it (acting on my voices) he just said that I could control what I was doing and that I should get on with my work and stuff.' (Grealish 2013, page 142)*	Moderate concerns[5]	No/very minor concerns	Moderate concerns[6]	Serious concerns[7]	VERY LOW
Sub-theme 2.3: Building relationships							
7 (Alderson 2019, Davison 2017, Grealish 2013, Harper 2014, Holley 2018, Taylor 2010,	Semi-structured interviews and focus groups	Data from 7 studies showed that building relationships with children and young people allows them to feel comfortable with healthcare staff. This can range from the practical (e.g. reliability with appointments) to the emotional (e.g. emotional support). A good rapport with babies, children and young people encourages them to be truthful with healthcare staff, building a better therapeutic partnership. Similarly, a	Minor concerns[8]	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
Walsh 2011)		consistent relationship with a healthcare provider can encourage young people to seek help about more personal healthcare disorders such as mental health or sexual health concerns. *'they had a laugh with me. . . and that helped me to relax and I felt I could open up to them they were so caring friendly and always listened to me talk me and stuff and they tried to understand me as well and I had fun with them as well'. (Grealish 2013, page144)*					
Sub-theme 2.4: Respecting boundaries							
3 (Alderson 2019, Davies 2017, Walsh 2011)	Semi-structured interviews and focus groups	Data from 3 studies showed that healthcare professionals should be aware that different people wish to be involved to different extents or in different areas. This can be due to poor past experiences with healthcare/social services or current concerns regarding healthcare decisions. Therefore, they should try to ascertain this level and ensure children and young people are involved to the extent they wish to be. *'Some people will treat us differently but you have come to us to ask us whether we want to do it. Rather than just going to a group of young people, "Right, do you want to do*	Moderate concerns[5]	Minor concerns[2]	No/very minor concerns	Minor concerns[9]	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
		this?" you've come to children that are in care and given us the opportunity to get our voices heard' (Alderson 2019, page 4)					

1 Evidence was downgraded due to moderate concerns about methodological limitations as per CASP qualitative checklist
2 The evidence was downgraded for coherence of findings as the theme was a combination of a few varying but related experiences
3 Evidence was downgraded for relevance of evidence as the finding contains the experiences of children and young people when developing a Patient and Public Involvement group, rather than direct experiences with healthcare services
4 Evidence was downgraded for adequacy because studies together offered some rich data
5 Evidence was downgraded due to moderate concerns about methodological limitations as per CASP qualitative checklist
6 Evidence was downgraded for relevance as the finding contains young people's experiences regarding psychosis which may impact how much they are believed
7 Evidence was downgraded for adequacy because studies together did not offer rich data
8 Evidence was downgraded due to minor concerns about methodological limitations as per CASP qualitative checklist
9 Evidence was downgraded for adequacy because studies together offered moderately rich data

Table 9: Evidence summary (GRADE-CERQual) for theme 3: Working together

Study information		Description of theme or finding	CERQUAL Quality assessment				
No of studies	Design		Methodological limitations	Coherence of findings	Applicability of evidence	Adequacy of data	Overall confidence
Sub-theme 3.1: Active partnership							
6 (Alderson 2019, Davison 2017, Grealish 2013, Harper 2014, Holley 2018 and Taylor 2010)	Semi-structured interviews and focus groups	Data from 6 studies showed that active participation (including children and young people to engage in their consultations and discussions surrounding treatment) encourages them to get involved in their healthcare, empowering them to make healthcare decisions. If they were not listened to, children and young people report inappropriate healthcare decisions being made and feeling disconnected from services. *'They just didn't quite understand […] they made wrong decisions […] that*	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**	**Applicability of evidence**	**Adequacy of data**	**Overall confidence**
		kind of made me worse […] I should have been involved in those decisions' (Davison 2017, page 101)					
Sub-theme 3.2: Changing needs							
1 (Harper 2014)	Semi-structured interviews	Data from 1 study showed that healthcare professionals need to be aware that education, emotional and healthcare needs young people change with their age, and make amendments to their supportive approaches. *'I think it does change so compared to 4 years ago, 12 to 16, I've got different worries and I need someone who can cope with those…' (Harper 2014, page 92)*	Minor concerns[2]	No/very minor concerns	No/very minor concerns	Moderate concerns[3]	MODERATE
Sub-theme 3.3: Developing coping techniques							
3 (Davies 2017, Grealish 2013 and Harper 2014)	Semi-structured interviews	Data from 3 studies showed that healthcare professionals should work with children and young people to develop coping mechanisms that work for them. This is particularly effective when professionals help enhance coping mechanisms that babies, children and young people have come up with themselves. *'They taught me different methods to use like m.. listening to my discs put the earphones into your ears so that it's right. And like getting an elastic band to pulling at it and stuff.' (Grealish 2013, page 143)*	Moderate concerns[4]	No/very minor concerns	No/very minor concerns	Minor concerns[5]	MODERATE

Study information		Description of theme or finding	CERQUAL Quality assessment				
No of studies	**Design**		**Methodological limitations**	**Coherence of findings**	**Applicability of evidence**	**Adequacy of data**	**Overall confidence**
Sub-theme 3.4: Education							
5 (Astbury 2017, Davies 2017, Grealish 2013, Holley 2018 and Taylor 2010)	Observations of consultations, semi-structured interviews and, focus groups	Data from 5 studies showed that when healthcare professionals ensure that they provide children and young people with information and education about their healthcare condition, it increases their understanding about diagnosis and possible treatment routes. Additionally, educating babies, children and young people on the services that are available to them increases their access to advocacy and support organisations. These all serve to empower babies, children and young people in their healthcare decision making and care. *'It helped me. . . the knowledge. . .I think it's a lot of help when she explains something to me. . . it's made it a lot easier to manage cause I know what's happening'. (Holley 2018, page 948)*	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
2 Evidence was downgraded due to minor concerns about methodological limitations as per CASP qualitative checklist
4 Evidence was downgraded due to moderate concerns about methodological limitations as per CASP qualitative checklist
5 Evidence was downgraded for adequacy because studies together offered moderately rich data
6 Evidence was downgraded due to minor concerns about methodological limitations as per CASP qualitative checklist

Appendix G – Economic evidence study selection

Economic evidence study selection for review question: How do children and young people want healthcare staff to support them?

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

Appendix H – Economic evidence tables

Economic evidence tables for review question: How do children and young people want healthcare staff to support them?

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

Appendix I – Economic evidence profiles

Economic evidence profiles for review question: How do children and young people want healthcare staff to support them?

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

Appendix J – Economic analysis

Economic evidence analysis for review question: How do children and young people want healthcare staff to support them?

No economic analysis was conducted for this review question.

Appendix K – Excluded studies

Excluded studies for review question: How do children and young people want healthcare staff to support them?

Clinical studies

Table 10: Excluded studies and reasons for their exclusion

Study	Reason for Exclusion
Aarthun, A., Akerjordet, K., Parent participation in decision-making in health-care services for children: an integrative review, Journal of nursing management, 22, 177-191, 2014	Population of included studies did not match protocol. Individual studies checked for inclusion.
Abbott, M., Bernard, P., Forge, J., Communicating a diagnosis of Autism Spectrum Disorder - a qualitative study of parents' experiences, Clinical Child Psychology and Psychiatry, 18, 370-382, 2013	Outcomes not in protocol - No themes relating to advocacy and support in healthcare, and views are very parent-centric
Abrines Jaume, N., Hoffman, J., Wolpert, M., Law, D., Wright, E., Shared decision making in child and adolescent mental health services, Neuropsychiatrie de l'Enfance et de l'Adolescence, 1), S294, 2012	Conference abstract
Actrn,, Improving outcomes in mental health for children and families: a study of Enhanced Stepping Stones Triple P, Http://www.who.int/trialsearch/trial2.aspx?Trialid=actrn12618000981224, 2018	Protocol for ongoing clinical trial
Ahuja, Alka S., Williams, Richard, Telling stories: Learning from patients' and families' experiences of specialist child and adolescent mental health services, International Journal of Consumer Studies, 34, 603-609, 2010	Population not in protocol - 15 parents/carers of patients aged 5-15. Patients only (jointly) participated in 2 of the interviews.
Alderdice, F., Gargan, P., McCall, E., Franck, L., Online information for parents caring for their premature baby at home: A focus group study and systematic web search, Health Expectations, 30, 30, 2018	Outcomes not in protocol - No themes relating to advocacy and support in healthcare
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
Allcock, D., Smith, K., Exploring parent views of community matrons, Nursing Times, 110, 21-23, 2014	Outcomes not in protocol - No qualitative data analysis performed
Allen, D., Scarinci, N., Hickson, L., The Nature of Patient- and Family-Centred Care for Young Adults Living with Chronic Disease and their Family Members: A Systematic Review, International Journal of Integrated Care [Electronic Resource]Int J Integr Care, 18, 14, 2018	Population of included studies did not match protocol. Individual studies checked for inclusion.
Allen, N., McFarlane, L., Shanahan, R., Bassett, E. Z. A., Wellcome home: The work of shelter, a charitable organisation in facilitating the discharge of children with medical complexities (CMIC) at birmingham children's hospital, Developmental medicine and child neurology, 59 (Supplement 4), 76, 2017	Conference abstract
Anderson, L., Wilson, J., Williams, G., Cognitive Orientation to daily Occupational Performance (CO-OP) as group therapy for children living with motor coordination difficulties: An integrated literature review, Australian occupational therapy journal, 64, 170-184, 2017	Study design of included studies did not match protocol. Individual studies checked for inclusion.

Study	Reason for Exclusion
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
Aranda, K., Coleman, L., Sherriff, N. S., Cocking, C., Zeeman, L., Cunningham, L., Listening for commissioning: A participatory study exploring young people's experiences, views and preferences of school-based sexual health and school nursing, Journal of Clinical Nursing, 27, 375-385, 2018	Outcomes not in protocol - No themes related to advocacy and support
Arenson, M., Hudson, P. J., Lee, N., Lai, B., The Evidence on School-Based Health Centers: A Review, Lobal Pediatric HealthGlob, 6, 2333794X19828745, 2019	Study design not in protocol - Narrative review.
Armitage, S., Swallow, V., Kolehmainen, N., Ingredients and change processes in occupational therapy for children: a grounded theory study, Scandinavian journal of occupational therapy, 24, 208-213, 2017	Population and outcomes not in protocol - Any themes relating to advocacy and support were from parents of children aged 7-11.
Armstrong, V. G., Howatson, R., Parent-infant art psychotherapy: A creative dyadic approach to early intervention, Infant mental health journal, 36, 213-222, 2015	Study design not in protocol - No qualitative data analysis presented.
Ashcraft, L. E., Asato, M., Houtrow, A. J., Kavalieratos, D., Miller, E., Ray, K. N., Parent Empowerment in Pediatric Healthcare Settings: A Systematic Review of Observational Studies, Patient, 12, 199-212, 2019	Population not in protocol - Focuses on parental empowerment within healthcare decision-making rather than how children would like their parent's involved in their healthcare
Ashfield-Watt, P., Philips, A., Dale, P., Hale, M., McDowell, I., Exploring digital arts-based approaches that empower children and young people with Familial Hypercholesterolaemia (FH), Atherosclerosis Supplements, 28, e6, 2017	Conference abstract
Aston, Hermione Jane, An ecological model of mental health promotion for school communities: Adolescent views about mental health promotion in secondary schools in the UK, International Journal of Mental Health Promotion, 16, 289-307, 2014	Phenomenon of interest not in protocol - Mental health promotion within a secondary school curriculum.
Audrey, S., Batista Ferrer, H., Ferrie, J., Evans, K., Bell, M., Yates, J., Roderick, M., Macleod, J., Hickman, M., Impact and acceptability of self-consent procedures for the school-based human papillomavirus vaccine: A mixed-methods study protocol, BMJ open, 8 (3) (no pagination), 2018	Published protocol for ongoing trial
Babbage, C., Jackson, G. M., Nixon, E., Desired Features of a Digital Technology Tool for Self-Management of Well-Being in a Nonclinical Sample of Young People: Qualitative Study, JMIR Mental Health, 5, e10067, 2018	Outcomes not in protocol - No themes relating to advocacy and support in healthcare
Cavaleri, Mary A., Olin, S., Kim, Annie, Hoagwood, Kimberly E., Burns, Barbara J., Family support in prevention programs for children at risk for emotional/behavioral problems, Clinical Child and Family Psychology Review, 14, 399-412, 2011	Study design of included studies did not match protocol. Individual studies checked for inclusion.
Dale, H., Watson, L., Adair, P., Moy, M., Humphris, G., The perceived sexual health needs of looked after young people: findings from a qualitative study led through a partnership between public health and health psychology, Journal of Public Health, 33, 86-92, 2011	Phenomenon of interest not in protocol - Sexual health and contraception with no generalizable themes.
Daniels, Karen, Cultural agents creating texts: A collaborative space adventure, Literacy, 48, 103-111, 2014	Setting not in protocol - Early years compulsory education setting

Study	Reason for Exclusion
Datt, C., Travers, M., Odell, C., Improving the hospital experience for young people (YP) with autism, Archives of disease in childhood, 102 (Supplement 1), A20, 2017	Conference abstract
Dawson, A., Jackson, D., The primary health care service experiences and needs of homeless youth: a narrative synthesis of current evidence, Contemporary nurse, 44, 62-75, 2013	Phenomenon of interest of included studies did not match protocol. Individual studies checked for inclusion.
Dublon, V. E., Green, S., Benitez-Castillo, M., Edwards, T., Leiva, A., The production of a diabetes information film, by young people who have diabetes, as a means of educating others, Archives of disease in childhood, 103 (Supplement 1), A166, 2018	Conference abstract
Dunn, V., O'Keeffe, S., Stapley, E., Midgley, N., Facing Shadows: working with young people to coproduce a short film about depression, Research Involvement & Engagement, 4, 46, 2018	Study design not in protocol - No qualitative data analysis presented
Dunne, A., Carolan, R., Swords, L., Fortune, G., Patient and family perspectives of paediatric psychogenic non-epileptic seizures: A systematic review, Seizure, 71, 279-285, 2019	Phenomenon of interest of included studies did not match protocol. Individual studies checked for inclusion.
Eaton, Kim, Ohan, Jeneva L., Stritzke, Werner G., Courtauld, Hannah M., Corrigan, Patrick W., Mothers' decisions to disclose or conceal their child's mental health disorder, Qualitative health research, 27, 1628-1639, 2017	Country: Australia
Edbrooke-Childs, J., Edridge, C., Averill, P., Delane, L., Hollis, C., Craven, M. P., Martin, K., Feltham, A., Jeremy, G., Deighton, J., Wolpert, M., A Feasibility Trial of Power Up: Smartphone App to Support Patient Activation and Shared Decision Making for Mental Health in Young People, JMIR MHealth and UHealth, 7, e11677, 2019	Outcomes not in protocol - No themes relating to how children want their healthcare staff to support them
Edwards, D., Noyes, J., Lowes, L., Haf Spencer, L., Gregory, J. W., An ongoing struggle: A mixed-method systematic review of interventions, barriers and facilitators to achieving optimal self-care by children and young people with Type 1 Diabetes in educational settings, BMC pediatrics, 14 (1) (no pagination), 2014	Phenomenon of interest of included studies did not match protocol. Individual studies checked for inclusion.
Ellis, J., Boger, E., Latter, S., Kennedy, A., Jones, F., Foster, C., Demain, S., Conceptualisation of the 'good' self-manager: A qualitative investigation of stakeholder views on the self-management of long-term health conditions, Social Science and Medicine, 176, 25-33, 2017	Population not in protocol - Over 18 years old
Fargas-Malet, Montserrat, McSherry, Dominic, Pinkerton, John, Kelly, Greg, Home on a care order: Who the children are and what the care order is for, Child & Family Social Work, 22, 813-821, 2017	Outcomes not in protocol - No themes relating to advocacy and support in healthcare
Fasciano, K., Souza, P., Bielaczyc, A., Englander, S., Building connection and creating community through the development of a young adult cancer conference, Psycho-Oncology, 3), 191-192, 2014	Conference abstract
Fawcett, R., Porritt, K., Stern, C., Carson-Chahhoud, K., Experiences of parents and carers in managing asthma in children: A qualitative systematic review, JBI Database of Systematic Reviews and Implementation Reports, 17, 793-984, 2019	Population of included studies did not match protocol. Individual studies checked for inclusion.

Study	Reason for Exclusion
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 did not match protocol. Individual studies checked for inclusion.
Franck, L. S., Oulton, K., Bruce, E., Parental involvement in neonatal pain management: an empirical and conceptual update, J Nurs Scholarsh, 44, 45-54, 2012	Parental views of under 5s but poor proxy. Themes are developed around how parents want to be included in their children's care, rather than how they think their child would want them to be involved.
Giambra, B. K., Stiffler, D., Broome, M. E., An integrative review of communication between parents and nurses of hospitalized technology-dependent children, Worldviews on evidence-based nursing / Sigma Theta Tau International, Honor Society of Nursing, 11, 369-375, 2014	Population of included studies did not match protocol. Individual studies checked for inclusion.
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 - Qualitative analysis of goals set by patients rather than their views on/experiences with goal setting
Jacob, J., Edbrooke-Childs, J., Law, D., Wolpert, M., Measuring what matters to patients: Using goal content to inform measure choice and development, Clinical Child Psychology and Psychiatry, 22, 170-186, 2017	Study design not in protocol - No qualitative data presented. Secondary analysis of goal themes devised by children to build framework for outcomes measurements.
Kohut, Sara Ahola, Stinson, Jennifer, van Wyk, Margaret, Giosa, Lidia, Luca, Stephanie, Systematic review of peer support interventions for adolescents with chronic illness, International Journal of Child and Adolescent Health, 7, 183-197, 2014	Study design of included studies did not match protocol. Individual studies checked for inclusion.
Larkin, M., Boden, Z. V., Newton, E., On the Brink of Genuinely Collaborative Care: Experience-Based Co-Design in Mental Health, Qualitative health research, 25, 1463-1476, 2015	Study design not in protocol - Narrative description and reflection on study with no data presented.
Lea, S., Martins, A., Morgan, S., Cargill, J., Taylor, R. M., Fern, L. A., Online information and support needs of young people with cancer: A participatory action research study, Adolescent Health, Medicine and Therapeutics, 9, 121-135, 2018	Population not in protocol - Aged 13 - 24 years old (50% under 18 years) with no way of attaching themes to ages
Lerch, Matthew F., Thrane, Susan E., Adolescents with chronic illness and the transition to self-management: A systematic review, Journal of Adolescence, 72, 152-161, 2019	Outcomes not in protocol - No themes relating to how children want their healthcare staff to support them
Lester, H., Marshall, M., Jones, P., Fowler, D., Amos, T., Khan, N., Birchwood, M., Views of young people in early intervention services for first-episode psychosis in England, Psychiatric Services, 62, 882-887, 2011	Population not in protocol - Age 14-35 years (mean male age 21 years, mean female age 23) with no way of assigning age to themes.
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	Outcomes not in protocol - No themes relating to how children want their healthcare staff to support them

Study	Reason for Exclusion
Macdonald, K., Greggans, A., 'Cool friends': an evaluation of a community befriending programme for young people with cystic fibrosis, Journal of Clinical Nursing, 19, 2406-14, 2010	Outcomes not in protocol - No themes relating to advocacy or support
Mattacola, E., "They Think It's Helpful, but It's Not": a Qualitative Analysis of the Experience of Social Support Provided by Peers in Adolescents with Type 1 Diabetes, International journal of behavioral medicine, 27, 444-454, 2020	Phenomenon of interest not in protocol - No relevant type of support for young people
McMillan, S. S., Wilson, B., Stapleton, H., Wheeler, A. J., Young people's experiences with mental health medication: A narrative review of the qualitative literature, Journal of Mental Health, 2020	Population of included studies did not match protocol. Individual studies checked for inclusion.
McTavish, J. R., Kimber, M., Devries, K., Colombini, M., MacGregor, J. C. D., Wathen, N., MacMillan, H. L., Children's and caregivers' perspectives about mandatory reporting of child maltreatment: A meta-synthesis of qualitative studies, BMJ open, 9 (4) (no pagination), 2019	Population of included studies did not match protocol. Individual studies checked for inclusion.
Mehmood, A., Cammidge, S., Guy, E., Peckham, D., Duff, A., Evaluation of youth work support for teenagers and young adults with cystic fibrosis, Journal of Cystic Fibrosis, 17 (Supplement 3), S128, 2018	Conference abstract
Mitchell, Wendy, Parents' accounts: Factors considered when deciding how far to involve their son/daughter with learning disabilities in choice-making, Children and Youth Services Review, 34, 1560-1569, 2012	Outcomes not in protocol - No themes relating to how children want their healthcare staff to support them
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	Parental views of under 5's but poor proxy. Themes are developed around how parents want to be included in their children's care, rather than how they think their child would want them to be involved.
Nightingale, R., Hall, A., Gelder, C., Friedl, S., Brennan, E., Swallow, V., Desirable Components for a Customized, Home-Based, Digital Care-Management App for Children and Young People With Long-Term, Chronic Conditions: A Qualitative Exploration, Journal of medical Internet research, 19, e235, 2017	Outcomes not in protocol - No themes relating to how children want their healthcare staff to support them
O'Neill, T., Wakefield, J., Fifteen-minute consultation in the normal child: Challenges relating to sexuality and gender identity in children and young people, Archives of Disease in Childhood: Education and Practice Edition, 102, 298-303, 2017	Study design not in protocol - Narrative review with 2 case studies included.
Oulton, K., Sell, D., Kerry, S., Gibson, F., What do children and young people with learning disabilities want from hospital services?, Archives of disease in childhood, 3), A84-A85, 2015	Conference abstract
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	Study design not in protocol - Description of the development/implementation of a unique learning mentor with illustrative quotes
Richardson, C., Paslakis, G., Men's experiences of eating disorder treatment: A qualitative systematic review of men-only studies, Journal of psychiatric and mental health nursing, 2020	Systematic review. References checked for possible included studies - none were identified.

Study	Reason for Exclusion
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	Outcomes not in protocol - No themes relating to how children want their healthcare staff to support them
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
Robinson, S., Children and young people's views of health professionals in England, Journal of Child Healthcare: for professionals working with children in the hospital and community, 14, 310-326, 2010	Publication dates of included studies did not match protocol. Individual studies checked for inclusion.
Rodrigues, S., Melchionda, V., Rodney, K., Coppens, K., Comparing children's and parents' perspectives on hospital care, Archives of disease in childhood, 1), A101, 2014	Conference abstract
Rossiter, C., Levett-Jones, T., Pich, J., The impact of person-centred care on patient safety: An umbrella review of systematic reviews, International journal of nursing studies, 109, 103658, 2020	Population of included studies did not match protocol. Individual studies checked for inclusion.
Scholefield, B., Gosney, J., Callens, C., Duncan, H., Morris, K., Draper, H., Consultation with children regarding deferred consent in emergency care research, Pediatric critical care medicine, 1), A44, 2011	Conference abstract
Scott, E., Dale, J., Russell, R., Wolke, D., Young people who are being bullied - do they want general practice support?, BMC family practice, 17, 116, 2016	Outcomes not in protocol - No themes relating to advocacy and support for healthcare
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	Outcomes not in protocol - No themes relating to advocacy or support for healthcare
Stenberg, U., Haaland-Overby, M., Koricho, A. T., Trollvik, A., Kristoffersen, L. G. R., Dybvig, S., Vagan, A., How can we support children, adolescents and young adults in managing chronic health challenges? A scoping review on the effects of patient education interventions, Health expectations : an international journal of public participation in health care and health policy, 2019	Scoping review: included studies checked for inclusion.
Sutcliffe, P., Martin, S., Sturt, J., Powell, J., Griffiths, F., Adams, A., Dale, J., Systematic review of communication technologies to promote access and engagement of young people with diabetes into healthcare, BMC endocrine disorders, 11 (no pagination), 2011	Study design of included studies did not match protocol. Individual studies checked for inclusion.
Troy, E., Doltani, D., Harmon, D., The role of a companion attending consultations with the patient. A systematic review, Irish Journal of Medical Science, 188, 743-750, 2019	Population not in protocol - Companions to adult patients only
Ulph, F., Cullinan, T., Qureshi, N., Kai, J., Informing children of their newborn screening carrier result for sickle cell or cystic fibrosis: qualitative study of parents' intentions, views and support needs, Journal of Genetic Counseling, 23, 409-20, 2014	Parental views of under 5's but poor proxy. Themes are developed around how parents want to tell their child about medical information relating to genetic risks, rather than how and when children want to be informed of these.

Study	Reason for Exclusion
Valentine, J. C., Leach, S. M., Fowler, A. P., Stojda, D. K., Macdonald, G., Families and schools together (FAST) for improving outcomes for children and their families, Cochrane Database of Systematic Reviews, 2019, 2019	Study design of included studies did not match protocol. Individual studies checked for inclusion.
Vasey, J., Smith, J., Kirschbaum, M., Chirema, K., Tokenism or true partnership: Parental involvement in the child's acute pain care, Archives of disease in childhood, 101 (Supplement 1), A189, 2016	Conference abstract
Watts, R., Zhou, H., Shields, L., Taylor, M., Munns, A., Ngune, I., Family-centered care for hospitalized children aged 0-12 years: A systematic review of qualitative studies, JBI Database of Systematic Reviews and Implementation Reports, 12, 204-283, 2014	Population of included studies did not match protocol. Individual studies checked for inclusion.
Yamaji, Noyuri, Suto, Maiko, Takemoto, Yo, Suzuki, Daichi, Lopes, Katharina da Silva, Ota, Erika, Supporting the Decision Making of Children With Cancer: A Meta-synthesis, Journal of pediatric oncology nursing : official journal of the Association of Pediatric Oncology Nurses, 1043454220919711, 2020	Population of included studies did not match protocol. Individual studies checked for inclusion.

Economic studies

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

Appendix L – Research recommendations

Research recommendations for review question: How do children and young people want healthcare staff to support them?

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 do children and young people want healthcare staff to support them?

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

Table 11: Evidence from reference groups and focus groups

Age < 7 years	**Age 7-11 Years**	**Age 11-14 years**	**Overall quality of the evidence**
• I think doctors are nice because (6/13): ○ 'Because they help you a lot' ○ 'They give us medicine' ○ 'I do because I take my teddy' ○ 'They like you' • I don't think doctors are nice because (7/13): ○ 'They give me injections' ○ 'I don't like them' ○ 'I just don't like them' ○ 'It is scary' • I like getting stickers at the doctors because (13/13): ○ 'Because I like stickers' ○ 'I like the pictures on them' ○ 'Because they have dinosaurs on them' ○ 'I like them because they have green on them' • I like fun stickers (12/12): ○ 'I want unicorns on my stickers' ○ 'Planets on stickers'	• How do you want healthcare staff to support you? ○ 'Have a therapist who helps you make decisions but does not tell you what to do' • What should the doctor do to make you feel more comfortable [having appendix out/having an x-ray]? ○ ‘Bring animals or toys’ ○ ‘Should reassure you – tell you ‘you’re not going to die’’ ○ ‘Telling you it’s not going to hurt’ x2 ○ ‘Say ‘you’ll be asleep the whole time’’ • What can healthcare professionals do to make you feel more comfortable [having a tooth out]? ○ ‘Sofa, kitchen etc. if the room felt like home’ ○ ‘If it is fun – e.g. like a bedroom, put your feet up’ ○ ‘Need to be really friendly – so you feel you have known them for a long time so you can trust them more’	• How do you want healthcare staff to support you? ○ ‘Care about our feelings’ • ‘Someone to explain what happens next – looks at lots of options, in advance’ • ‘Someone to help me make decisions’ • What might influence if you feel able to ask a healthcare professional a question: ○ ‘Privacy’ ○ ‘1 on 1’ ○ ‘Smaller room’ ○ ‘Quiet’ ○ ‘Not overheard’ ○ ‘Proper training - trusting the person knows what is going to happen’ ○ ‘Paper to write questions down so don’t have to ask verbally’	• Low

Age < 7 years	Age 7-11 Years	Age 11-14 years	Overall quality of the evidence
○ 'An elephant on stickers' ○ 'Picacho' ○ 'Transformers' ○ 'A vet on my sticker' ○ 'Rabbits on stickers' • I like going to the doctor because (7/16): ○ 'Because my mum is there, she is a nurse' x2 ○ 'I like going to the belly doctor' ○ 'I like injections' ○ 'I am happy going to the doctor because they are nice to me' ○ 'They talk to me' • I don't like going to the doctor because (8/16): ○ 'I don't like having injection in my arm' ○ 'I am not happy to go to the doctor because I feel a bit nervous and scared' • I'm unsure about going to the doctors because: ○ 'Sometimes I get nervous and don't like what they have to do. Don't like it if they are giving an injection, but… I would be happy if they didn't have to give an injection and just give medicine' • What makes someone the world's best doctor or nurse? ○ 'The biggest smile' ○ 'A big smile' ○ 'He is smiling' ○ Looks friendly' • What would make someone a bad doctor or nurse/ the world's worst doctor or nurse? ○ 'They are scary, cruel or mean' x4 ○ 'They will hurt you' x2	○ 'Especially if they talked about what things they liked so you get to know them better, so you can know who they are' ○ 'Get to know them better ' ○ 'Fun games – bouncy castle, Wii, X-box' ○ 'Would be nice to have animals in doctors' surgeries, hospitals be more comfortable' ○ 'Animals just make you feel better' ○ 'I actually don't like animals, only cats, would need to choose… actually I don't think we should have pets. One word to explain it: allergies… hair balls could transmit diseases' ○ 'When you stroke them it calms down your blood' ○ 'Before I had surgery, I was scared as hell as I thought I was going to lose… my mum was crying, I would like to have had an animal to calm me down, would have helped me feel calm' ○ 'Getting to bring a cuddly toy in, that would help' ○ 'A huge teddy to squeeze' x2 ○ 'Needs to be a friendly animal, not one in the jungle who would attack' • What would help [seeing a therapist or GP]? ○ 'What is the person I am going to see's names? It would make me feel better and less nervous if I knew things about them and didn't need to ask their name' ○ 'Picking a [different] counsellor if you didn't like the other one, someone you like who is friendly – I could ask to go and see someone else if I found out which doctor I was going to and knew I didn't like them'	○ 'Question box for nurse if you don't want to see them' ○ 'Gender' ○ 'Adults better than people your age – preferable parent' ○ 4 said easier if parents/carers in room; 3 said harder if parents/carers in room	

Age < 7 years	Age 7-11 Years	Age 11-14 years	Overall quality of the evidence
○ 'They give you injections or hurt you with something sharp' x5 ○ 'If they trapped you' ○ 'They might say something to our parents about what we have done which isn't true' ○ 'They won't give you breakfast, lunch or dinner' ○ 'They wouldn't help you' ○ They wouldn't let you play with your phone or iphone' ○ 'They might ask your mum and dad to leave and then say mean things to you when your mum or dad aren't there, like 'why are you so stupid'' ○ 'They wouldn't save you if you needed saving, they would go home' ○ 'They won't work well with others' ○ 'They won't give stickers at the end' x2 ○ 'They wouldn't show you respect' ○ 'They wouldn't help you when you ask them to' ○ 'The doctor does not care how you are feeling when you tell them' ○ 'They might shout at you and tell you that you did something wrong' x2 ○ 'They might do something bad to you' • If you could change one thing to make you feel less scared or give you a better experience what would it be? ○ 'Mum and dad with me always' ○ 'Same doctor every time' ○ 'Come to my house' ○ 'Getting a lollypop or sticker every time and have toys to play with so I am less scared of an injection'	○ 'Would want to mention 'I like this but don't like this'' ○ 'Bringing a friend or family member – you'll feel comfortable because there is someone there you are really familiar with, you have known them for a really long time' x2 - Sub-question: Would you feel more comfortable having someone familiar with you? 5 said more comfortable, 2 said they would feel the same, 0 said they would feel worse • I like it when the doctor explains things to me about my treatment ○ 13 agreed - 'If its urgent you could get surgery really really quickly, 'but isn't that going to make your mum nervous?' (asked by another child) 'in case it's really bad I would want to know about it' - 'I'd like to know so it's not a big surprise and then they don't scare me by myself' - 'They told me first and I tried it and then my dad helps me' - 'It might be scary not knowing' - 'Sometimes I don't like to hear it and sometimes I don't want to hear it' - 'I don't want anything to happen if they lied or did not explain it, I want them to tell me the truth' - '[I] want to know what's going to happen before it happens' - 'Makes me feel less worried'		

Age < 7 years	Age 7-11 Years	Age 11-14 years	Overall quality of the evidence
○ 'Give you stickers afterwards' (x4) ○ 'Being friendly and kind' ○ 'Not giving injections when you are afraid ○ 'Do not give injections' ○ 'Let you be asleep if something bad is going to happen' ○ 'Get a toy if you have been good' ○ 'Playing games' ○ 'Seeing the same people' ○ 'Giving you medicine you need' ○ 'TV so can watch the tv when bad stuff is happening' ○ 'If you can get better' ○ 'If you can take your favourite toy or teddy' ○ 'If mummy and daddy can stay' ○ 'Bringing my tablet' ○ 'Reassuring me/encouraging me not to be scared' ○ 'Watch my favourite TV show' ○ 'Having squeaky toys to play with' ○ 'Breakfast in bed!' ○ 'Cuddly toys (Eric!)' ○ 'Colouring' ○ 'Having a drink and some food (would like a choice)' ○ 'Sweets and chocolate'	- ‘I once had something on my elbow and they told me everything and I can’t imagine what it would be like if they didn’t tell me’ ○ 4 disagreed - ‘They make it sound urgent and I don’t like urgency. Dr makes me nervous – they need to be calm, looks scary. Doctors are supposed to make you calm but they make more nervous. I would prefer it if they told me in a calm way’ - ‘I don’t want to think about it’ - ‘Sometimes you don’t really want to know what is going to happen to you’ - ‘Sometimes it makes you freak out when you know what they are going to do but sometimes if you don’t know they’ll put you to sleep’ - ‘I might get scared when it’s happened’ ○ 2 unsure - ‘If it’s something bad, I don’t want to know but I also do want to know because it will make me better.’ - ‘If it wasn’t urgent, it depends what it is’ • If I was going to have an operation, I would want the doctor to tell me the risks and why they were doing it. ○ 3 agreed - ‘I want to know what not to do so if I can’t eat something, I’d rather know what not to eat or what to eat’ - ‘I’d rather know what it means’ ○ 1 unsure (no quotes)		

Appendix N – Evidence from national surveys

Evidence from national surveys for review question: How do children and young people want healthcare staff to support them?

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

Table 12: Evidence from national surveys

Survey	**Findings**	**Overall quality of the evidence**
Association for Young People's Health. Young people's views on involvement and feedback in healthcare 2014	• No relevant findings were identified for this question	• N/A
Care Quality Commission. Children and young people's inpatient and day case survey 2018	EMOTIONAL SUPPORT: • 92% of 8-15 year olds who had worries said that staff talked with them about their concerns	• Low
Child Outcomes Research Consortium. Child- and Parent-reported Outcomes and Experience from Child and Young People's Mental Health Services 2011-2015	VIEWS AND WORRIES: • 84.1% of children and young people said their views and worries were taken seriously	• 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
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	BEING TAKEN SERIOUSLY: • Children and young people aged 12 to 19 reported that 'Staff don't always take you seriously or pay attention to you' and 'It's scary [going into hospital] because you don't know what's going to happen'	• Moderate

Survey	Findings	Overall quality of the evidence
	• Disabled young people aged 15 to 21 recommended that performance assessments for staff working with disabled young people and those with long-term conditions should include a focus on the extent to which they are fostering self-care and independence, and that protocols for the safe management of medicine maximise young people's independence and control around self-medication. MENTAL HEALTH SERVICES FOR YOUNG PEOPLE: • Young people aged 16-25 consulted about mental health professionals had mixed views and said: 'Last time I went to counselling...she judged me. She judged me from every angle, you don't know nothing, you're this you're that, it's your fault' 'If you have mild …or bad mental health problems, they are there to help you, to give you a name for what you have got … as well as for whatever is going on.' 'You can speak to them and like talk to them and tell them things that you haven't told no one else, and it's all confidential isn't it, and you know it's not going out of that room.' 'I was sitting in this little room and it was like it's all my fault, like I was the naughty one.'	
Opinion Matters. Declare your care survey 2018	LACK OF RESPECT: • Of young people who had raised a concern or made a complaint, in 65% the subject had been lack of respect from staff or poor patient care	• Low
Picker Institute. Children and Young People's Patient Experience Survey 2018.	• No relevant findings were identified for this question	• N/A
Picker Institute. Paediatric Emergency Department Survey 2015 and Children and Young People's Outpatient Survey 2015	• No relevant findings were identified for this question	• N/A

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).*	EMOTIONAL SUPPORT: • Were you offered emotional support or counselling services from neonatal unit staff? Score = 57 TRUST: • Overall, did you have confidence and trust in the staff caring for your baby? Score = 92	• 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	• No relevant findings were identified for this question	• N/A

N/A: not applicable