National Institute for Health and Care Excellence

Draft for consultation

Babies, children and young people's experience of healthcare

[K] Design of healthcare services

NICE guideline <number>

Evidence reviews underpinning recommendations 1.7.1 to 1.7.4 in the NICE guideline

March 2021

Draft for consultation

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

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Review question

How can, and how should, the perspective of children and young people, and of the parents or carers of babies inform the design of healthcare services?

Introduction

Babies, children and young people accessing healthcare services have needs that may be different to those of adults. These can be related to their size, age, developmental stage, and their different perceptions compared to adults. It is therefore important when designing healthcare services for this population that the perspectives and needs of babies, children and young people are taken into consideration, and that services designed for adults are not adopted without consideration of these needs and perspectives.

The aim of this review is to determine how the views and perspective of babies, children and young people can and should be taken into consideration when designing healthcare services.

Summary of the protocol

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

Table 1: Summary of the protocol

Population	• People <18 years old who have experience of healthcare • Studies that use the responses of parents or carers as proxies for their child will be included only if they are responding on behalf of their child or charge, and: ○ the baby or child of the parent or carer is under-5 years-old, or ○ there is a clear rationale provided as to why the study is using parents' or carers' views on healthcare as proxies for their child.
Phenomenon of interest	Experience of healthcare, in particular of contributing being involved into the design of healthcare services.
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): • Areas in which babies, children and young people (and parent/carers) would like their perspectives to be taken into account (e.g. design of physical spaces, amenities such as Wi-Fi etc., transport services, feedback regarding staff attitudes and values including participation in staff selection, making services inclusive for marginalised and socially excluded groups, monitoring and evaluation of patient experience etc.) • Ease of complaints and compliments procedures • Engagement through social media • Feedback about how views have affected design of healthcare services • Input into commissioning and decision making • Role of co-production with children and young people, and the parents/carers of babies, for example through gaining perspectives and collective engagement through forums and local groups (including via service user representation on groups,

	youth councils, Patient Participation Groups, maternity and babies etc.) into areas such as CAMHS and others • Use of age - or developmentally - appropriate format to express views (e.g. drawings)

CAMHS: Child and Adolescent Mental Health Service

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 can and should be involved in the design of healthcare services.

A systematic review of the literature was conducted using a combined search. Seven studies were included in this review. Five studies used qualitative methods (Alderson 2019, Fletcher 2011, Maconochie 2018, Manning 2018, Whiting 2016). In addition, 2 of the included studies used mixed methods (Ellis 2014, Whiting 2018). All studies were conducted in the UK.

Three studies examined the views of children and young people reflecting on their participation in groups intended to involve them in the design of healthcare services (Alderson 2019, Whiting 2016, Whiting 2018). Two of these examined the views of 15-22 year-old members of the NHS England Youth Forum (NHSEYF) about their participation in the forum itself using, respectively, a focus group design and a mixed methods (including semi-structured interviews) design (Whiting 2016, Whiting 2018); 1 study, using a semi-structured interview and co-produced group design, examined the views of looked after children (LAC) and care leavers, aged 15-21 years, about their experience of participating in a Patient and Public Involvement (PPI) group for a health service intervention trial with LAC.

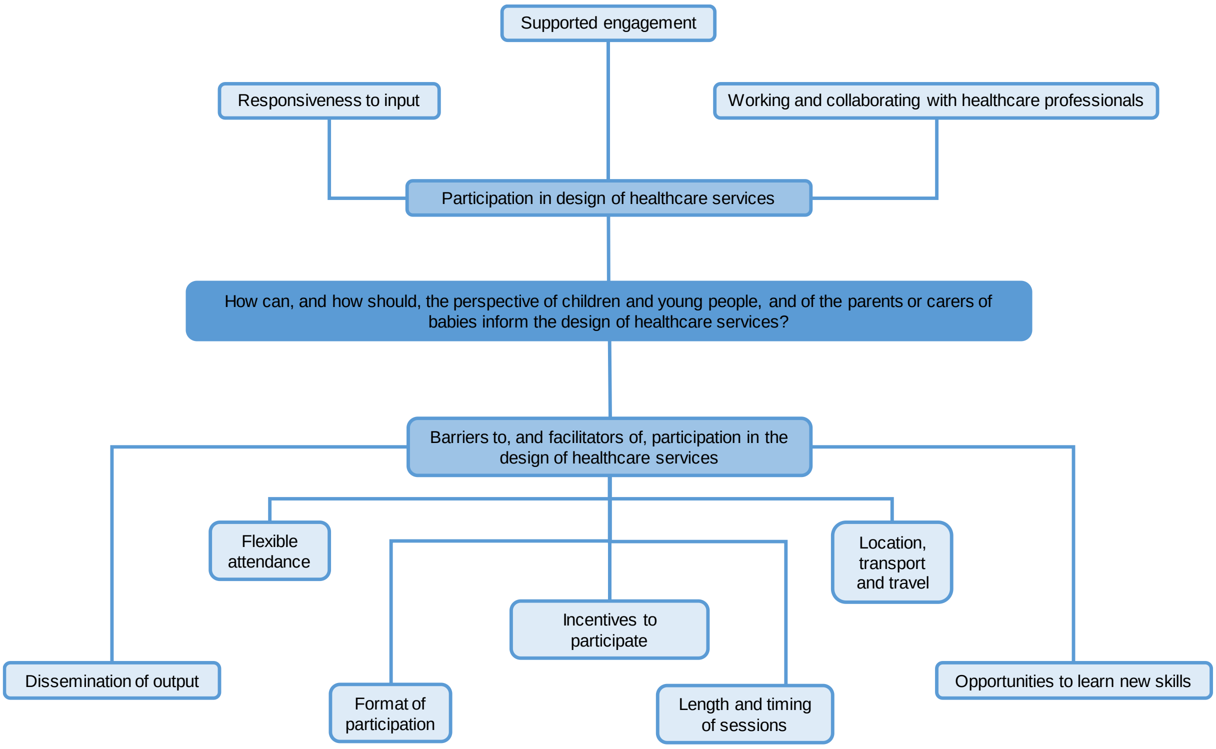
Four of the included studies were service evaluation studies of specific parts of the UK healthcare services that have involved children and young people, and parents of babies, to either affect change in their design and consequent delivery of services (Ellis 2014, Maconochie 2010) or to identify relevant areas for change (Fletcher 2011, Manning 2018). These studies were included because they provided examples of ways in which specific parts of the UK health services have involved children and young people in either the design of healthcare services or the identification of areas in need of change from their perspective. These studies did not contribute to the themes or to the qualitative evidence assessed using GRADE-CERQual, but were reviewed by the committee as they included useful information on participatory methods.

Three of the participatory methods studies used techniques such as ‘Draw, write/tell’ (Fletcher 2011, Maconochie 2018, Manning 2018), whilst 1 study used an experience-based mixed method design (Ellis 2014). One study involved children and young people, aged approximately 4 to 18 years-old, who were either hospital patients or members of a Youth Parliament to identify, respectively, what they think the fundamental attributes and skills of nurses should be, and what they think about when they are about to be and have been admitted to hospital (Fletcher 2011); 1 study involved babies and young children under 4 years old and their parents attending a post-natal health visitor parent-baby group to adapt the group to take into account infants’ perspectives (Maconochie 2018); 1 study involved children and young people, aged 7-15 years, who are survivors of critical illness, and their parents, to identify support needs and preferences for future research priorities (Manning 2018). Finally, 1 study involved children and young people, aged 10-16 years, attending an orthodontic clinic to improve the consultation experience (Ellis 2014).

The included studies are summarised in Table 2 and Table 3.

The data from the 3 included studies examining children and young people's views were synthesised and explored in a number of central themes and sub-themes (as shown in Figure 1). Main themes are shown in dark blue and sub-themes in pale blue.

Figure 1: Theme map



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

Excluded studies

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

Summary of studies included in the evidence review

Summaries of the studies that were included in this review are presented in Table 2 and Table 3.

Table 2: Summary of included qualitative studies.

Study	Population	Methods	Themes
Alderson 2019 **Study design** Semi-structured	N=16 people • n=11 looked after children and care leavers	**Recruitment** Convenience sample of the 11 young people participating in a Patient Public Involvement group	• Participation in design of healthcare services: Responsiveness to input

Study	Population	Methods	Themes
interview and co-produced group **Aim of the study** To examine experience and reflection of a group of children and young people, and academic researchers, who developed a Patient and Public Involvement group that was set up in context of ongoing health service intervention trial with looked after children and care leavers. North-East England, UK	• n=1 participation officer • n=4 researchers *Semi-structured interview* N=12 people • n=7 looked after children and care leavers • n=1 participation officer • n=4 researchers *Co-produced group* N=15 people • n=11 looked after children and care leavers • n=1 participation officer • n=3 researchers Data from participation officer and researchers were not extracted nor included in this review **Characteristics** Age (range): 15-19 years Gender of PPI participants (M/F): 6/5	and attending a Children in Care Council session **Data collection** Two rounds of semi-structured interviews with topic guide, plus 9 co-produced group sessions with last session to determine 'top tips' for working with looked after children, care leavers, and other marginalised children **Analysis** Thematic analysis using constant comparison	• Participation in design of healthcare services: Supported engagement • Participation in design of healthcare services: Working and collaborating with healthcare professionals • Barriers to, and facilitators of, participating in design of healthcare services: Flexible attendance • Barriers to, and facilitators of, participating in design of healthcare services: Format of participation • Barriers to, and facilitators of, participating in design of healthcare services: Incentives to participate • Barriers to, and facilitators of, participating in design of healthcare services: Length and timing of sessions • Barriers to, and facilitators of, participating in design of healthcare services: Location, transport and travel distance • Barriers to, and facilitators of, participating in design of healthcare services: Opportunities to learn new skills
Whiting 2016 **Study design** Focus group **Aim of the study** To provide insight and understanding of the role, value and potential	N=14 • n=5 young people • n=5 adults • n=4 NHS or British Youth Council employees Data from adults and NHS/British Youth Council employees were not extracted nor included in this review	**Recruitment** Purposive sampling of the 20 members of the NHS England Youth Forum, members of an adult reference group and employees of NHS England/British Youth Council **Data collection**	• Barriers to, and facilitators of, participating in design of healthcare services: Dissemination of output • Barriers to, and facilitators of, participating in design of healthcare services: Format of participation • Barriers to, and facilitators of, participating in design

Study	Population	Methods	Themes
effects of the NHS England Youth Forum England, UK	**Characteristics** Age of young people (range): 15-21 years Gender of young people (M/F): not reported	Two focus groups, one for young people and one for Adult Reference Group **Analysis** Thematic analysis	of healthcare services: Location, transport and travel distance
Whiting 2018 **Study design** Mixed methods including semi-structured interview **Aim of the study** To examine role of the members of the NHS England Youth Forum and the strategies used to influence provision of health services for children and young people. England, UK	N=8 young people **Characteristics** Age (range): 15-21 years Gender (M/F): not reported	**Recruitment** Purposive sampling of the 25 members of the NHS England Youth Forum **Data collection** Semi-structured interviews **Analysis** Thematic analysis	• Barriers to, and facilitators of, participating in design of healthcare services: Dissemination of output • Barriers to, and facilitators of, participating in design of healthcare services: Flexible attendance • Barriers to, and facilitators of, participating in design of healthcare services: Incentives to participate • Barriers to, and facilitators of, participating in design of healthcare services: Location, transport and travel distance • Barriers to, and facilitators of, participating in design of healthcare services: Opportunities to learn new skills

1 *F: female; M: male; N/n: number; NHS: National Health Service; NHSEYF: NHS England youth forum; PPI:*
2 *Patient and Public Involvement*

3 **Table 3: Summary of included service evaluation studies**

Study	Population	Methods	CASP quality assessment rating
Ellis 2014 **Study design** Mixed methods questionnaire **Aim of the study** To use an experience-based design approach to	N=150 children and young people **Characteristics** Age (range): 10-16 years Gender (M/F): not reported	**Recruitment** Consecutive orthodontic patients attending the clinic **Data collection** Experience-based design approach to ‘Capture, Understand, Improve, and Measure’ using multiple choice and free text questionnaire **Analysis**	Moderate concerns

Study	Population	Methods	CASP quality assessment rating
examine, improve and measure the consultation experience of patients and staff Dorset, UK		Free text questionnaire analysed using word clouds and emotion maps	
Fletcher 2011 **Study design** Participatory-based activities and focus group **Aim of the study** To involve children and young people in the development of a new undergraduate children's nursing programme curriculum. South England, UK	N=69 children and young people *Participatory-based activities with child and parent on ward* n=61 *Focus group with members of youth parliament* n=8 **Characteristics** *Participatory-based activities with child and parent on ward* Age of children: • Preschool age, n=8 • 5-11 years, n=28 • >11 years, n=25 Gender (M/F): not reported *Focus group with members of youth parliament* Age: not reported Gender (M/F): not reported	**Recruitment** Convenience sampling of children (and their parents) admitted to one of 2 inpatient children wards, or young people attending young parliament meeting **Data collection** Participatory-based 'Draw and write/tell' method using customised instrument and script for activity with child and parent on ward or focus group using customised instrument with members of youth parliament **Analysis** Thematic analysis	Moderate concerns
Maconochie 2010 **Study design** Participatory-based activities **Aim of the study**	N=42 • n=18 child-mother dyads • n=2 health visitors • n= support staff • n=1 community midwife • n=1 doctoral researcher **Characteristics**	**Recruitment** Participants recruited from weekly postnatal parent-baby group held at children's centre **Data collection** Participatory-based activities adapted from Mosaic Approach including: focus groups with parents, informal conversation, observation	Moderate concerns

Study	Population	Methods	CASP quality assessment rating
To examine the perspectives of young children of parents who participate in a weekly postnatal parent-baby group Sheffield, UK	Age of children (range): 0-4 years Gender (M/F): not reported	and reflection, and picture-taking using cameras; books created using materials garnered from activities **Analysis** Thematic analysis	
Manning 2018 **Study design** Participatory-based activities **Aim of the study** To identify priorities for services and research with children and young people and families who have survived critical childhood illness. Midlands, UK	N=24 • n=8 children and young people • n=6 parents/carers • n=8 health professionals • n=1 commissioner • n=1 service manager **Characteristics** Age of children and young people (range): 7-15 years Gender (M/F): not reported	**Recruitment** Purposive sampling using chain-referral of subjects invited to a 5-hour consultation event **Data collection** Participatory-based group activities using ‘Draw, write/tell’ method followed by debrief **Analysis** Inductive thematic analysis by 2 researchers	Moderate concerns

CASP: Critical Appraisal Skills Programme

See the full evidence tables in appendix D.

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:

Main theme 1: Participation in design of healthcare services

- Sub-theme 1.1: Responsiveness to input. The overall confidence in this sub-theme was judged to be low.
- Sub-theme 1.2: Supported engagement. The overall confidence in this sub-theme was judged to be low.
- Sub-theme 1.3: Working and collaborating with healthcare professionals. The overall confidence in this sub-theme was judged to be low.

Main theme 2: Barriers to, and facilitators of, participation in design of healthcare services

- Sub-theme 2.1: Dissemination of output. The overall confidence in this sub-theme was judged to be very low.
- Sub-theme 2.2: Flexible attendance of sessions. The overall confidence in this sub-theme was judged to be very low.
- Sub-theme 2.3: Format of participation. The overall confidence in this sub-theme was judged to be low.
- Sub-theme 2.4: Incentives to participate. The overall confidence in this sub-theme was judged to be very low.
- Sub-them 2.5: Length and timing of sessions. The overall confidence in this sub-theme was judged to be very low.
- Sub-theme 2.6: Location, transport and travel distance. The overall confidence in this sub-theme was judged to be low.
- Sub-theme 2.7: Opportunities to learn new skills. The overall confidence in this sub-theme was judged to be low.

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

Evidence from reference groups and focus groups

There was no evidence from the children and young people's reference groups and focus groups for this review so there is no evidence summary in appendix M.

Evidence from national surveys

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

Table 4: Summary of the evidence from national surveys

National surveys	• Association for Young People's Health. Young people's views on involvement and feedback in healthcare 2014 • National Children's Bureau. Listening to children's views on health provision 2012 • Word of Mouth Research and Point of Care Foundation. An options appraisal for obtaining feedback on the experiences of children and young people with cancer 2018
Areas covered	• Giving views about health and wellbeing • Successful participation • Importance of using patient experience information • Incentives • Age-appropriate methods
Key findings	• Young people preferred providing their views using questionnaires or focus groups, rather than in large groups or at meetings and activities led by adults • Young people thought it was useful for them to be involved in most areas of service design and thought their feedback should be used to improve the quality of care provision

See full the full evidence summary in appendix N.

Economic evidence

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

Excluded studies

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

Summary of studies included in the economic evidence review

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

Economic model

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

The committee's discussion of the evidence

Interpreting the evidence

The outcomes that matter most

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

- Areas in which babies, children and young people (and parent/carers) would like their perspectives to be taken into account (e.g. design of physical spaces, amenities such as Wi-Fi etc., transport services, feedback regarding staff attitudes and values including participation in staff selection, making services inclusive for marginalised and socially excluded groups, monitoring and evaluation of patient experience etc.)
- Ease of complaints and compliments procedures
- Engagement through social media
- Feedback about how views have affected design of healthcare services
- Input into commissioning and decision making
- Role of co-production with children and young people, and the parents/carers of babies, for example through gaining perspectives and collective engagement through forums and local groups (including via service user representation on groups, youth councils, Patient Participation Groups, maternity and babies etc.) into areas such as CAMHS and others
- Use of age- or developmentally- appropriate format to express views (e.g. drawings)

The main themes that were identified related to participation in the design of healthcare services and barriers to, and facilitators of, participation, such as practicalities of attendance and participation. The committee did not prioritise any of these themes above other ones, and considered all the evidence as valuable in making their recommendations.

There was no evidence found specifically on complaints or compliment procedures.

The quality of the evidence

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

The overall confidence in the review findings ranged from low to very low. Themes were commonly downgraded because of the relevance and adequacy of the data, with all three studies that contributed to the findings (Alderson 2019, Whiting 2016, Whiting 2018) including only participants 15-years and over and participants over the age of 18-years. Unfortunately, these studies did not report sufficient data to determine the number of such participants. Regarding adequacy, few of the themes were supported by rich data and they were accordingly downgraded. All themes were downgraded for methodological limitations although there were only minor concerns about the three studies individually and together. Some themes were also downgraded for coherence because the primary studies did not discuss them in detail and/or it is not clear whether underlying data support the review finding.

The 4 service evaluation case studies, which did not contribute to the qualitative evidence assessed using GRADE-CERQual, were all assessed using the CASP qualitative checklist as having moderate concerns about the reported methodology.

Overall, due to the small amount and poor quality of the evidence, the committee also used their knowledge and experience when drafting the recommendations.

Benefits and harms

The committee discussed the fact that, based on their knowledge and experience, it was important to involve children and young people in the design of healthcare services, and that parents or carers should be involved as proxies for babies or young children, and so they recommended this.

There was little evidence on the involvement of diverse groups, under-represented groups or people who do not use services, although one study involved looked-after children and care leavers participating in a Patient and Public Involvement (PPI) group (Alderson 2019). The committee agreed that it was important to involve people from under-represented groups to ensure that representative input was obtained from across the community who were likely to use the services, but also discussed the fact that people who had not used services may be able to provide insight into reasons for this. They therefore emphasised in the recommendations that it was not just current service-users who should be targeted – it may be that the most valuable feedback would come from previous service users who had used a service but had discontinued for one reason or another, or potential users who had reasons why they had not accessed the service. The committee discussed how to identify these under-represented groups but were aware of pro-active methods that could be used such as outreach work to engage and ask opinions from people who are not accessing services, targeting economically deprived areas, using index of multiple deprivation for schools and home addresses, and using snowball sampling. The committee also included a separate recommendation, based on their knowledge and experience, that healthcare professionals should not make assumptions about who should and could be involved in healthcare design, and that all children and young people would have relevant opinions.

The committee discussed the evidence from the theme on barriers and facilitators to participation. The major barriers to participation by children and young people appeared to be practical concerns such as travel to venues, convenient timing of sessions, and flexibility of participation. Children and young people did not seem to think it was necessary to be paid to provide input, although the group of looked after children had more concerns about travel expenses and meal vouchers. However, there were other incentives to participation such as certificates, learning new skills, helping other people, or learning more about the NHS. Young people also expressed the view that the content should be interactive, age and developmentally appropriate, and had concerns that some topics would be too difficult for younger children to understand. The committee therefore made a recommendation stating that contributing should be made easy, engaging, and that practical issues should not prevent involvement.

The systematic review evidence from the theme of participation in design of healthcare service showed that young people are motivated to provide input into the design of healthcare services. Young people also value being supported during their participation and engagement with the process, and valued working and collaborating with healthcare professionals for both the expert knowledge they have and the professional relationships they cultivate with them, but they want to know that their voices are genuinely being heard and listened to, and acted upon. The committee agreed that it was important to provide feedback on the action that had been taken and were aware of a number of ways to do this, including methods such as ‘Ask Listen Do’ and ‘You Said We Did’, and made a recommendation to state this. The committee agreed that obtaining input from children and young people should be meaningful and not tokenistic, and that if children and young people felt their input was not being taken seriously and acted upon then they were less likely to engage in the future.

The 4 service evaluation studies provided examples of ways in which specific parts of the UK health services have involved children and young people in either the design of healthcare services or the identification of areas in need of change from their perspective. The committee reviewed this evidence and discussed the examples (such as the draw/write/tell technique, an experience-based design approach, a multi-faceted participatory approach, and the use of social media). The committee agreed that it was not possible to recommend a single method in this guideline as the best way to involve children and young people but that a variety of methods could be used, and this backed up their recommendation that obtaining input into service design needed to be engaging and age-appropriate.

In addition to the systematic review evidence there was some additional evidence from the national surveys of children and young people’s experience. One survey had identified that young people were keen to input into care and treatment, to improve the service for others, and young people in another survey indicated that they felt they should be involved in identifying needs or problems, designing physical spaces, designing publicity materials, and be involved in budgets, policies and recruitment, as well as mystery shopping and reviewing services. Children and young people suggested different ways of obtaining this input with preferred methods including small focus groups, as well as age-appropriate surveys or questionnaires, which could be completed by parents on behalf of younger children. Incentives to complete surveys, such as small payments, were also considered a good idea. The committee agreed that the evidence from the national surveys reinforced the evidence from the systematic review, and that their recommendations on involvement in design of services and co-production would allow organisations to involve young people in all these areas and using these different techniques.

Cost effectiveness and resource use

There was no existing economic evidence for this review. The committee agreed that meaningful involvement of children and young people in the design of services would require resources and time, but that this should still be regarded as a best practice as it should lead to the design of more appropriate and acceptable services in the long term. The committee agreed that many healthcare organisations already did this and that there were pockets of good practise already, but that the recommendations would make this more consistent across the health service.

Other factors the committee took into account

The committee discussed that the United Nations Convention on the Rights of the Child states that ‘Every child has the right to express their views, feelings and wishes in all matters affecting them, and to have their views considered and taken seriously’ and that the recommendations made reinforced this position.

Recommendations supported by this evidence review

This evidence review supports recommendations 1.7.1 to 1.7.4 in the NICE guideline.

References

Alderson 2019

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Maconochie 2010

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Manning 2018

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Whiting 2016

Whiting, L., Roberts, S., Etchells, J., Evans, K., & Williams, A. (2016). An evaluation of the NHS England Youth Forum. Nursing Standard.

Whiting 2018

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Appendices

Appendix A – Review protocol

Review protocol for review question: How can, and how should, the perspective of children and young people, and of the parents or carers of babies inform the design of healthcare services?

Table 5: Review protocol

Field	Content
PROSPERO registration number	CRD42019152565
Review title	Using perspectives of babies, children and young people to design healthcare services
Review question	5.1 How can, and how should, the perspective of children and young people, and of the parents or carers of babies inform the design of healthcare services?
Objective	To investigate how the perspectives of children, young people and the parents or carers of babies can inform the design of healthcare services
Searches	The following databases will be searched: • CCTR • CDSR • Embase • MEDLINE • MEDLINE IN-Process • PsycINFO Searches will be restricted by: • Date: 2009 • Language of publication: English language only • Publication status: Conference abstracts will be excluded because these do not typically provide sufficient information to fully assess risk of bias • Standard exclusions filter (animal studies/low level publication types) will be applied • 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

Field	Content
Condition or domain being studied	Babies, children and young people's experience of healthcare
Population	• People <18 years-old who have experience of healthcare ○ Studies that use the responses of parents or carers as proxies for their child will be included only if they are responding on behalf of their child or charge, and ○ The baby or child of the parent or carer is under-5 years-old, or ○ There is a clear rationale provided as to why the study is using parents' or carers' views on healthcare as proxies for their child. Note: Studies where part of the population is <18 years-old and part of the population is ≥18 years-old will only be included if at least 66% of the sample is less than 18 years-old. Results will be stratified according to the following age groups: • <1 year-old (i.e. 364 days-old or less) • ≥1 to <12 years-old (i.e. 365 days-old to 11 years and 364 days-old) • ≥12 to <18 years-old (i.e. 12 years and 0 days-old to 17 years and 364 days-old)
Phenomenon of interest	Experience of healthcare, in particular of contributing being involved into the design of healthcare services.
Comparator/Reference standard/Confounding factors	Not applicable
Types of study to be included	• Systematic reviews of qualitative studies • Studies using qualitative methods: focus groups, semi-structured and structured interviews, observations • Surveys conducted using open ended questions and a qualitative analysis of response. Note: Mixed methods studies will be included but only qualitative data will be extracted and risk of bias assessed. Systematic reviews that include evidence from countries not listed in the search strategy will be excluded if the sources of the themes and evidence from high-income countries cannot be clearly established. Evidence from individual qualitative studies conducted in the high-income countries listed in the search strategy will be included only if no relevant systematic review evidence is identified.
Other exclusion criteria	STUDY DESIGN • Quantitative studies (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: • Measuring experience of non-NHS commissioned health promotion interventions • Non-NHS commissioned health promotion interventions

Field	Content
	• Views and experiences of healthcare professionals and service managers • Views and experiences of people reporting on shared decision making in the context of social care planning Studies that focus explicitly on the following topics rather than focussing on the views on and experiences of babies, children and young people in healthcare will be excluded as they are covered by the following NICE guidelines: • Child abuse and maltreatment: o Child abuse and neglect (NG76) o Child maltreatment: when to suspect maltreatment in under 18s (CG89) • Community engagement o Community engagement (NG44) • Drug misuse in children and young people: o Alcohol: school-based interventions (PH7) o Alcohol-use disorders: diagnosis, assessment and management of harmful drinking and alcohol dependence (CG115) o Alcohol-use disorders: prevention (PH24) o Drug misuse prevention: targeted interventions (NG64) • End of life care for infants, children and young people with life-limiting conditions: planning and management (NG61) • Immunisations: reducing differences in uptake in under 19s (PH21) • Oral health promotion: general dental practice (NG30) • Physical activity and weight management: o Maternal and child nutrition (PH11) o Obesity prevention (CG43) o Physical activity for children and young people (PH17) o Weight management: lifestyle services for overweight or obese children and young people (PH47) • Pregnancy, including routine antenatal, intrapartum or postnatal care: o Antenatal and postnatal mental health: clinical management and service guidance (CG192) o Antenatal care for uncomplicated pregnancies (CG62) o Intrapartum care for healthy women and babies (CG190) o Intrapartum care for women with existing medical conditions or obstetric complications and their babies (NG121)

Field	Content
	○ Multiple pregnancy: antenatal care for twin and triplet pregnancies (CG129) ○ Postnatal care up to 8 weeks after birth (CG37) ○ Pregnancy and complex social factors: a model for service provision for pregnant women with complex social factors (CG110) • Self-harm: ○ Self-harm in over 8s: long-term management (CG133) ○ Self-harm in over 8s: short-term management and prevention of recurrence (CG16) • Sexual health and contraception ○ Contraceptive services for under 25s (PH51) ○ Sexually transmitted infections and under-18 conceptions: prevention (PH3) ○ Harmful sexual behaviour among children and young people (NG55) • Smoking prevention: ○ Smoking: preventing uptake in children and young people (PH14) ○ Smoking prevention in schools (PH23) ○ Stop smoking interventions and services (NG92) • Transition from children's to adults services for young people using health or social care services (NG43)
Context	UK studies from 2009 onwards will be prioritised for decision making by the committee as those conducted in other countries may not be representative of current expectations about either services or current attitudes and behaviours of healthcare professionals. The committee presumes that due to their development, particular circumstances and/or condition, there are some topics that babies, children and young people may not be in a position to pronounce on, and that in these circumstances, it may be necessary to treat the 'indirect' responses 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 responses are being used instead of their child or charge, and reasons for exclusion if appropriate will be documented. 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): • Areas in which babies, children and young people (and parent/carers) would like their perspectives to be taken into account (e.g. design of physical spaces, amenities such as wi-fi etc., transport services, feedback regarding staff attitudes and values including participation in staff selection, making services

Field	Content
	inclusive for marginalised and socially excluded groups, monitoring and evaluation of patient experience etc.) • Ease of complaints and compliments procedures • Engagement through social media • Feedback about how views have affected design of healthcare services • Input into commissioning and decision making • Role of co-production with children and young people, and the parents/carers of babies and young children, for example through gaining perspectives and collective engagement through forums and local groups (including via service user representation on groups, youth councils, Patient Participation Groups, maternity and babies etc.) into areas such as CAMHS and others • Use of age- or developmentally- appropriate format to express views (e.g. drawings) Themes related to this topic but that will not be covered by this review include: • Involvement of babies, children and young people in planning their healthcare and making shared decision making (reviewed in RQ 1.1) • Confidentiality, privacy and consent for children and young people in healthcare (reviewed in RQ 1.3)
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 Qualitative checklist. Risk of bias of systematic reviews of Qualitative studies will be assessed using the CASP (Critical Skills Appraisal Programme) Systematic Review checklist. See Appendix H in Developing NICE guidelines: the manual for further details. The quality assessment will be performed by one reviewer and this will be quality assessed by a senior reviewer.
Strategy for data synthesis	• Extracted second-order study themes and related first-order quotes will be synthesised by the reviewer into third-order themes and related sub-themes.

Field	Content	
	• The GRADE-CERQual (Confidence in the Evidence from Reviews of Qualitative research; Lewin 2015) approach will be used to summarise the confidence in the third-order themes or sub-themes synthesized from the qualitative evidence. The overall confidence in evidence about each theme or sub-theme will be rated on four dimensions: methodological limitations, coherence, adequacy, and relevance. • Methodological limitations refer to the extent to which there were problems in the design or conduct of the studies and will be assessed with the CASP checklist for qualitative studies or systematic reviews as appropriate. Coherence of findings will be assessed by examining the clarity of the data. Adequacy of data will 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	

Field	Content		
Anticipated or actual start date			
Anticipated completion date	07 April 2021		
Stage of review at time of this submission	Review stage	Started	Completed
	Preliminary searches	☑	☑
	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	-		

Field	Content	
Reference/URL for published protocol	https://www.crd.york.ac.uk/PROSPERO/display_record.php?RecordID=152565	
Dissemination plans	NICE may use a range of different methods to raise awareness of the guideline. These include standard approaches such as: • notifying registered stakeholders of publication • publicising the guideline through NICE's newsletter and alerts • issuing a press release or briefing as appropriate, posting news articles on the NICE website, using social media channels, and publicising the guideline within NICE.	
Keywords	Acceptability; assessment; babies; children; experience; healthcare; infants; measurement; mode effect; questionnaire; survey; 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	

CAMHS: Child and Adolescent Mental Health Service; CASP: critical appraisal skills programme; CCTR: Cochrane controlled trials register (also known as CENTRAL); CDSR: Cochrane database of systematic reviews; 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; PRESS: peer review of electronic search strategies; RCT: randomised controlled trial

Appendix B – Literature search strategies

Literature search strategies for review question: How can, and how should, the perspective of children and young people, and of the parents or carers of babies inform the design of healthcare services?

Databases: Embase/Medline/PsycINFO

Date searched: 29/07/2020

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

#	Searches
26	"speech and language therap*".tw.
27	general practice*.tw.
28	(health* and (nursery or nurseries or school*)).tw.
29	(respite adj2 care).tw.
30	(foster care or "looked after children" or "children in care").tw.
31	or/11-30
32	(Experience/ or personal experience/ or attitude to health/ or patient attitude/ or patient preference/ or patient satisfaction/) use emez
33	(attitude to death/ or patient advocacy/ or consumer advocacy/ or professional-patient relationship/) use emez
34	(adverse childhood experience/ or exp attitude to health/ or exp Patient satisfaction/) use ppez
35	(exp Consumer Participation/ or "Patient Acceptance of Health Care"/ or *exp consumer satisfaction/ or patient preference/ or Attitude to Death/ or health knowledge, attitudes, practice/ or Patient Advocacy/ or consumer advocacy/ or narration/ or focus groups/ or Patient-Centered Care/ or exp Professional-Patient Relations/) use ppez
36	(exp Client Attitudes/ or exp Client Satisfaction/ or exp Attitudes/ or exp Health Attitudes/ or exp Preferences/ or exp Client Satisfaction/ or exp Death Attitudes/ or exp Advocacy/ or exp Preferences/ or client centered therapy/) use psyh
37	(attitude* or choice* or dissatisf* or expectation* or experienc* or inform* or opinion* or perceive* or perception* or perspective* or preferen* or priorit* or satisf* or thought* or view*).tw.
38	((adolescen* or baby or babies or child* or infant* or patient* or teen* or young person*) adj4 (decisi* or decid* or involv* or participat*)).tw.
39	("informed choice" or "shared decision making").tw.
40	empowerment.tw.
41	(patient-focused or patient-cent?red).tw.
42	(advocate or advocacy).tw.
43	((aversion or barrier* or facilitat* or hinder* or obstacle* or obstruct*) adj2 (care or health* or intervention* or pathway* or program* or service* or therap* or treat*)).ti,ab.
44	or/32-43
45	10 and 31 and 44
46	Qualitative Research/
47	exp interview/ use emez
48	interview/ use ppez
49	interviews/ use psyh
50	interview*.tw.
51	thematic analysis/ use emez
52	(theme$ or thematic).mp.
53	qualitative.af.
54	questionnaire$.mp.
55	ethnological research.mp.
56	ethnograph$.mp.
57	ethnonursing.af.
58	phenomenol$.af.
59	(life stor$ or women* stor$).mp.
60	(grounded adj (theor$ or study or studies or research or analys?s)).af.
61	((data adj1 saturat$) or participant observ$).tw.
62	(field adj (study or studies or research)).tw.
63	biographical method.tw.
64	theoretical sampl$.af.
65	((purpos$ adj4 sampl$) or (focus adj group$)).af.
66	open ended questionnaire/ use emez
67	(account or accounts or unstructured or openended or open ended or text$ or narrative$).mp.
68	(life world or life-world or conversation analys?s or personal experience$ or theoretical saturation).mp.
69	((lived or life) adj experience$).mp.
70	narrative analys?s.af.
71	or/46-70
72	45 and 71
73	limit 72 to (yr="2009 - current" and english language)

#	Searches
74	exp United Kingdom/
75	(national health service* or nhs*).ti,ab,in,ad,cq.
76	(english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab.
77	(gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*).ti,ab,jx,in,ad,cq.
78	(bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))).ti,ab,in,ad,cq.
79	(bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's").ti,ab,in,ad,cq.
80	(aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's").ti,ab,in,ad,cq.
81	(armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's").ti,ab,in,ad,cq.
82	or/74-81
83	((exp africa/ or exp americas/ or exp antarctic regions/ or exp arctic regions/ or exp asia/ or exp oceania/) not (exp united kingdom/ or europe/)) use ppez
84	((exp "arctic and antarctic"/ or exp oceanic regions/ or exp western hemisphere/ or exp africa/ or exp asia/ or exp "australia and new zealand"/) not (exp united kingdom/ or europe/)) use emez
85	83 or 84
86	82 not 85
87	73 and 86
88	Letter/ use ppez
89	letter.pt. or letter/ use emez
90	note.pt.
91	editorial.pt.
92	Editorial/ use ppez
93	News/ use ppez
94	news media/ use psyh
95	exp Historical Article/ use ppez
96	Anecdotes as Topic/ use ppez
97	Comment/ use ppez
98	Case Report/ use ppez
99	case report/ or case study/ use emez
100	Case report/ use psyh
101	(letter or comment*).ti.
102	or/88-101
103	randomized controlled trial/ use ppez
104	randomized controlled trial/ use emez
105	random*.ti,ab.
106	cohort studies/ use ppez
107	cohort analysis/ use emez
108	cohort analysis/ use psyh
109	case-control studies/ use ppez

#	Searches
110	case control study/ use emez
111	or/103-110
112	102 not 111
113	animals/ not humans/ use ppez
114	animal/ not human/ use emez
115	nonhuman/ use emez
116	"primates (nonhuman)"/
117	exp Animals, Laboratory/ use ppez
118	exp Animal Experimentation/ use ppez
119	exp Animal Experiment/ use emez
120	exp Experimental Animal/ use emez
121	animal research/ use psyh
122	exp Models, Animal/ use ppez
123	animal model/ use emez
124	animal models/ use psyh
125	exp Rodentia/ use ppez
126	exp Rodent/ use emez
127	rodents/ use psyh
128	(rat or rats or mouse or mice).ti.
129	or/112-128
130	87 not 129
131	meta-analysis/
132	meta-analysis as topic/
133	systematic review/
134	meta-analysis/
135	(meta analy* or metanaly* or metaanaly*).ti,ab.
136	((systematic or evidence) adj2 (review* or overview*)).ti,ab.
137	((systematic* or evidence*) adj2 (review* or overview*)).ti,ab.
138	(reference list* or bibliograph* or hand search* or manual search* or relevant journals).ab.
139	(search strategy or search criteria or systematic search or study selection or data extraction).ab.
140	(search* adj4 literature).ab.
141	(medline or pubmed or cochrane or embase or psychlit or psyclit or psychinfo or psycinfo or cinahl or science citation index or bids or cancerlit).ab.
142	cochrane.jw.
143	((pool* or combined) adj2 (data or trials or studies or results)).ab.
144	((comprehensive* or integrative or systematic*) adj3 (bibliographic* or review* or literature)).ti,ab,id.
145	(meta-analy* or metaanaly* or "research synthesis").ti,ab,id.
146	(((information or data) adj3 synthesis) or (data adj2 extract*)).ti,ab,id.
147	(review adj5 (rationale or evidence)).ti,ab,id. and "Literature Review".md.
148	(cinahl or (cochrane adj3 trial*) or embase or medline or psyclit or pubmed or scopus or "sociological abstracts" or "web of science").ab.
149	("systematic review" or "meta analysis").md.
150	(or/131-132,135,137-142) use ppez
151	(or/133-136,138-143) use emez
152	(or/144-149) use psyh
153	150 or 151 or 152
154	73 and 153
155	154 not 130
156	155 not 129

Database: Cochrane Library

Date searched: 29/07/2020

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

#	Search
54	MeSH descriptor: [Hospitalization] this term only
55	MeSH descriptor: [Inpatients] this term only
56	MeSH descriptor: [Outpatients] this term only
57	(hospital* or inpatient* or outpatient*):ti,ab,kw
58	(health* near/3 (care or center* or centre* or clinic* or facility or facilities or service* or setting* or specialist*)):ti,ab,kw
59	((dental or communit* or emergency or hospital* or home or intensive or high-dependen* or mental* or primary or secondary or tertiary) near/3 (care or health*)):ti,ab,kw
60	(emergency near/2 room*):ti,ab,kw
61	(ambulance* or CAMHS or dentist* or dietics or dieti*ian or hospice* or NICU or nutritionist* or orthodont* or ophthalmolog* or (outreach near/2 team*) or pharmacy or pharmacies or physio* or SCBU or SENCO or telemedicine*):ti,ab,kw
62	((virtual* or online) near/2 (physician* or clinician* or doctor*)):ti,ab,kw
63	(communit* near/3 (p*ediatric* or nurs*)):ti,ab,kw
64	(home near/3 visit*):ti,ab,kw
65	((walk-in or "urgent care") near/2 (centre* or center* or clinic* or service*)):ti,ab,kw
66	("speech and language therap*"):ti,ab,kw
67	(general practice*):ti,ab,kw
68	(health* and (nursery or nurseries or school*)):ti,ab,kw
69	(respite near/2 care):ti,ab,kw
70	(foster care or "looked after children" or "children in care"):ti,ab,kw
71	#12 OR #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20 OR #21 OR #22 OR #23 OR #24 OR #25 OR #26 OR #27 OR #28 OR #29 OR #30 OR #31 OR #32 OR #33 OR #34 OR #35 OR #36 OR #37 OR #38 OR #39 OR #40 OR #41 OR #42 OR #43 OR #44 OR #45 OR #46 OR #47 OR #48 OR #49 OR #50 OR #51 OR #52 OR #53 OR #54 OR #55 OR #56 OR #57 OR #58 OR #59 OR #60 OR #61 OR #62 OR #63 OR #64 OR #65 OR #66 OR #67 OR #68 OR #69 OR #70
72	MeSH descriptor: [Adverse Childhood Experiences] this term only
73	MeSH descriptor: [Attitude to Health] explode all trees
74	MeSH descriptor: [Patient Satisfaction] explode all trees
75	MeSH descriptor: [Community Participation] explode all trees
76	MeSH descriptor: [Patient Acceptance of Health Care] this term only
77	MeSH descriptor: [Patient Preference] this term only
78	MeSH descriptor: [Attitude to Death] this term only
79	MeSH descriptor: [Health Knowledge, Attitudes, Practice] this term only
80	MeSH descriptor: [Patient Advocacy] this term only
81	MeSH descriptor: [Consumer Advocacy] this term only
82	MeSH descriptor: [Narration] this term only
83	MeSH descriptor: [Focus Groups] this term only
84	MeSH descriptor: [Professional-Patient Relations] explode all trees
85	(attitude* or choice* or dissatisf* or expectation* or experienc* or inform* or opinion* or perceive* or perception* or perspective* or preferen* or priorit* or satisf* or thought* or view*):ti,ab,kw
86	((adolescen* or baby or babies or child* or infant* or patient* or teen* or young person*) near/4 (decisi* or decid* or involv* or participat*)):ti,ab,kw
87	("informed choice" or "shared decision making"):ti,ab,kw
88	(empowerment):ti,ab,kw
89	(patient-focused or patient-cent*red):ti,ab,kw
90	(advocate or advocacy):ti,ab,kw
91	((aversion or barrier* or facilitat* or hinder* or obstacle* or obstruct*) near/2 (care or health* or intervention* or pathway* or program* or service* or therap* or treat*)):ti,ab,kw
92	#72 OR #73 OR #74 OR #75 OR #76 OR #77 OR #78 OR #79 OR #80 OR #81 OR #82 OR #83 OR #84 OR #85 OR #86 OR #87 OR #88 OR #89 OR #90 OR #91
93	MeSH descriptor: [Qualitative Research] this term only
94	MeSH descriptor: [Interview] this term only
95	(interview*):ti,ab,kw
96	(theme* or thematic):ti,ab,kw
97	(qualitative):ti,ab,kw
98	(questionnaire*):ti,ab,kw
99	(ethnological research):ti,ab,kw

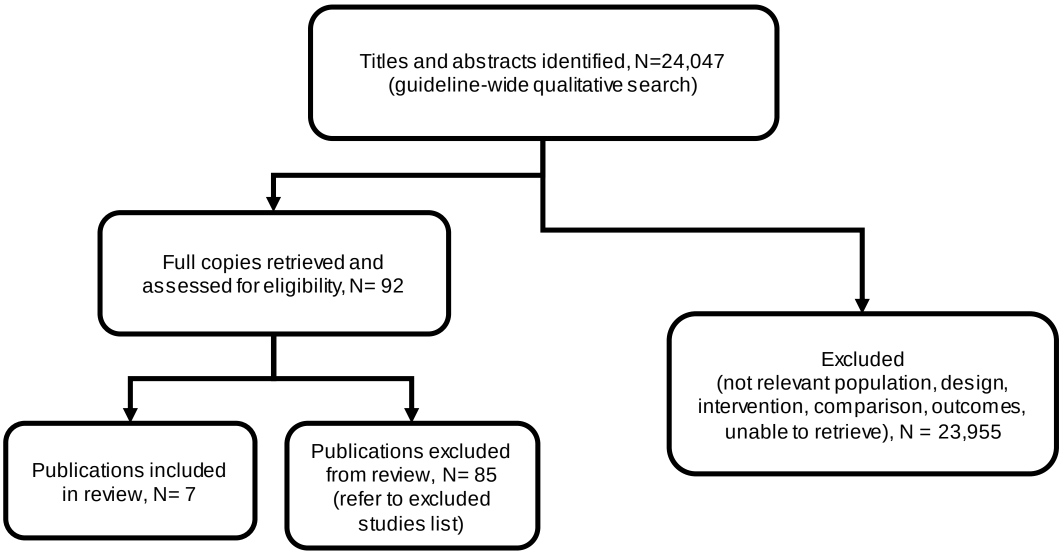
#	Search
100	(ethnograph*):ti,ab,kw
101	(ethnonursing):ti,ab,kw
102	(phenomenol*):ti,ab,kw
103	(life stor* or women* stor*):ti,ab,kw
104	(grounded near (theor* or study or studies or research or analys*s)):ti,ab,kw
105	((data near/1 saturat*) or participant observ*):ti,ab,kw
106	(field near (study or studies or research)):ti,ab,kw
107	(biographical method):ti,ab,kw
108	(theoretical sampl*):ti,ab,kw
109	((purpos* near/4 samp**) or (focus near group*)):ti,ab,kw
110	(account or accounts or unstructured or openended or open ended or text* or narrative*):ti,ab,kw
111	(life world or life-world or conversation analys*s or personal experience* or theoretical saturation):ti,ab,kw
112	((lived or life) near experience*):ti,ab,kw
113	(narrative analys*s):ti,ab,kw
114	#93 OR #94 OR #95 OR #96 OR #97 OR #98 OR #99 OR #100 OR #101 OR #102 OR #103 OR #104 OR #105 OR #106 OR #107 OR #108 OR #109 OR #110 OR #111 OR #112 OR #113
115	#11 AND #71 AND #92 AND #114 with Cochrane Library publication date Between Jan 2009 and Aug 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

#	Search
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 can, and how should, the perspective of children and young people, and of the parents or carers of babies inform the design of healthcare services?

Figure 2: Clinical evidence study selection flow chart



Appendix D – Clinical evidence tables

Evidence tables for review question: How can, and how should, the perspective of children and young people, and of the parents or carers of babies inform the design of healthcare services?

Table 6: Evidence tables

Study details	Participants	Methods	Themes and findings	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** North-East England, UK	**Sample size** N=16 people • n=11 looked after children and care leavers • n=1 participation officer • n=4 researchers *Semi-structured interview* N=12 people • n=7 looked after children and care leavers • n=1 participation officer • n=4 researchers *Co-produced group* N=15 people • n=11 looked after children and care leavers • n=1 participation officer	**Setting** Children's council **Recruitment** Researchers attended Children in Care Council (CICC) meeting as mediated by CICC participation officer with young people asked to register interest with officer in participating in Patient Public Involvement project (as part of the Supporting Looked After Children and Care Leavers In Decreasing Drugs, and alcohol [SOLID] study). Young people were recruited from those attending a CICC session, run by a local authority, by volunteering for interviews. Informed assent-guardian consent/informed consent obtained as applicable. Eleven young people (6 male, 5 female) participated in PPI project and 9 CICC sessions were held. Attendance by	**Author's themes:** • Desire to be involved; Involvement as a fluid and evolving process • Building and maintaining relationships • Awareness of power • Respecting everyone's knowledge and skills • Reciprocity in the PPI project • Producing 'top tips' of working with young people Top tips from co-produced group exercise: • Organising a CICC session: Provide transport to sessions; Interactive sessions; Keep sessions short; Meetings after school;	**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. Although convenience sampling used, specific nature of young people involved (looked after children or care leavers) makes recruitment strategy appropriate. *Q5: Were the data collected in a way that addressed the research issue?* Yes. *Q6: Has the relationship between researcher and participants been adequately considered?* Yes.

Study details	Participants	Methods	Themes and findings	Limitations
Study type Semi-structured interview and co-produced group **Aim of the study** To examine experience and reflection of a group of children and young people, and academic researchers, who developed a Patient and Public Involvement group that was set up in context of ongoing health service intervention trial with looked after children and care leavers. **Study dates** Study conducted over 18 month period, probably after 2016, but dates not reported **Source of funding** Patient Public Involvement work funded by the Catherine Cookson Foundation and linked to the NIHR-funded Supporting Looked After Children and Care Leavers In Decreasing Drugs, and alcohol (SOLID) study. SOLID funded by	- n=3 researchers Data from participation officer and researchers were not extracted nor included in this review **Characteristics** Age (range): 15-19 years Gender of PPI participants (M/F): 6/5 **Inclusion criteria** - Looked after child or care leaver attending Children In Care Council (CICC) sessions **Exclusion criteria** Not reported	young people in sessions voluntary and they could leave/enter as desired. **Data collection** Semi-structured interviews with topic guide set up and conducted at 2 time points (before CICC sessions and in final CICC session) with collaboration of young people/CICC participation officer. Seven of the 11 young people participating in PPI group participated in interviews, conducted by researchers involved in the Patient Public Involvement project, at first time point, exploring their views on understanding of the term 'research', how they felt they could contribute to research project, and expectations and feelings about working with researchers. Interview occurred in different room than CICC session. Researchers also interviewed twice by independent researcher. After completion of PPI work, second round of interviews conducted with 4 of the 7 young people, CICC's participation officer and PPI researchers. Third and final round of interviews conducted	Location needs to be familiar - Running a CICC session: A researcher who understands; Provide a certificate; Incentives **Findings** Young people used PPI group to produce 5-min video about why other young people should be involved in research. Overall findings suggested that development of research-related PPI group is feasible. Young people also co-produced 10 'top tips' for working with vulnerable young people as result of their involvement in the PPI project.	*Q7: Have ethical issues been taken into consideration?* Yes. Informed consent/assent obtained. Ethical approval obtained for SOLID trial, of which PPI project was part. *Q8: Was the data analysis sufficiently rigorous?* Unclear. Although thematic analysis of interview data described and supporting quotes provided, the explanation of themes is minimal. *Q9: Is there a clear statement of findings?* Yes. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability).* Yes. 1. Contextualises research in literature and provides detailed discussion. 2. Possibly no. Sample size small and authors note that PPI project was 'extremely resource intensive', making generalisability and replicability difficult. *Overall judgement of quality:* Minor concerns **Other information** Participants given £10 voucher for each session attended to demonstrate that their contributions are valued and their expertise respected. Children in Care Council (CICC) sessions are run by each UK local authority and are intended to

Study details	**Participants**	**Methods**	**Themes and findings**	**Limitations**
NIHR Public Health Research Programme, trial Registration number ISRCTN80786829.		with 4 of the 7 young people interviewed in first round (2 of the 7 had relocated; 1 was not well enough to attend) within CICC session. In this round of interviews, participants were asked about their involvement in the PPI research, if expectations had been met, and whether there was need for any change to facilitate improved involvement in future research. Interviews audio-recorded and transcribed verbatim. Transcripts anonymised and participant key stored separately. A list of 10 'top tips' for working with looked after children and care leavers, and other marginalised children and young people, was co-produced by the young people in a group exercise in which they wrote down their tips individually and then worked together to agree on them. **Analysis** Thematic analysis of interview data using constant comparison method.		give children in care and care leavers opportunity to have voice and give opinions on how council should run children's services. Three researchers involved in both interviews and focus groups at any one time but one researcher was replaced for second round of interviews.
Full citation	**Sample size**	**Setting** Specialist clinic	**Author's themes:** Not applicable	**Limitations (assessed using the <u>CASP checklist for qualitative studies).</u>**

Study details	**Participants**	**Methods**	**Themes and findings**	**Limitations**
Ellis, P. E., Silverton, S., Using the experience-based design approach to improve orthodontic care, Journal of orthodontics, 41, 337-344, 2014 **Ref Id** 1055410 **Country/ies where the study was carried out** Dorset, UK **Study type** Mixed methods including open-ended questionnaire; qualitative **Aim of the study** To use experience-based design approach to improve orthodontic care **Study dates** April to May 2013 (first round), September to October 2013 (second round) **Source of funding**	N=150 children and young people **Characteristics** Age (range): 10-16 years Gender (M/F): not reported **Inclusion criteria** • New orthodontic patients at Dorset County Hospital NHS Foundation Trust **Exclusion criteria** Not reported	**Recruitment** Consecutive patients at orthodontic clinic were recruited. Reception staff explained the questionnaire to them and collected it from them. **Data collection** Mixed methodology with qualitative data collected using a modified Experience-Based Design (EBD) questionnaire. First round of qualitative data collection used paper-based questionnaire; in second round 6-mo later, use of electronic touch screen tablets was attempted. These were not as effective as paper-based versions as patients required more support to complete electronic versions and paper-based version was reverted to. **Analysis** RaTE (Real Time Experience, 2013) website tool was used to map the emotions to the contact points and collated in graph format. This tool also produced word clouds from the patient comments at each contact point.	**Findings** Experience-based design approach is a useful tool for measuring patient experience and targeting areas for service improvements. It enabled capturing, understanding and appreciating that what may have seemed ‘obvious’ or ‘little things’ to us were actually important in the delivery of high-quality care to the patient group. This was evident from the improvement in the positive emotions of patients. The questionnaire has been validated for orthodontic patients; a list of the most commonly used emotions was identified and successfully used. It could therefore be used by other hospital orthodontic departments, although other departments may wish to make modifications to the patient journey dependant on how their consultation appointments are set up. The questionnaire could	*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. All eligible participants were included. Q5: Were the data collected in a way that addressed the research issue? Yes. *Q6: Has the relationship between researcher and participants been adequately considered?* No. No description of potential bias/influence between researcher and participants. *Q7: Have ethical issues been taken into consideration?* Unclear. No mention about approval from ethics committee. *Q8: Was the data analysis sufficiently rigorous?* Unclear. The website used for data analysis does not provide sufficient details to determine. *Q9: Is there a clear statement of findings?* Yes. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2.*

Study details	Participants	Methods	Themes and findings	Limitations
Reports none received			also be used in a specialist orthodontic practice setting, again modifying the journey to reflect local practice.	*Transferability).* Yes. 1. Detailed discussion about departments experience but does not cite any literature. 2. Possibly yes, conducted in a UK outpatient clinic but specific to orthodontic context. *Overall judgement of quality:* Moderate concerns **Other information** No qualitative data extracted for this study.
Full citation Fletcher, T., Glasper, A., Prudhoe, G., Battrick, C., Coles, L., Weaver, K., Ireland, L., Building the future: Children's views on nurses and hospital care, British Journal of Nursing, 20, 39-45, 2011 **Ref Id** 470328 **Country/ies where the study was carried out** South England, UK **Study type**	**Sample size** N=69 children and young people *Participatory-based activities with hospital patients* n=61 *Focus group with members of youth parliament* n=8 **Characteristics** *Participatory-based activities with hospital patients* Age: • Preschool age, n=8	**Setting** Children’s ward, youth parliament **Recruitment** Children and their parents were contacted for recruitment in in-patient children's wards in arm 1 of the study, whilst they were recruited in arm 2 from a youth parliament. No children/parents refused to participate, though some children could not be recruited for practical reasons (e.g. child sleeping, child doing something else). **Data collection**	**Author’s themes:** Not applicable **Findings** Although limited by small convenience sample sizes, there are key messages about the thoughts of children and young people pertinent to hospital admission and the nurses who provide care for them for curriculum programme developers and clinical children’s nurses. In triangulating the data from both arms of the study it is possible to see	**Limitations (assessed using the <u>CASP checklist for qualitative studies</u>).** *Q1: Was there a clear statement of the aims of the research?* Yes. *Q2: Was a qualitative methodology appropriate?* Yes. *Q3: Was the research design appropriate to address the aims of the research?* Yes. *Q4: Was the recruitment strategy appropriate to the aims of the research?* Unclear. Appropriate for arm 1 of the study. Unclear how the members of the Youth Parliament were recruited nor how many did not in fact participate.

Study details	**Participants**	**Methods**	**Themes and findings**	**Limitations**
Participatory-based activities and focus group; qualitative **Aim of the study** To examine the views of children and young people on what skills, knowledge and attitudes, children's nurses of the future will need to care for sick children and their families and to explore the views of young people on what children think about before, and while being admitted to, the hospital **Study dates** Study conducted in 2010 **Source of funding** Not reported	• 5-11 years, n=28 • >11 years, n=25 Gender (M/F): 25/36 *Focus group with members of youth parliament* Age: not reported Gender (M/F): not reported **Inclusion criteria** • Children attending 1 of 2 hospitals where study was conducted or member of youth parliament held at Connexions headquarters **Exclusion criteria** Not reported	'Draw and write/tell' participatory-based technique method using A4-size paper was used to collect data from both arms. Data was collected in arm 2 using a focus group format. **Analysis** Riley's technique of coding data through the use of coloured highlighter pens was used to identify common themes. Written embellishments from drawings were separately transcribed and delineated for each child.	the child's perspective of those who undergo the lived experience of hospital admission, and what it might mean for the tuition of tomorrow's children's nurses. It is important to stress to clinical nurse mentors that they are part of a team consisting of the commissioners of nurse education, an approved educational institution such as a university, and a healthcare institution such as a hospital. All three play an equitable part in the training of nurses; however, it is the mentor who provides the vital hands-on link between theory and practice. With 50% of a student nurse's time spent in practice, the NMC gives equal weighting to this dimension of the course, and data from service users is vital in ensuring that the nurse preparation programme remains relevant, up-to-date and contemporary.	Q5: Were the data collected in a way that addressed the research issue? Unclear. Unclear how discussions with the children were recorded (taped/notes written) to capture all their points that might not have been drawn on the pictures or written down. Method draw/write/tell was justified. *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?* Unclear. Play specialists were given instructions on how to gain consent but no other information reported. *Q8: Was the data analysis sufficiently rigorous?* Unclear. Thematic analysis conducted using highlighters. No description of how much data supports the findings, or if there is any contradictory data. *Q9: Is there a clear statement of findings?* Yes. Overarching themes described. More than one researcher conducted analysis although there is no discussion about how congruent their findings were. Findings discussed in relation to original question. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2.*

Study details	Participants	Methods	Themes and findings	Limitations
				Transferability). Yes. 1. Discusses results from both arms in context of literature. 2. Yes. Large sample size and 2 different contexts in which participants come from. *Overall judgement of quality:* Moderate concerns **Other information** No qualitative data extracted for this study.
Full citation Maconochie, H., McNeill, F., User involvement: children's participation in a parent-baby group, Community Practitioner, 83, 17-20, 2010 **Ref Id** 826086 **Country/ies where the study was carried out** Sheffield, UK **Study type** Participatory-based activities; qualitative	**Sample size** N=42 - n=18 child-mother dyads - n=2 health visitors - n=2 support staff - n=1 community midwife - n=1 doctoral researcher **Characteristics** Age of children (range): 0-4 years Gender of children (M/F): not reported	**Setting** Community children's centre **Recruitment** Recruited from postnatal group at a children's centre. No further details reported. **Data collection** Six participatory-based activities, based on the Mosaic approach, were used: participant observation to determine babies' and preverbal children's interests and dislikes about group, followed by staff and parents reflection on data gathered; informal conversations with verbal children and parents;	**Author's themes:** Not applicable **Findings** Several changes were made to professional practice. First, reflexive thinking led to staff letting babies take more control by picking up cues from them to initiate and terminate interaction and not taking children's attention away from what they wanted. This change was acknowledged by staff. Reciprocity between baby and staff was key to this. Second, knowledge	**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?* Unclear. No description of how many participated from the listed group/ if any declined, how many sessions they were recruited over; and no information on the number of siblings involved. *Q5: Were the data collected in a way that addressed the research issue?* Unclear.

Study details	Participants	Methods	Themes and findings	Limitations
Aim of the study To determine what children's perspectives of a baby group are and how they can be used to develop the group further **Study dates** Conducted over 3-month period but dates not reported **Source of funding** Not reported	**Inclusion criteria** • Mothers and babies with/without siblings who attended a postnatal group at a children's centre **Exclusion criteria** Not reported	photography by parents and children using cameras given to them to capture what they liked or appreciated about group, which were then subsequently used for discussion; focus groups with parents; book making with parents and children using observations, photographs and comments produced during data gathering phase; recording/transcribing of practitioner team meetings to enable reflexive analysis of assumptions/power relations, conflicts of interests, professional practice and researcher subjectivity **Analysis** Thematic analysis was iterative and took place with practitioners and parents during the data generation phase, whilst the health practitioners and doctoral students occurred at the end of the phase. Data was mapped onto a grid to reflect research questions.	about individual children's preferences for toys, activities and developing schemas was incorporated into planning for future sessions/home visits. Third, need to review original parent-focused aim of group evident to staff and so were broadened to include young children's perspectives in planning, delivering and evaluating sessions, thus extending involvement to children in addition to parents.	Data was collected in different ways (observation, focus groups [no mention of how the data was captured in the groups], books of evidence, practitioner meetings). Three main themes found though no sub themes reported. *Q6: Has the relationship between researcher and participants been adequately considered?* No. Description of potential bias/influence between researcher and participants not provided. *Q7: Have ethical issues been taken into consideration?* Yes. Ethical approval and research governance was sought from the local NHS research ethics committee and health and social care consortium. Informed consent from the parents of the participating children obtained. Data generation was paused/ stopped if the children appeared distressed/ disinterested. *Q8: Was the data analysis sufficiently rigorous?* Unclear. Data mapping to a grid and thematic analysis used but it is unclear how they were derived/ limited description. *Q9: Is there a clear statement of findings?* Yes. Uses examples from observers, parents comments, staff discussions, to support themes. Findings were discussed and changes implemented.

Study details	Participants	Methods	Themes and findings	Limitations
				Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability). Yes. 1. Possibly not. Contextualizes results in context of how it changes professional practice but discussion relatively superficial. 2. Yes. Although small sample size and study specific to parent-baby group, findings plausibly applicable to other types of parent-children groups and different age groups *Overall judgement of quality:* Moderate concerns **Other information** No qualitative data extracted for this study.
Full citation Manning, Joseph C., Hemingway, Pippa, Redsell, Sarah A., Survived so what? Identifying priorities for research with children and families post-paediatric intensive care unit, Nursing in critical care, 23, 68-74, 2018 **Ref Id** 1059031	**Sample size** N=24 • n=8 children and young people • n=6 parents/carers • n=8 health professionals • n=1 commissioner • n=1 service manager **Characteristics** Age (range): 7-15 years	**Setting** Participated in previous project, community **Recruitment** Purposive sampling using embedded chain-referral method with all invitees asked to invite other potential parties. Eight children and young people, and their families, who had participated in 'The SCETCH Project' were invited by post to attend 5-hour	**Author's themes:** Not applicable **Findings** The consultation exercise provides further evidence as to value of meaningful PPI in the development of priorities for research and health care services to ensure they are appropriate, relevant and acceptable.	**Limitations (assessed using the <u>CASP checklist for qualitative studies).</u>** *Q1: Was there a clear statement of the aims of the research?* Yes. *Q2: Was a qualitative methodology appropriate?* Yes. *Q3: Was the research design appropriate to address the aims of the research?* Yes. *Q4: Was the recruitment strategy appropriate to the aims of the research?*

Study details	Participants	Methods	Themes and findings	Limitations
Country/ies where the study was carried out Midlands, UK **Study type** Participatory-based activities; qualitative **Aim of the study** To understand how the needs of children and young people, and their families, can be better supported and to identify future research priorities **Study dates** November 2015 **Source of funding** Supported by a Research Impact Grant awarded to lead author	Gender (M/F): not reported PICU survivors=3; their siblings=2; other children who had experienced health services=3 **Inclusion criteria** • Children and young people who have experienced a critical illness/injury, and their parents/carers, siblings or other family members, and related health professionals, service managers and commissioners **Exclusion criteria** Not reported	weekend consultation event at university, which was accessible via personal and public transport. Other stakeholders recruited using local and regional email distribution lists. **Data collection** 'Draw, write and tell' technique used in a group format with discussion, facilitated by 3 researchers and a 13-year old young person who had engaged with health services, to gain feedback about experience of receiving or providing care, and to identify priorities for future research/services. Two separate rooms for activities were used, one for parents and health professionals facilitated by 2 researchers, and one room for children and young people facilitated by researcher and young person. Data was collated, transcribed and entered into NVivo 11 software. **Analysis** Inductive content analytical approach was employed with immersion in the data/ full comprehension, open coding and grouping into categories,	Importance of CYP PICU survivors in PPI highlighted as in some cases the priorities for them differed to those of adults, who are recognized in the literature and clinical practice as their proxies and advocates. Consultation findings detail a number of important areas for future paediatric critical care research that focus on supporting transitions as well as the outcomes of CYP PICU survivors and their families. A number of potential sustainable interventions have been identified by CYP and families to meet their diverse needs following survival of critical illness, which requires development and testing. Furthermore, there is also definite scope for the development of a screening tool that discriminates between CYP and families, who may require support following PICU, and directs the input required.	Yes. However, no discussion about people who did not want to take part. *Q5: Were the data collected in a way that addressed the research issue?* Unclear. Setting/data collection via a group/ methods justified. Unclear form of data e.g. just the drawings. Unclear if conversations were transcribed etc. as no examples of raw data given. No discussion of saturation of data. *Q6: Has the relationship between researcher and participants been adequately considered?* No. Description of potential bias/influence between researcher and participants not provided. *Q7: Have ethical issues been taken into consideration?* Yes. NHS Research Ethics Committee permission was granted from East Midlands REC. Informed consent was obtained from all advisors. Assent was obtained for under-16s and informed consent from parent or legal guardian. Participation was voluntary and participants could leave at any time. Throughout the event the team strived to ensure ethical standards were maintained, including safeguarding advisors' privacy. DBS checked and DPA adherence for all team members. *Q8: Was the data analysis sufficiently rigorous?* No. No data presented to support findings, only the themes. Unclear how the data was recorded from the draw,

Study details	Participants	Methods	Themes and findings	Limitations
		comparing groups through a conceptual map of the codes and categories.		write, tell. Unclear how the themes were derived. *Q9: Is there a clear statement of findings?* Yes. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability).* Yes. 1. Yes, provide context and situates in literature. 2. Yes. Although relatively small number of children and young people, findings plausibly applicable to other contexts (e.g. different health condition)/settings. *Overall judgement of quality:* Moderate concerns **Other information** All participants were provided a complimentary lunch and were remunerated for travel expenses. No qualitative data extracted for this study.
Full citation Whiting, L., Roberts, S., Etchells, J., Evans, K., Williams, A., An evaluation of the NHS England Youth Forum, Nursing Standard, 31, 45-53, 2016 **Ref Id**	**Sample size** N=14 • n=5 young people • n=5 adults • n=4 NHS or British Youth Council employees	**Setting** Youth forum **Recruitment** Purposive sampling of the(-then) 20 members of the NHS England Youth Forum, members of the Adult Reference Group (total number not specified),	**Author's themes:** • Challenges associated with participation in the youth forum • Feedback about how views have affected design of healthcare services	**Limitations (assessed using the <u>CASP checklist for qualitative studies</u>).** *Q1: Was there a clear statement of the aims of the research?* Yes. *Q2: Was a qualitative methodology appropriate?* Yes.

Study details	Participants	Methods	Themes and findings	Limitations
994051 **Country/ies where the study was carried out** UK **Study type** Focus group; qualitative **Aim of the study** To understand the role, value and potential effects of NHS England Youth Forum **Study dates** October 2014 to March 2015 **Source of funding** Funded by a NHS grant to the University of Hertfordshire	Data from adults and NHS/British Youth Council employees were not extracted nor included in this review **Characteristics** Age of young people (range): 15-21 years Gender (M/F): not reported **Inclusion criteria** • Used NHS England Youth Forum **Exclusion criteria** Not reported	employees of NHS England and the British Youth Council (BYC). Young people recruited by BYC day-to-day coordinator of NHS England Youth Forum, whilst members of Reference Group recruited via its chairperson. Employees of NHS England/BYC identified using 'good informant' approach. **Data collection** Two focus groups held, ~47-60 min in duration, one with young people and one with Adult Reference Group. Interviews with NHS/BYC employees were conducted after focus groups. All focus groups and interviews were digital audio-recorded with participants' consent, and transcribed verbatim. **Analysis** Data analysed manually using Braun and Clarke's 6-phase method of thematic analysis.	• Role of healthcare professionals **Findings** The young people's commitment to the work of the NHS England Youth Forum was evident and it required a substantial amount of their personal time. They participated in a range of activities, including residential weekends, national and local events, responding to emails and engaging in the Youth Forum Facebook pages and Twitter account. The young people explained that at early NHS England Youth Forum meetings, they had identified three areas to focus on in the first year: mental health, communication between clinicians and young people, and sexual health. The residential weekends primarily addressed these areas, primarily from a national perspective. These weekends were also used to plan other events such as the Children's	*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. Purposive sampling used to recruit participants. *Q5: Were the data collected in a way that addressed the research issue?* Yes. Focus groups with topic guides audio recorded. *Q6: Has the relationship between researcher and participants been adequately considered?* Unclear. Description of potential bias/influence between researcher and participants not provided. *Q7: Have ethical issues been taken into consideration?* Yes. Ethical approval obtained. All participants had information sheets and completed a consent form. Pseudonym name, personal data kept as hard copy and encrypted memory stick in a locked cabinet. Care was taken to prevent participant identification. *Q8: Was the data analysis sufficiently rigorous?* Unclear. Insufficient information about methods used reported such as number of researchers involved in analysis. *Q9: Is there a clear statement of findings?* Yes.

Study details	Participants	Methods	Themes and findings	Limitations
			Commissioner's Takeover Day, which provided children and young people with the opportunity to work with adults for the day and be involved in decision-making related to healthcare. The participants felt that their involvement in the planning of this event made sure that 'Takeover Day is really something which works practically and isn't tokenism' (Tristan). The young people stated that an important aspect of the NHS England Youth Forum role was collaboration with others so that the work of the forum was disseminated; Tristan referred to this as a 'ripple effect'. Therefore, as well as the national focus, the members of the forum also had links with local initiatives and events. For example, Harry explained that he had recently been involved in the development of local pre- CAMHS (Child and Adolescent Mental	*Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability).* Yes. 1. Yes, discusses findings and situates in literature. 2. Yes. Although study includes some participants aged over-18 years, NHS Youth Forum is one of the main avenues in which children and young people, aged 14-24, can contribute to design of health services in England. *Overall judgement of quality:* Minor concerns

Study details	Participants	Methods	Themes and findings	Limitations
			Health Services) facilities, which involved liaising with a range of personnel including young people and youth workers. The participants were confident that their work with the NHS England Youth Forum had been recognised and acknowledged, and provided examples of this. The young people suggested how others could become involved in the NHS England Youth Forum and share their thoughts and opinions. These suggestions included accessing the forum Facebook page or Twitter feed, participating in local activities and developing links with schools. The young people also mentioned the challenges associated with participation in the forum; these were primarily related to travel distances and the logistics of managing the number of events they were involved in. In addition, they were aware that the age range	

Study details	Participants	Methods	Themes and findings	Limitations
			of the membership (15–21 years) did not include younger children. However, it was generally agreed that the involvement of younger children could present difficulties. However, Vijay commented on a Young Health Champions event he had been involved in and said that children and young people between the ages of 4 and 5 years and up to 18 or 19 years had attended; therefore, he felt that the younger age range was participating to some extent, via associated activities.	
Full citation Whiting, L., Roberts, S., Petty, J., Meager, G., Evans, K., Work of the NHS England Youth Forum and its effect on health services, Nursing children and young people, 30, 34-40, 2018 **Ref Id** 1063716	**Sample size** N=8 young people **Characteristics** Age (range): 15-22 years Gender (M/F): 4/4 Two participants had been members of the NHS England Youth	**Setting** Youth forum **Recruitment** Purposive sampling of the 25 members of the NHSEYF who wanted to participate. Nine participated in the activity logs and 8 participated in the interviews. One NHSEYF member participated in both activity logs and interviews. **Data collection**	**Author's themes:** • • The young people: 'We want to make an impact' • Motivation: 'The reasons behind why I wanted to join' • Commitment: 'You can't just say "Oh, actually I'm busy"' • Community: 'You're working with a bunch of	**Limitations (assessed using the <u>CASP checklist for qualitative studies</u>).** *Q1: Was there a clear statement of the aims of the research?* Yes. *Q2: Was a qualitative methodology appropriate?* Yes. *Q3: Was the research design appropriate to address the aims of the research?* Yes.

Study details	Participants	Methods	Themes and findings	Limitations
Country/ies where the study was carried out England, UK **Study type** Mixed-methods including semi-structured interview **Aim of the study** To examine the role of members of the NHS England Youth Forum (NHSEYF) and the strategies used to influence health service provision for children and young people. **Study dates** July 2015 to September 2016 **Source of funding** Commissioned and funded by NHS England	Forum for 24 months, whilst 6 had been members for 12 months. **Inclusion criteria** • Member of the NHS England Youth Forum (NHSEYF) **Exclusion criteria** Not reported	Semi-structured interviews, lasting 17-45 min, conducted by one researcher at convenient date, time and location for participants. Activity log quantitative data collected prior to interviews. Interviews were audio-recorded and transcribed verbatim. **Analysis** Thematic analysis	people who actually are all like-minded' • Knowledge experts: 'They've got the NHS knowledge' • Youth workers: 'They've supported me' • Funding: ‘All my expenses are paid’ **Findings** The young people commented on the ‘robust’ (Millie) selection and recruitment process to become a member of the NHSEYF. There was also agreement that the forum included male and female members from a range of ethnicities, backgrounds and locations. It was evident that the participants enjoyed being part of the NHSEYF and they demonstrated an enthusiastic approach to the work. The NHSEYF members participated in a wide range of initiatives and thought that there was evidence of the NHSEYF’s success. The participants said that they had benefited from	*Q4: Was the recruitment strategy appropriate to the aims of the research?* Yes. Purposive sampling of NHSEYF members. *Q5: Were the data collected in a way that addressed the research issue?* Yes. *Q6: Has the relationship between researcher and participants been adequately considered?* Unclear. Description of potential bias/influence between researcher and participants not provided. *Q7: Have ethical issues been taken into consideration?* Yes. Ethical approval from University of Hertfordshire and young people gave written consent for interview and verbal agreement for it to be recorded. Pseudonyms also used to protect identities of participants. *Q8: Was the data analysis sufficiently rigorous?* Unclear. Reports following Cresswell 2012 method but insufficient information reported such as number of researchers involved in analysis. *Q9: Is there a clear statement of findings?* Yes. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability).* Yes. 1. Yes, discussion situates findings in literature. 2. Yes. Although small number of participants,

Study details	Participants	Methods	Themes and findings	Limitations
			their NHSEYF membership: they spoke about their own personal development as well as their enhanced communication skills and self-confidence. The motivation of the members to be part of the NHSEYF was primarily related to personal experiences that had led to an interest in health issues. However, the young people had become members of the NHSEYF for a range of other reasons: some had seen it advertised and others had had it pointed out to them by a colleague or friend. A minority thought that the NHSEYF could assist with their career goals and/or university applications, although this was never the only rationale given for joining the forum. Perhaps most importantly, motivation stemmed from a desire to enable the voice of young people to be heard: The participants demonstrated a strong	NHS England Youth Forum is one of the main avenues in which young people can participate and contribute to the design of health services in England. *Overall judgement of quality:* Minor concerns

Study details	Participants	Methods	Themes and findings	Limitations
			commitment to the NHSEYF. The activity logs had indicated that the time spent undertaking NHSEYF work varied from week to week and the interviews supported this finding. The young people discussed the travel that was needed as part of their NHSEYF role, which included transport to the residential weekends as well as important events across England. The travel requirements could be time-consuming, meaning that they could not always attend activities. It was agreed that it was beneficial to be an NHSEYF member for two years, as this facilitated an insight and understanding of the NHS, and provided more opportunities to be involved in initiatives. This was particularly important for those undertaking GCSE/ALevel examinations. An important aspect of the young people's roles	

Study details	Participants	Methods	Themes and findings	Limitations
			as NHSEYF members involved working and collaborating with a range of people, which could be at a national or a local level.The participants had an excellent insight into the needs of their local youth community, much of which had arisen from growing up in the locality and accessing services. As a result, professional relationships had been formed with important people, such as health professionals, leaders of support groups and councillors. For example, Usman explained how his local knowledge had helped him to liaise with a GP practice to highlight health issues relating to young people, specifically teenage cancer and mental health. Chloe described her involvement with her local child and adolescent mental health services support group and how she had been involved with the making of a film focusing on the transition of young	

Study details	Participants	Methods	Themes and findings	Limitations
			people to adult services. All the members had participated in locally-based projects; as a result, there was a bidirectional dissemination of the work being undertaken. Sometimes the young people would share the initiatives they had been involved in locally at the residential weekends, for example, Chloe's film. On other occasions the national, more strategic NHSEYF activities were taken back to the young people's home locality. This theme also encompassed the 'community spirit' that was fostered through the NHSEYF: the young people spoke of their commitment to common goals and the resulting friendships that had been formed. The collegiality and friendships enabled the young people to work together on important initiatives, for example, the design and production of posters and booklets relating to young people's rights in	

Study details	Participants	Methods	Themes and findings	Limitations
			a health context (NHS England 2016). The participants highlighted the important role of NHS England employees: they had not only been pivotal to the instigation and implementation of the NHSEYF, but they also had expert knowledge of the NHS. This expert knowledge provided the NHSEYF members with a much-needed insight into the structure, organisation and policies associated with NHS England. The knowledge and insight that the NHS employees were able to impart to the young people meant that their confidence grew. The participants highlighted the facilitative approach that was nurtured by the NHS employees, which in turn enabled the forming of a professional partnership approach that had the common aim of listening to the voice of young people. The NHSEYF members all discussed the guidance, advice and	

Study details	Participants	Methods	Themes and findings	Limitations
			support that had been given by the BYC youth workers. Their role focused on the daily management of the NHSEYF with communication being central. A range of different approaches was drawn on, which included email, telephone and face-to-face discussions. Despite this, the main and most popular communication methods were the Wednesday Weekly, an electronic newsletter, and the closed Facebook page; these methods were used to provide details of forthcoming events as well as to ask the members for their opinions. The participants were extremely positive about the youth workers and the support that they provided. The members had all developed a good rapport with them, meaning that they felt able to ask questions or share any anxieties or worries.	

Study details	Participants	Methods	Themes and findings	Limitations
			The young people were aware that funding was required to underpin the running of NHSEYF. However, they did not demonstrate understanding of the details. The participants had not had any challenges in terms of claiming travel costs, but Alastair mentioned that he thought that it would be 'a bit expensive' to stay overnight so he tried to go to events that were manageable in a day. In relation to payment for their time, there was absolute agreement by the young people that this was not required. The interview data demonstrated that the NHSEYF members were extremely motivated and committed to their role and to enabling the voice of young people to be heard.	

CASP: critical appraisal skills programme; DBS: Disclosure and Barring Service; DPA: Data Protection Act; EBD: experience-based design; NHS: National Health Service; NHSEYF: NHS England youth forum; PAR: participatory action research: PICU: paediatric intensive care unit

Appendix E – Forest plots

Forest plots for review question: How can, and how should, the perspective of children and young people, and of the parents or carers of babies inform the design of healthcare services?

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 can, and how should, the perspective of children and young people, and of the parents or carers of babies inform the design of healthcare services?

Table 7: Summary of evidence (GRADE–CERQual): Theme 1: Participation in design of healthcare services

Study information			CERQUAL Quality Assessment				
Number of studies	**Design**	**Description of Theme or Finding**	**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
Sub theme 1.1: Responsiveness to input							
3 (Alderson 2019, Whiting 2016, Whiting 2018)	Semi-structured interview and co-produced group, focus group, semi-structured interview	Data from 3 studies showed that young people who are participating in the design of healthcare services want to know that their views (‘voices’) are being heard and listened to. Professionals collecting data from children and young people should thus be responsive to, and involve, them in how their views are documented or elicited and avoid ‘token’ activities in which they appear to be listened to but are in fact ignored. *‘It's all very well and good doing a project, but then if you don't know how it turns out, you know… was it totally useless, sort of thing?’* (Alderson 2019, page 662) *‘Some people will treat us differently but you have come*	Minor concerns[1]	Minor concerns[2]	Moderate concerns[3]	Moderate concerns[4]	LOW

Study information		**Description of Theme or Finding**	**CERQUAL Quality Assessment**				
Number of studies	**Design**		**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
		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 this?' you've come to children that are in care and given us the opportunity to get our voices heard' (Alderson 2019, page 661)					
Sub theme 1.2: Supported engagement							
2 (Alderson 2019, Whiting 2018)	Semi-structured interview and co-produced group, semi-structured interview	Data from 2 studies showed that young people who are participating in the design of healthcare services value the support they receive from professionals to aid their engagement in the design of health services, which can range from administrative tasks (e.g. reminders about meeting, help with travel) to answering questions about relevant processes. For looked after children, supporting them to play an equal role in the co-production of outcomes may present difficulties as they may conform to a more traditional teacher-student dynamic. Support provided by the same or a known person may also be advisable to overcome looked after	Minor concerns[1]	Minor concerns[2]	Moderate concerns[3]	Moderate concerns[4]	LOW

Study information			**CERQUAL Quality Assessment**				
Number of studies	**Design**	**Description of Theme or Finding**	**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
		children's potential insecure attachments. *'You want to do something you just ring them up, you call them and they will give you advice, they will tell you which way to go'* (Whiting 2018, page 38)					
Sub theme 1.3: Working and collaborating with healthcare professionals							
1 (Whiting 2018)	Semi-structured interview	Data from 1 study showed that young people who are participating in the design of healthcare services via the NHS England Youth Forum (NHSEYF), value working and collaborating with healthcare professionals for both the expert knowledge they have and the professional relationships they are able to cultivate with them. In addition to providing children and young people with a voice, this can allow them to disseminate national activities to the local level, and vice versa, and also increase their confidence in expressing their views. *'You're actually learning a lot more about the structure and the framework of the NHS and how things operate and… it's rewarding that professionals are listening to*	Minor concerns[1]	Minor concerns[2]	Moderate concerns[3]	Moderate concerns[4]	LOW

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
		you and you can have those mutual conversations even though you're at completely different age levels. You know, that doesn't matter, you're still listened to and valued' (Whiting 2018, page 38)					

1 Evidence downgraded for methodological limitations as per CASP qualitative checklist

2 Evidence downgraded for coherence because findings mainly descriptive and not discussed in detail

3 Evidence downgraded for relevance because of differences in setting/population with no specific clinical groups represented; some participants in studies were over 18 years-old although not clear precise number due to insufficient reporting

4 Evidence downgraded for adequacy because studies together offered some rich data

Table 8: Summary of evidence (GRADE–CERQual): Theme 2: Barriers to, and facilitators of, participation in the design of healthcare services

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
Sub theme 2.1: Dissemination of output							
2 (Whiting 2016, Whiting 2018)	Focus group, semi-structured interview	Data from 2 studies showed that young people who are participating in the design of healthcare services via the NHS England Youth Forum (NHSEYF) favoured disseminating its outputs and involving others by using social media, participating in local activities, and developing links with schools. *'We got everyone on Twitter to say what it is that they want. We don't just want it to*	Minor concerns[1]	Moderate concerns[2]	Moderate concerns[3]	Moderate concerns[4]	VERY LOW

Study information			**CERQUAL Quality Assessment**				
Number of studies	**Design**	**Description of Theme or Finding**	**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
		be about the things that we believe are important. And the hashtag, DearNHS, made for our campaign, was a letter where we actually wrote to the NHS about transitioning and about young carers in our campaign. So, that led to board members hearing about it – you can imagine, we had a pretty big impact’ (Whiting 2018, page 36).					
Sub theme 2.2: Flexible attendance of sessions							
2 (Alderson 2019, Whiting 2018)	Semi-structured interview and co-produced group, semi-structured interview	Data from 2 studies showed that young people who are participating in the design of healthcare services want to be able to do so in a way that affords them flexibility to accommodate the demands of their lives. *‘It varies throughout the week… I haven’t even checked my emails these few weeks. But the best thing about NHSEYF is that you’re never forgotten about, you’re never cut off. They know that you’re busy, we’ve got our lives, but I’m still part of the team’* (Whiting 2018, page 37).	Minor concerns[1]	Moderate concerns[2]	Moderate concerns[5]	Serious concerns[6]	VERY LOW
Sub theme 2.3: Format of participation							

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
2 (Alderson 2019, Whiting 2016)	Semi-structured interview and co-produced group, focus group	Data from 2 studies show that the way young people are involved in designing healthcare services should be age- and developmentally-appropriate and tailored to the individual's needs as specific formats may not be appropriate for them and specific topics may be difficult for them to understand. For looked after children, this is even more important as they may have reduced literary levels and behavioural diagnoses such as attention-deficit hyperactivity disorder. In particular, looked after children wanted the format of sessions to be interactive and not an extension of the 'teacher-student' learning dynamic. *'In the past we've looked at the Gillick case and the Fraser guidelines and things like that around the ability to consent to medical treatment, so obviously, you know, younger young people may find that a bit overwhelming.'* (Whiting 2016, page 49)	Minor concerns[1]	Minor concerns[7]	Moderate concerns[5]	Serious concerns[6]	LOW
Sub theme 2.4: Incentives to participate							

Study information		**Description of Theme or Finding**	**CERQUAL Quality Assessment**				
Number of studies	**Design**		**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
2 (Alderson 2019, Whiting 2018)	Semi-structured interview and co-produced group, semi-structured interview	Data from 2 studies showed that young people who are participating in the design of healthcare services (or may be considering doing so) do not typically want financial remuneration but may be receptive to other types of incentives to participate (e.g. opportunity to learn or help other people). However, for looked after children, who may lack formal qualifications, incentives that may be of some use to them in their everyday lives such as learning new transferable skills (e.g. interview technique), receiving a certificate to record their participation/attendance, or even food vouchers, may increase participation. *'It's for the better of young people, so I don't want to be paid'* (Whiting 2018, page 38) *'I mean interviewing skills, like life skills, you know, I can take away from that and just the different formats of research that you can do'* (Alderson 2019, page 61)	Minor concerns[1]	Moderate concerns[2]	Moderate concerns[5]	Serious concerns[6]	VERY LOW
Sub theme 2.5: Length and timing of sessions							

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
1 (Alderson 2019)	Semi-structured interview and co-produced group	Data from 1 study showed that young people who are participating in the design of healthcare services want sessions to be relatively short and after school so they can satisfy their daily commitments or other responsibilities. *No raw data reported for this theme/finding.*	Minor concerns[1]	Minor concerns[8]	Serious concerns[3]	Serious concerns[4]	VERY LOW
Sub theme 2.6: Location, transport and travel distance							
3 (Alderson 2019, Whiting 2016, Whiting 2018)	Semi-structured interview and co-produced group, focus group, semi-structured interview	Data from 3 studies showed that young people who are participating in the design of healthcare services find the transport and travel logistics involved in attending sessions to be the major barrier to participation. For looked after children, this is especially important as they may not have the resources to travel available to them. Moreover, is important that the location of sessions be familiar as the combination of different workers and locations that they can experience, can provoke anxiety.	Minor concerns[1]	Minor concerns[8]	Moderate concerns[5]	Serious concerns[6]	LOW

Study information			**CERQUAL Quality Assessment**				
Number of studies	**Design**	**Description of Theme or Finding**	**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
		No raw data reported for this theme/finding.					
Sub-theme 2.7: Opportunities to learn new skills							
2 (Alderson 2019, Whiting 2018)	Semi-structured interview and co-produced group, semi-structured interview	Data from 2 studies showed that young people who are participating in the design of healthcare services value learning new (perhaps transferable) skills, such as interview technique or how to communicate, which can stand them in good stead for the future and improve their self-confidence. This is especially important for looked after children as they may lack formal qualifications. *'Learn something new innit? Obviously I've never really done that kind of stuff before'* (Alderson 2019, page 660) *'I developed team working skills, public speaking skills, you know, just confidence in general'* (Whiting 2018, page 37)	Minor concerns[1]	Minor concerns[7]	Moderate concerns[5]	Serious concerns[6]	LOW

1 Evidence downgraded for methodological limitations as per CASP qualitative checklist

2 Evidence downgraded for coherence because studies do not discuss theme in detail and not clear that underlying data support review finding

3 Evidence downgraded for relevance because no specific clinical groups represented; participants in both studies were aged between 15-21 years but not clear precise number over-18 years due to insufficient reporting

4 Evidence downgraded for adequacy because studies together offered some rich data

5 Evidence downgraded for relevance because no specific clinic groups represented; studies included some participants over-18 years but not clear precise number years due to insufficient reporting

6 Evidence downgraded for adequacy because studies together did not offer rich data
7 Evidence downgraded for coherence because neither study discusses theme in detail
8 Evidence downgraded for coherence because studies do not discuss theme in detail

Appendix G – Economic evidence study selection

Economic evidence study selection for review question: How can, and how should, the perspective of children and young people, and of the parents or carers of babies inform the design of healthcare services?

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

Appendix H – Economic evidence tables

Economic evidence tables for review question: How can, and how should, the perspective of children and young people, and of the parents or carers of babies inform the design of healthcare services?

No economic evidence was identified for this review.

Appendix I – Economic evidence profiles

Economic evidence analysis for review question: How can, and how should, the perspective of children and young people, and of the parents or carers of babies inform the design of healthcare services?

No economic evidence was identified for this review.

Appendix J – Economic analysis

Economic evidence analysis for review question: How can, and how should, the perspective of children and young people, and of the parents or carers of babies inform the design of healthcare services?

No economic analysis was conducted for this review question.

Appendix K – Excluded studies

Excluded studies for review question: How can, and how should, the perspective of children and young people, and of the parents or carers of babies inform the design of healthcare services?

Clinical studies

Table 9: Excluded studies and reasons for their exclusion

Study	Reason for Exclusion
Bergman, H., Kornør, H., Nikolakopoulou, A., Hanssen-Bauer, K., Soares-Weiser, K., Tollefsen, T. K., Bjørndal, A., Client feedback in psychological therapy for children and adolescents with mental health problems, Cochrane Database of Systematic Reviews, 2018	Does not include qualitative evidence
Chandra-Mouli, V., Lenz, C., Adebayo, E., Lang Lundgren, I., Gomez Garbero, L., Chatteriee, S., A systematic review of the use of adolescent mystery clients in assessing the adolescent friendliness of health services in high, middle, and low-income countries, Global health action, 11, 1536412, 2018	Systematic review about mystery clients with no separate analysis on high- income countries
Daniels, Karen, Cultural agents creating texts: A collaborative space adventure, Literacy, 48, 103-111, 2014	Not related to BCYP engagement in design of healthcare services
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
D'Aulerio, M., Carli, V., Iosue, M., Basilico, F., De Marco, A. M., Recchia, L., Balazs, J., Germanavicius, A., Hamilton, R., Masip, C., Mschin, N., Varnik, A., Wasserman, C., Hoven, C., Sarchiapone, M., Wasserman, D., Young and suicide prevention programs through internet and media: Supreme, European Psychiatry. Conference: 21st European Congress of Psychiatry, EPA, 28, 2013	Conference abstract
Davey, A., Asprey, A., Carter, M., Campbell, J. L., Trust, negotiation, and communication: young adults' experiences of primary care services, BMC family practice, 14, 202, 2013	Age group of subjects is 18-25 years
Davies, Adam, Randall, Duncan, Perceptions of children's participation in their healthcare: A critical review, Issues in comprehensive pediatric nursing, 38, 202-221, 2015	This review focusses on children's participation in their healthcare, but not their engagement in design of healthcare services
Davies, K., Armitage, C. J., Lin, Y. L., Munro, J., Walsh, T., Callery, P., Development of an implementation intention-based intervention to change children's and parent-carers' behaviour, Pilot and Feasibility Studies, 4 (1) (no pagination), 2018	Not related to BCYP engagement in design of healthcare services
Davis, C., www.clicsargent.org.uk/relationships-how clic sargent developed an online tool to help 16 to 24-year-olds manage the impact of cancer ontheir personal and sexual relationships,	Conference abstract

Study	Reason for Exclusion
Pediatric Blood and Cancer, 63 (Supplement 3), S224-S225, 2016	
Davis, E., Young, D., Gilson, K. M., Swift, E., Chan, J., Gibbs, L., Tonmukayakul, U., Reddihough, D., Williams, K., A Rights-Based Approach for Service Providers to Measure the Quality of Life of Children with a Disability, Value in Health, 21, 1419-1427, 2018	Not related to BCYP engagement in design of healthcare services
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	This paper is about BCYP experiences of the CAMHS service, and does not include data on BCYP engagement in design of healthcare services
Day, C., Michelson, D., Hassan, I., Child and adolescent service experience (ChASE): measuring service quality and therapeutic process, The British journal of clinical psychology / the British Psychological Society, 50, 452-464, 2011	Not a qualitative study
Desai, A. D., Burkhart, Q., Parast, L., Simon, T. D., Allshouse, C., Britto, M. T., Leyenaar, J. K., Gidengil, C. A., Toomey, S. L., Elliott, M. N., Schneider, E. C., Mangione-Smith, R., Development and Pilot Testing of Caregiver-Reported Pediatric Quality Measures for Transitions Between Sites of Care, Academic pediatrics, 16, 760-769, 2016	Not related to BCYP engagement in design of healthcare services
Dixon, E., Murray, N., Collins, N., Carr, S. B., The good, the bad and the future: Families' views on the Royal Brompton Hospital (RBH) paediatric cystic fibrosis (CF) homecare service, Journal of Cystic Fibrosis, 14, S125, 2015	Conference abstract
Dovey-Pearce, Gail, Price, Christine, Wood, Helen, Scott, Tracy, Cookson, Jennifer, Corbett, Sally, Young people (13 to 21) with disabilities in transition from childhood to adulthood: An exploratory, qualitative study of their developmental experiences and health care needs, Educational and Child Psychology, 29, 86-100, 2012	Not related to BCYP engagement in design of healthcare services
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
Duckett, Paul, Kagan, Carolyn, Sixsmith, Judith, Consultation and participation with children in healthy schools: Choice, conflict and context, American Journal of Community Psychology, 46, 167-178, 2010	Qualitative study on schools. Looks at pupil wellbeing - positive (relationships in school, involvement in decision making for school management) and negative (bullying/ boredom etc. but no mention/ involvement with healthcare design
Duncombe, R., Evans Fry, R., An innovative app designed to reduce healthcare-related anxiety in young children, Archives of Disease in Childhood, 103 (Supplement 1), A160, 2018	Conference abstract
Duran, C., Curtis-Tyler, K., Exploring children's healthcare experiences of haematopoietic stem cell transplantation (HSCT)-a small scale study for service improvement, Bone Marrow Transplantation, 1), S257, 2016	Conference abstract

Study	Reason for Exclusion
Edgington, L., Hill, V., Pellicano, E., The design and implementation of a CBT-based intervention for sensory processing difficulties in adolescents on the autism spectrum, Research in Developmental Disabilities, 59, 221-233, 2016	CBT intervention for sensory processing difficulties in adolescents with autism. Not related to design of services
Edwards, M., Lawson, C., Rahman, S., Conley, K., Phillips, H., Uings, R., What does quality healthcare look like to adolescents and young adults? Ask the experts!, Clinical Medicine, Journal of the Royal College of Physicians of London, 16, 146-151, 2016	Mixed age population without separate analysis for BCYP group
Eisen, Isabel, Cunningham, Barbara Jane, Campbell, Wenonah, Al-Busaidi, Batorowicz Bell Bergold Boxall Bruce Burles Capewell Carlsson Carnahan Carter Cheak-Zamora Cheak-Zamora Clark-Ibanez Cluley Coad Collier Connelly Cussen Danker Dassah Dockrell Faircloth Fereday Galloway Germain Gibson Gibson Gillam Goldbart Goodwin Ha Harper Harrington Holliday Jones King Kirk Lal Lamb Lariviere-Bastien Lindsay Lloyd Mahon Molloy Nguyen Obrusnikova Owen Phelan Pinborough-Zimmerman Prins Ripat Savin-Baden Singhal Smith Sunderland Teti Wang Wang Ware Whitney Wiart, Conducting participatory photography with children with disabilities: A literature review, Disability and Rehabilitation: An International, Multidisciplinary Journal, 41, 1943-1954, 2019	Systematic review. References Included studies checked for inclusion - none were identified
Ely, B., Chen Lim, M., Becker, E., Wilson Jr, B., The pain experience of hospitalized youth: Assessment and management preferences, Journal of Pain, 1), S3, 2016	Conference abstract
Ely, E., Chen-Lim, M. L., Carpenter, K. M., Wallhauser, E., Friedlaender, E., Pain Assessment of Children with Autism Spectrum Disorders, Journal of developmental and behavioral pediatrics : JDBP, 37, 53-61, 2016	Study from USA and not related to engagement of BCYP in design of healthcare services
Entwistle, V. A., McCaughan, D., Watt, I. S., Birks, Y., Hall, J., Peat, M., Williams, B., Wright, J., Patient Involvement in Patient Safety, Group, Speaking up about safety concerns: multi-setting qualitative study of patients' views and experiences, Quality & Safety in Health Care, 19, e33, 2010	Only one condition included in the study included children (childhood asthma). The interview reported does not include themes related to design of healthcare services
Everley, S., Children's understanding of physical activity and health, Obesity facts, 10 (Supplement 1), 227, 2017	Conference abstract
Fern, L. A., Taylor, R. M., Whelan, J., Pearce, S., Grew, T., Brooman, K., Starkey, C., Millington, H., Ashton, J., Gibson, F., The art of age-appropriate care: Reflecting on a conceptual model of the cancer experience for teenagers and young adults, Cancer Nursing, 36, E27-E38, 2013	Not related to BCYP engagement in design of healthcare services. Study specific to health condition (cancer)
Gersch, Irvine, Lipscomb, Anna, Stoyles, Gerard, Caputi, Peter, Using philosophical and spiritual conversations with children and young people: A method for psychological assessment, listening	Not related to BCYP engagement in design of healthcare services

Study	Reason for Exclusion
deeply and empowerment, Educational and Child Psychology, 31, 32-47, 2014	
Ghisoni, M., Wilson, C. A., Morgan, K., Edwards, B., Simon, N., Langley, E., Rees, H., Wells, A., Tyson, P. J., Thomas, P., Meudell, A., Kitt, F., Mitchell, B., Bowen, A., Celia, J., Priority setting in research: user led mental health research, Research Involvement & Engagement, 3, 4, 2017	Not related to BCYP engagement in design of healthcare services
Gray, N., Mepani, B., Reed, H., Sassoon, R., Starbuck, L., Developing a collaborative adolescent health research charter with young people, Turk Pediatri Arsivi, 2), 96, 2013	Conference abstract
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	Not related to BCYP engagement in design of healthcare services
Hayter, Mark, Involving service users in the development and evaluation of health care and services - good practice and the need for a research agenda, Contemporary Nurse, 40, 103-105, 2011	Editorial
Hopwood, B., Tallett, A., Little voice: giving young patients a say, Nursing times, 107, 18-20, 2011	Survey without qualitative data
Hulin, J., Baker, S. R., Marshman, Z., Albadri, S., Rodd, H. D., Development of a decision aid for children faced with the decision to undergo dental treatment with sedation or general anaesthesia, International journal of paediatric dentistry, 27, 344-355, 2017	Not related to BCYP engagement in design of healthcare services
Jaume, N., Abbiss, M., Wray, J., Ashworth, J., Brown, K., Cairns, J., CHILDSPLA: a collaboration between children and researchers to design and animate health states, Child: care, health and development, 41, 1140-1151, 2015	Study is about development of an app/ character in different health states. No use of the tool to inform healthcare services
Jensen, H. I., Ammentorp, J., Kofoed, P. E., Assessment of health care by children and adolescents depends on when they respond to the questionnaire, International Journal for Quality in Health Care, 22, 259-265, 2010	Not a qualitative study
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	Population > 18 years
Lin, P. H., Intille, S., Bennett, G., Bosworth, H. B., Corsino, L., Voils, C., Grambow, S., Lazenka, T., Batch, B. C., Tyson, C., et al.,, Adaptive intervention design in mobile health: intervention design and development in the Cell Phone Intervention for You trial, Clinical trials (london, england), 12, 634â€• 645, 2015	Development of an intervention for weight loss in adults
McGraw, M., Fellows, S., Long, A., Millar, H., Muir, G., Thomson, A., Uddin, S., Watt, J., Williams, S., Feedback on doctors' performance from parents and carers of children: A national pilot study, Archives of Disease in Childhood., 26, 2011	Not a qualitative study
McNicholas, F., Reulbach, U., Hanrahan, S. O., Sakar, M., Are parents and children satisfied with	Quantitative survey

Study	Reason for Exclusion
CAMHS?, Irish Journal of Psychological Medicine, 33, 143-149, 2016	
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	Related to design of a specific app. Not related to design of healthcare services
Noonan, R. J., Boddy, L. M., Fairclough, S. J., Knowles, Z. R., Write, draw, show, and tell: a child-centred dual methodology to explore perceptions of out-of-school physical activity, BMC public health, 16, 326, 2016	The study relates to perceptions regarding non NHS commissioned health promotion intervention
Nuti, A., Pryce, R., Assessing service satisfaction levels of adolescents with diabetes in out-patient clinic setting: A patient response outcome measure, Hormone Research in Paediatrics, 1), 291, 2013	Conference abstract
Ochieng, B. M., Black African migrants: the barriers with accessing and utilizing health promotion services in the UK, European Journal of Public Health, 23, 265-269, 2013	Study related to access of health promotion services
Ogston-Tuck, S., Baume, K., Clarke, C., Heng, S., Understanding the patient experience through the power of film: A mixed method qualitative research study, Nurse education today, 46, 69-74, 2016	Not related to BCYP engagement in design of healthcare services
Oldham, G., Sidhu-Bevan, H., Wray, J., Using patient-reported experience measures as quality improvement tools in a specialist children's hospital, Archives of disease in childhood, 102 (Supplement 1), A24-A25, 2017	Conference abstract
O'Loughlin, K., Dimmock, V., Runnacles, J., Botting, N., Lanlehin, R., Wong, S., Lofton, L., Promoting multiprofessional learning through the development of a standardised paediatric in situ simulation programme; A multi-centred approach, Archives of disease in childhood, 102 (Supplement 1), A83, 2017	Conference abstract
O'Reilly, M., Dogra, N., Hughes, J., Reilly, P., George, R., Whiteman, N., Potential of social media in promoting mental health in adolescents, Health promotion international, 30, 30, 2018	Not related to BCYP engagement in design of healthcare services
Oulton, K., Wray, J., Carr, L., Hassiotis, A., Jewitt, C., Kerry, S., Tuffrey-Wijne, I., Gibson, F., Pay More Attention: a national mixed methods study to identify the barriers and facilitators to ensuring equal access to high-quality hospital care and services for children and young people with and without learning disabilities and their families, BMJ open, 6, 2016	Not related to BCYP engagement in design of healthcare services
Owens, C., Sharkey, S., Smithson, J., Hewis, E., Emmens, T., Ford, T., Jones, R., Building an online community to promote communication and collaborative learning between health professionals and young people who self-harm: an exploratory study, Health expectations : an international journal of public participation in health care and health policy, 18, 81-94, 2015	Not related to BCYP engagement in design of healthcare services

Study	Reason for Exclusion
Pak, S., McMillan, S., Cohen, C., Jones, R., Think U know? Think again: Tailoring services for young people, HIV Medicine, 3), 41, 2014	Conference abstract
Pert, Hayley, Diaz, Clive, Thomas, Nigel, Children's participation in LAC reviews: A study in one English local authority, Child & Family Social Work, 22, 1-10, 2017	Study relates to children's participation in looked after children reviews. Not related to BCYP engagement in design of healthcare services
Phillips, R., Absolom, K., Stark, D., Glaser, A., A simple practical patient-reported clinic satisfaction measure for young adults, British journal of cancer, 103, 1485-1488, 2010	Adult population
Plax, K., Donnelly, J., Federico, S. G., Brock, L., Kaczorowski, J. M., An Essential Role for Pediatricians: Becoming Child Poverty Change Agents for a Lifetime, Academic Pediatrics, 16, S147-S154, 2016	Not related to BCYP engagement in design of healthcare services
Ramaswami, U., Stull, D. E., Parini, R., Pintos-Morell, G., Whybra, C., Kalkum, G., Rohrbach, M., Raluy-Callado, M., Beck, M., Chen, W. H., Wiklund, I., Measuring patient experiences in Fabry disease: validation of the Fabry-specific Pediatric Health and Pain Questionnaire (FPHPQ), Health and quality of life outcomes, 10 (no pagination), 2012	Not related to BCYP engagement in design of healthcare services
Richardson, P., George, B., Doyle, A., Kelly, S., Kisler, J., How should we listen to the children? Developing a child reporting assessment questionnaire in a tertiary spasticity clinic, Developmental medicine and child neurology, 2), 54, 2013	Conference abstract
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	Not related to BCYP engagement in design of healthcare services
Robinson, J., Bailey, E., Hetrick, S., Paix, S., O'Donnell, M., Cox, G., Ftanou, M., Skehan, J., Developing Social Media-Based Suicide Prevention Messages in Partnership With Young People: Exploratory Study, JMIR Mental Health, 4, e40, 2017	Study conducted in Australia
Ryninks, K. E., Burren, C. P., Garratt, V. L., Developing a patient reported outcome and experience measure for a specialised paediatric service, Archives of disease in childhood, 1), A101, 2014	Conference abstract
Salema, N. M., Elliott, R. A., Glazebrook, C., Click, capture, converse: Using photography to elicit adolescents' views regarding asthma management, International journal of pharmacy practice, 1), 12, 2010	Conference abstract
Scott, Judith, Wishart, Jennifer, Currie, Candace, Including children with intellectual disabilities/special educational needs into national child health surveys: A pilot study, Journal of Applied Research in Intellectual Disabilities, 24, 437-449, 2011	Study is about piloting 2 administration methods for survey questionnaire. Not related to BCYP engagement in design of healthcare services
Sexton, K., Heinz, P., Lothian, K., Young people get active! focus group involvement to improve the experience of adolescent paediatric patients	Conference abstract

Study	Reason for Exclusion
in emergency departments, Archives of Disease in Childhood: Education and Practice Edition, 1), A109, 2013	
Sharkey, S., Lloyd, C., Tomlinson, R., Thomas, E., Martin, A., Logan, S., Morris, C., Communicating with disabled children when inpatients: barriers and facilitators identified by parents and professionals in a qualitative study, Health expectations : an international journal of public participation in health care and health policy, 19, 738-750, 2016	Not related to engagement of BCYP in design of healthcare services
Small, N., Raghavan, R., Pawson, N., An ecological approach to seeking and utilising the views of young people with intellectual disabilities in transition planning, Journal of Intellectual Disabilities, 17, 283-300, 2013	Not related to BCYP experience in healthcare
Smith, J., Parent-professional collaboration when a child presents with potential shunt malfunction, Nursing children and young people, 27, 22-27, 2015	Not related to BCYP engagement in design of healthcare services
Smith, N., Jandial, S., Rapley, T., Foster, H., Collaborative development of paediatric musculoskeletal matters (PMM)-an online evidence based information resource for paediatric musculoskeletal medicine, Annals of the rheumatic diseases, 2), 414, 2015	Conference abstract
Smith,A.H.K., Dixon,A.L., Page,L.A., Health-care professionals' views about safety in maternity services: a qualitative study, Midwifery, 25, 21-31, 2009	Not related to BCYP engagement in design of healthcare services
Stones, S. R., Swallow, V., Majeed-Aris, R., Hall, A., Involvement of children and young people with long-term conditions in the development of mobile app technology to promote disease self-management, Annals of the rheumatic diseases, 2), 163-164, 2015	Conference abstract
Sturt, J., Dliwayo, T. R., Forjaz, V., Hamilton, K., Bryce, C., Fraser, J., Griffiths, F., Eliciting the Impact of Digital Consulting for Young People Living With Long-Term Conditions (LYNC Study): Cognitive Interviews to Assess the Face and Content Validity of Two Patient-Reported Outcome Measures, Journal of medical internet research, 20, e268, 2018	Not related to engagement in design of healthcare services
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	Systematic review of quantitative studies
Taggart, Danny, Franks, Wendy, Osborne, Oz, Collins, Suzanne, 'We are the ones asking the questions': The experiences of young mental health service users conducting research into stigma, Educational and Child Psychology, 30, 61-71, 2013	Not related to BCYP engagement in design of healthcare services
Tallett, A., Hopwood, B., Using a child-friendly survey to obtain feedback about the hospital experience of young inpatients, Archives of	Conference abstract

Study	Reason for Exclusion
Disease in Childhood: Education and Practice Edition, 1), A67, 2013	
Taylor, R., Fern, L., Gibson, F., Whelan, J., Steps in the development of a patient-reported outcome measure for teenage and young adults with cancer: The brightlight survey, Pediatric Blood and Cancer, 59 (6), 1009, 2012	Conference abstract
Tsakos, G., Blair, Y. I., Yusuf, H., Wright, W., Watt, R. G., Macpherson, L. M. D., Developing a new self-reported scale of oral health outcomes for 5-year-old children (SOHO-5), Health and quality of life outcomes, 10 (no pagination), 2012	Study specifically related to development of scale for oral health outcomes. Not related to BCYP engagement in design of healthcare services
Tume, L. N., Preston, J., Blackwood, B., Parents' and young people's involvement in designing a trial of ventilator weaning, Nursing in Critical Care, 21, e10-8, 2016	Not related to BCYP engagement in design of healthcare services- this study is related to designing trial of a specific intervention
Van De Vijver, M., Bertaud, S., Nailor, S., Marais, G., Baby diaries: A tool to improve parental communication in the neonatal unit, Archives of Disease in Childhood, 99, A81-A82, 2014	Conference abstract
van den Driessen Mareeuw, F. A., Hollegien, M. I., Coppus, A. M. W., Delnoij, D. M. J., de Vries, E., In search of quality indicators for Down syndrome healthcare: a scoping review, BMC health services research, 17, 284, 2017	Not related to BCYP engagement in design of healthcare services
Van Doorn, W. A. T., Tallett, A., Burger, S., Witwicki, C., Collecting feedback from young outpatients using a survey suitable for children, Archives of disease in childhood, 101 (Supplement 1), A200-A201, 2016	Conference abstract
Waite-Jones, J. M., Majeed-Ariss, R., Smith, J., Stones, S. R., Van Rooyen, V., Swallow, V., Young People's, Parents', and Professionals' Views on Required Components of Mobile Apps to Support Self-Management of Juvenile Arthritis: Qualitative Study, JMIR MHealth and UHealth, 6, e25, 2018	Related to design of a specific app. Not related to design of healthcare services
Wall, Sarah E., Templeton, Lorna J., The use of drawings to explore young people's views of a service for those affected by parental alcohol misuse, Journal of Substance Use, 16, 439-451, 2011	Not related to experience in healthcare- related to views of a service for those affected by parental alcohol misuse
Wells, F., Ritchie, D., McPherson, A. C., 'It is life threatening but I don't mind'. A qualitative study using photo elicitation interviews to explore adolescents' experiences of renal replacement therapies, Child: care, health and development, 39, 602-612, 2013	Not related to BCYP engagement in design of healthcare services
Whitehouse, H. J., Lock, S., Slack, T. W., Layton, A. M., The Facebook effect: Using digital technology and social media to increase research participation from teenagers and healthcare professionals, British Journal of Dermatology, 175 (Supplement 1), 36, 2016	Conference abstract
Whiting, L. S., Roberts, S. A., "we want to influence": An evaluation of the national health service england youth forum, Archives of disease in childhood, 101 (Supplement 1), A365-A366, 2016	Conference abstract

Study	Reason for Exclusion
Williams, F., McCafferty, A., Dunkley, C., Kirkpatrick, M., A UK survey of the experience of service provision for children and young people with epilepsy, Seizure, 60, 80-85, 2018	Quantitative survey
Wolf, Sarah, Winkler, Roman, A systematic Analysis of Evaluation Methods for Inpatient Children and Adolescents Rehabilitation Programs, Eine systematische Analyse zu Evaluierungsmethoden fur stationare Kinder- und Jugendrehabilitationsprogramme., 232, 187-196, 2020	Review of measuring instruments for rehabilitation programs. Not related to design of healthcare services

CAMHS: Child and Adolescent Mental Health Service; LAC: looked after children

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 can, and how should, the perspective of children and young people, and of the parents or carers of babies inform the design of healthcare services?

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 can, and how should, the perspective of children and young people, and of the parents or carers of babies inform the design of healthcare services?

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.

No evidence from the reference groups or focus groups was identified for this review question.

Appendix N – Evidence from national surveys

Evidence from national surveys for review question: How can, and how should, the perspective of children and young people, and of the parents or carers of babies inform the design of healthcare services?

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

Table 10: 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	GIVING VIEWS ABOUT HEALTH AND WELLBEING: • Young people (age not specified) preferred providing their views using questionnaires, or small focus groups (fewer than 10 people), and their least preferred method was large focus groups (more than 10 people) or meetings/ activities led by adults • Young people (age not specified) thought it was useful for them to be involved in most areas of service design, especially identifying needs or problems, designing physical space, designing publicity materials. Other areas were reviewing services (mystery shopping), having a say on how budgets are spent, developing policies and recruiting staff. Quotes: '…take us seriously. Get more young people involved in roles in these services. Ask for regular feedback, and make it easy and quick to give. Don't be invasive (especially through sexual health services).'	• Low
Care Quality Commission. Children and young people's inpatient and day case survey 2018	• No relevant findings were identified for this question	• N/A
Child Outcomes Research Consortium.	• No relevant findings were identified for this question	• N/A

Survey	Findings	Overall quality of the evidence
Child- and Parent-reported Outcomes and Experience from Child and Young People's Mental Health Services 2011-2015		
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	SUCCESSFUL PARTICIPATION: • At a stakeholder event looking at NHS white papers and strategy the young people (age not specified) recommended that: ○ Service user involvement and active feedback should be sought and acted upon ○ Participation should be seen as a fundamental aspect of service evaluation and service improvement ○ Progress should be fed back to the young people.	• Moderate
Opinion Matters. Declare your care survey 2018	• No relevant findings were identified for this question	• N/A
Picker Institute. Children and Young People's Patient Experience Survey 2018.	• No relevant findings were identified for this question	• N/A
Picker Institute. Paediatric Emergency Department Survey 2015 and Children and Young People's Outpatient Survey 2015	• 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).*	• No relevant findings were identified for this question	• N/A
Word of Mouth Research and Point of Care Foundation. An options appraisal for obtaining feedback on the experiences of children and young people with cancer 2018	IMPORTANCE OF USING PATIENT EXPERIENCE INFORMATION: • Young people (13 to 17 years) were very keen that the views and wishes of young people like themselves should be sought and acted upon both ‘in the moment’, in relation to care and treatment affecting patients, and more generally, to improve the quality of service provision. • Young people (13 to 17 years) felt that a survey should be carried out that should be uniform across the country and that it should be used to assess services and to improve the quality of care provided. It was important to know that the information provided would be used to address both individual and local service level concerns, and to improve the quality of cancer services for children and young people overall. INCENTIVES: • Young people (13 to 17 years) said that the invitation to complete a survey should include clear information about the value and purpose of the survey and that answers would be used to help the NHS to improve care for other young people with cancer, and that a small financial incentive (£5-10) would help to ensure completion and return of the questionnaire. Quotes: ‘For the survey, online would be easiest. By email. A reward would motivate people to do it. I think about £10.’ (F15) AGE-APPROPRIATE METHODS:	• Low

Survey	Findings	Overall quality of the evidence
	- Young people (13 to 17 years) said that questionnaires should be age-appropriate with a simple one for children aged 7-11 and another version for secondary school age children. Younger children should be interviewed, or their parents could complete a survey on their behalf.	

N/A: not applicable