National Institute for Health and Care Excellence

FINAL

Babies, children and young people's experience of healthcare

[L] Measuring experience

NICE guideline NG204

Evidence reviews underpinning recommendations 1.7.5 to 1.7.9 and research recommendations in the NICE guideline

August 2021

Final

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

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ISBN: 978-1-4731-4231-2

Contents

Measuring experience

Review question

How can the experience of babies, children and young people be measured so as to improve their experience of healthcare?

Introduction

In order to provide a good experience of healthcare, and to continually improve that experience, healthcare services need to review the experiences of those using the services, and act on this feedback to make changes to their services. Babies, children and young people may have different needs, experiences and perceptions of healthcare services compared to adults and it is important to capture these, and not rely on feedback from an adult-only population. In addition, babies, children and young people may have specific needs with respect to the methods used to obtain this feedback.

The aim of this question is to determine the best ways to measure the healthcare experience of babies, children and young people.

Summary of the protocol

See Table 1 for a summary of the Population, Intervention, Comparison and Outcome (PICO) characteristics of this review.

Table 1: Summary of the protocol (PICO table)

Population	• People <18 years-old who have experience of healthcare • Studies that use the responses of parents or carers as proxies for their child will be included only if they are responding on behalf of their child or charge, and o The baby or child of the parent or carer is under 5 years-old, or o There is a clear rationale provided as to why the study is using parents' or carers' views on healthcare as proxies for their child.
Intervention	Any survey, questionnaire or other means of assessment designed to measure the healthcare experiences of babies, children and young people
Comparison	• Same survey, questionnaire, or other means of assessment in different setting, format, or at different time • Different survey, questionnaire, or other means of assessment
Outcomes	**Critical** • Acceptability to respondent • Response rate **Important** • Mode effect: phenomenon when a particular survey administration mode causes different data to be collected. o Data accuracy (proportion of number of errors to amount of missing data) o Data equivalence (proportion of missing data to total possible data) • Time taken to complete survey

For further details see the review protocol in appendix A.

Methods and process

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

Clinical evidence

Included studies

This was a quantitative review with the aim of:

- Determining if there is evidence to support the use of a particular method of collecting feedback on the healthcare experience of babies, children and young people.

A systematic review of the literature was conducted. One study (Horn 2010), a cluster-randomised controlled trial (RCT) was included in this review. This study compared different formats of questionnaire administration in 3 Child and Adolescent Mental Health Service (CAMHS) teams.

The included study is summarised in Table 2.

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

Excluded studies

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

Summary of studies included in the evidence review

A summary of the study included in this review is presented in Table 2.

Table 2: Summary of included study

Study	Population	Intervention	Comparison	Outcomes
Horn 2010 **Study design** Cluster-RCT UK	N (clusters) = 3 CAMHS teams randomised to 3 different treatment arms, including outcomes from N=178 children and young people, out of N = 268 eligible to participate **Characteristics** Age of children and young people: not reported Gender of children and young people: not reported	Postal reminder Same as control plus a postal reminder letter after 2 weeks to non-responders Telephone reminder Same as postal reminder intervention plus telephone call 2 weeks after postal reminder to non-responders	Control General improvements to the administration process of the initial 6 month post-assessment questionnaire	• Response rate

CAMHS: Child and Adolescent Mental Health Service; N: number; RCT: randomised controlled trial

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

Summary of the evidence

Evidence was found for 1 of the pre-defined critical outcomes set out in the protocol: response rate. No evidence was found for acceptability to respondent, mode effect or time taken to complete survey.

The included cluster-RCT compared response rates sent out 6 months after use of the Child and Adolescent Mental Health Service (CAMHS) for two questionnaires, the Strength and Difficulties Questionnaire (SDQ) and the Experience of Service Questionnaire (ESQ), which were sent during a 3-month baseline period and a 3-month intervention period. Interventions included a control intervention, which consisted of general administration improvements (centralisation of questionnaire administration, quality improvements to questionnaires, covering letters and information sheets, and increased presentation of feedback in patient waiting areas), and two additive interventions, which consisted of the general improvements plus a postal reminder only or both postal and telephone reminder. After adjustment for the cluster-RCT design assuming conservative intra-class correlations (ICCs), there were no significant differences between any of the three CAMHS team in response rates during the 3-month intervention period.

Quality assessment of studies included in the evidence review

See the evidence profiles in appendix F.

Evidence from reference groups and focus groups

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

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

Age groups	• 11-14 years
Areas covered	• Methods to obtain feedback • Questions to include
Illustrative quotes	• Methods to obtain feedback ○ 'Some text is too talky/intimidating' ○ 'Have surveys on iPads – cuts down on writing – some people can't write/press buttons – need audio/speech options' ○ 'Surveys delivered by people same age = easier to communicate – cuts out jargon. Better communication' • Questions to include ○ 'Do you think you are getting enough care?' ○ 'Did you like your treatment?' ○ 'What could we do differently?'

See the full evidence summary in appendix M.

Evidence from national surveys

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

Table 4: Summary of the evidence from national surveys

National surveys	• Association for Young People's Health. Young people's views on involvement and feedback in healthcare 2014 • Care Quality Commission. Children and young people's inpatient and day case survey 2018 • Opinion Matters. Declare your care survey 2018 • 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	• Complaints • Concerns • Importance of using patient experience information
Key findings	• More than half of the young people reported that they had wanted to make a complaint, but they did not do it. Of the ones who did it, half reported that nothing had happened as a result • Reasons for not making a complaint included: not knowing who the person to raise it with was, not wanting to be seen as a trouble-maker, or not thinking it would make a difference • Factors that would encourage young people to make a complaint included: receiving regular feedback on actions taken; a more open culture encouraging feedback; knowing which staff or services to raise it with • Young people felt that it was very important for the local services to collect information about the experiences of patients they treated

See the full evidence summary in appendix N.

Economic evidence

Included studies

One economic study was identified which was relevant to this question (Horn 2010).

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

Horn 2010 was a cost-effectiveness study conducted in the UK. The economic evaluation was conducted alongside an RCT (N = 268). The study compared three strategies: mailing only, mailing plus postal reminder, and mailing plus postal reminder plus telephone reminder. The study population comprised families who had used CAMHS. The study took a narrow NHS perspective and included only costs associated with administration, calls, stamps, and business reply envelopes. The time horizon was 4 weeks. The study reported outcomes in terms of cost per returned completed questionnaire. The study found that mailing plus postal reminder was extendedly dominated by other strategies and the incremental cost-effectiveness ratio of mailing plus postal reminder plus telephone reminder (versus mailing only) was £10.52 per additional completed and returned questionnaire.

See the economic evidence tables in appendix H and economic evidence profiles in appendix I.

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

The aim of this review was to identify what is the best method to measure babies, children and young people’s experience of healthcare, and therefore acceptability to the respondent and response rate were prioritised as critical outcomes by the committee. Acceptability is paramount to ensure healthcare services are not using experience measuring tools that children or young people find difficult to complete, or do not want to complete. Survey response rate is linked to acceptability but is also a critical outcome in its own right. The use of measurement tools that have a high response rate is likely to lead to the most representative and informative data.

The committee also agreed that measurements relating to the mode effect of a survey question (that is, data accuracy and data equivalence), and the time taken to complete the survey were important outcomes to capture. Mode effect was considered an important aspect that could considerably affect the reliability of an experience measuring tool when transferred between different formats. Time taken to complete the survey was also considered an important outcome because long surveys could result in respondent fatigue, and respondents tend to provide incomplete or less accurate responses the further through the questionnaire they get. Additionally, there may be a time factor to be considered for the healthcare practitioner who is implementing the questionnaire.

The quality of the evidence

The quality of included studies was assessed using GRADE methodology. Evidence was considered very low quality. There were concerns regarding the risk of bias, namely in the lack of blinding (both possible assessment and measurement bias) and indirectness (specific population of children and young people attending CAMHS). Importantly, families were sent two types of questionnaire – a health outcomes questionnaire and an experience questionnaire. A ‘return’ was counted if either of these was returned, and no further information was provided regarding the proportions of returned questionnaire types. Additionally, very serious imprecision was found in the estimate of effects for all comparisons. This was due to the adjusted sample size, which was small, of the included cluster RCT.

It should also be noted that the 6-month post assessment questionnaire was sent to families of CAMHS attendees. There is no information provided about who received the correspondence, nor who answered the questionnaire (for example, whether it was the young person or another family member).

No effectiveness data was found for acceptability to respondent, mode effect, or time taken to complete the survey.

Benefits and harms

The committee noted that the included study (Horn 2010) suggested that telephone follow-up may increase response rates to a postal survey compared to the control group, and compared to a postal reminder, but that due to the limitations with this study, such as the uncertainty over who had actually completed the surveys, the small study size, and the overall very low quality of the study, they were unable to use it as a basis for specific recommendations.

In addition to the evidence from the systematic review there was also evidence from the reference and focus groups and from the national surveys of children and young people's experience. The 11-14 years old reference group had suggested a variety of methods to collect feedback from children and young people including face-to face, using a variety of computer-based methods, audio surveys, token voting boxes and by having surveys delivered by other young people. The reference group thought it was best to carry out experience surveys while children or young people were still receiving care, and not leave it until later. The reference group also provided suggestions for the questions that should be included on experience surveys and these included numerical rankings, closed questions and open questions. The young people thought the surveys should be easy, smooth, positive, simple and quick.

The evidence from the national surveys of children and young people's experience also found that young people were keen to provide feedback (positive and negative) on healthcare experience. There were a variety of views on the timing for collecting feedback but most young people thought it should be at regular intervals during treatment, or at the end of treatment. As with the reference groups there were suggestions on the methods and content of the feedback – with most support for open questions or qualitative questions, and for questions covering many aspects of healthcare provision such as interactions with healthcare professionals, involvement in decision-making, the environment, food, privacy, and entertainment and social activities. There was also evidence that children and young people wanted to be told how their feedback had been implemented.

There were also a number of comments on complaint systems, with young people reporting that they were difficult to access, there were barriers to making complaints, concerns that no action was taken, or that complaints could lead to repercussions, and the committee therefore made a specific recommendation on the provision of accessible complaints systems for children and young people.

Based on the evidence from the reference and focus groups and the review of national surveys, as well as their knowledge and expertise, the committee agreed that it was possible to make some good practice recommendations. They agreed that it was good practice to collect feedback from children and young people, and the parents or carers of babies and young children, and that while some NHS organisations already had these systems in place, making a recommendation to this effect would encourage all organisations to do this. The committee also noted the importance of the United Nations Convention on the Rights of the Child which states that children have the right to 'express their views, feelings and wishes in all matters relating to them, and to have their views considered and taken seriously.' They agreed that this recommendation was therefore in accordance with this convention.

The committee did not feel that the evidence was strong enough to recommend one method for collecting feedback over another, but agreed that there were some common principles that could be applied, such as the need to develop the assessment tools in conjunction with babies, children and young people to make sure they were acceptable, to adapt tools to allow those with disabilities or communication difficulties to provide feedback, to ensure that feedback was obtained at an appropriate time, to ensure feedback was obtained from a representative population (for example children from under-represented groups, parents and carers to represent babies), and to use techniques to maximize response rates. 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 drew on the evidence for review question 5.1 which had identified that children and young people want feedback on their input, and the effect it has had on the design of services. The committee agreed that this would also be likely to be true about information collected about healthcare experience, and therefore they made a recommendation that information should be fed back to children and young people and parents or carers of babies and young children about the actions that had been taken.

The committee discussed if there were any potential harms from their recommendations. They identified that the need to provide feedback, especially if follow-up mechanisms were used to improve response rates, may lead to children and young people feeling under pressure to complete surveys at times in their life where they are dealing with health issues. The committee were also concerned that it was difficult to obtain responses from a truly representative sample (for example those with no fixed abode, those who had communication difficulties) and that this might lead to the results of surveys not being reflective of the whole population of babies, children and young people.

Due to the lack of published evidence available for this review and the fact that there are no comparative studies comparing different methods of measuring healthcare experience, the committee made a research recommendation.

Cost effectiveness and resource use

Evidence from a published cost-effectiveness study showed that, if complete and accurate telephone contact details were available, mailing plus postal reminder plus telephone reminder was potentially a cost-effective way to increase response rates compared to mailing only and mailing plus postal reminder. However, it was difficult to judge the cost-effectiveness as the cost per quality-adjusted life year (QALY) could not be estimated from the information provided in the publication. Also, this evidence was based on a single small UK study with potentially severe limitations and the committee could not draw any firm conclusions from this.

The committee discussed the fact that administering any kind of method to measure experience, and then to analyse the results, would have associated costs, although this would be likely to be similar across the different methods. Feedback data is routinely collected across most of the health service and therefore the recommendations do not represent a change in practice. Actions taken in response to this feedback may also have associated costs, however, this would apply to all methods. The committee also discussed the fact that sometimes feedback from service-users suggested ways that costs could be reduced, or could point out things that did not need to be done and would potentially result in the cost savings to the health service.

Other factors the committee took into account

The committee discussed the lack of evidence available for this review, and were aware that there was research on different methods of measuring the experience of babies, children and young people, but these were non-comparative studies and so had not met the protocol criteria for inclusion in the review.

The committee were also aware of an ongoing study comparing the administration of the National Inpatient Survey via online and paper formats, but it was unlikely this study would be published before the publication of the guideline.

The committee were aware that the right to complain about healthcare services was contained with the NHS constitution, including how complaints should be handled, and therefore they did not make detailed recommendations about complaint systems.

Recommendations supported by this evidence review

This evidence review supports recommendations 1.7.5 to 1.7.9 and the research recommendation on measuring experience of healthcare.

References

Horn 2010

Horn, R., Jones, S., Warren, K., The Cost-Effectiveness of Postal and Telephone Methodologies in Increasing Routine Outcome Measurement Response Rates in CAMHS, Child and Adolescent Mental Health, 15(1), 60-63, 2010.

Appendices

Appendix A – Review protocol

Review protocol for review question: How can the experience of babies, children and young people be measured so as to improve their experience of healthcare?

Table 5: Review protocol

Field	Content
PROSPERO registration number	CRD42019145600
Review title	Measuring healthcare experience
Review question	How can the experience of babies, children and young people be measured so as to improve their experience of healthcare?
Objective	To establish how the experience of babies, children and young people can be measured, in order to improve their experience of healthcare.
Searches	The following databases will be searched: • CCTR • CDSR • Embase • MEDLINE • MEDLINE IN-Process • PsycINFO Searches will be restricted by: • A UK filter will be applied to identify relevant UK studies, and a systematic review filter will be applied to the remainder of the results to identify relevant reviews that include evidence from non-UK high-income countries. If no systematic reviews of this type are identified, then a more focused search may be conducted to identify studies conducted in the following high-income countries: Australia, Austria, Belgium, Canada Denmark, Finland, France, Germany, Greece, Iceland, Ireland, Italy, Liechtenstein, Luxembourg, Malta, Monaco, Netherlands, New Zealand, Norway, Portugal, Spain, Sweden, Switzerland, and USA. • Date: 2009 • Language of publication: English language only

Field	Content
	• Publication status: Conference abstracts will be excluded because these do not typically provide sufficient information to fully assess risk of bias • Standard exclusions filter (animal studies/low level publication types) will be applied • For each search (including economic searches), the principal database search strategy is quality assured by a second information specialist using an adaption of the PRESS 2015 Guideline Evidence-Based Checklist
Condition or domain being studied	Babies, children and young people's experience of healthcare

Population	• People <18 years-old who have experience of healthcare
	• Studies that use the 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)

Intervention	• Any survey, questionnaire or other means of assessment designed to measure the healthcare experiences of babies, children and young people
Comparator/Reference standard/Confounding factors	• Same survey, questionnaire, or other means of assessment in different setting, format, or at different time • Different survey, questionnaire, or other means of assessment
Types of study to be included	• Systematic reviews/meta-analyses of RCTs • Randomised or quasi-randomised controlled trials (individual or cluster, crossover) Note: If no studies of the above type are identified, the committee will make research recommendations. Cross-over controlled trials (e.g. fill out electronic form, then get sent postal form) will be included but only data from the first stage will be extracted due to risk of contamination bias. For further details, see the algorithm in appendix H, Developing NICE guidelines: the manual.
Other exclusion criteria	STUDY DESIGN • Case control studies

Field	Content
	• Cohort studies • Cross-sectional studies • Epidemiological reviews or reviews on associations • Non-comparative studies • Non-RCTs • Studies using qualitative methods TOPIC OF STUDY Studies on the following topics will also be excluded: • Measuring experience on non-NHS commissioned health promotion interventions delivered by non-NHS services (e.g. sex education in schools or alcohol consumption reduction programmes) • Health promotion • Views and experiences of healthcare professionals and service managers • Views and experiences of people reporting only on social care planning and shared decision making 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 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)

Field	Content
	○ Obesity prevention (CG43) ○ Physical activity for children and young people (PH17) Weight management: lifestyle services for overweight or obese children and young people (PH47) • Pregnancy, including routine antenatal, intrapartum or postnatal care: ○ Antenatal and postnatal mental health: clinical management and service guidance (CG192) ○ Antenatal care for uncomplicated pregnancies (CG62) ○ Intrapartum care for healthy women and babies (CG190) ○ Intrapartum care for women with existing medical conditions or obstetric complications and their babies (NG121) ○ Multiple pregnancy: antenatal care for twin and triplet pregnancies (CG129) ○ Postnatal care up to 8 weeks after birth (CG37) ○ 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-

Field	Content
	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)	• Acceptability to respondent • Response rate
Secondary outcomes (important outcomes)	• Mode effect: phenomenon when a particular survey administration mode causes different data to be collected. ○ Data accuracy (Proportion of number of errors to amount of missing data) ○ Data equivalence (proportion of missing data to total possible data) • Time taken to complete survey
Data extraction (selection and coding)	• All references identified by the searches and from other sources will be uploaded into STAR and de-duplicated. Titles and abstracts of the retrieved citations will be screened to identify studies that potentially meet the inclusion criteria outlined in the review protocol. • Dual sifting will be performed on at least 10% of records; 90% agreement is required. • Disagreements will be resolved via discussion between the two reviewers, and consultation with senior staff if necessary. • Full versions of the selected studies will be obtained for assessment. Studies that fail to meet the inclusion criteria once the full version has been checked will be excluded at this stage. Each study excluded after checking the full version will be listed, along with the reason for its exclusion. A standardised form will be used to extract data from studies, including: study reference, study characteristics (e.g. design, type of statistical analysis), participant characteristics (e.g. age, ethnicity, sex, reason for using healthcare (e.g. condition, disease), intervention(s) characteristics (e.g. length, duration, frequency, mode), outcomes, and risk of bias. One reviewer will extract relevant data into a standardised form, and this will be quality assessed by a senior reviewer.
Risk of bias (quality) assessment	Risk of bias of systematic reviews of quantitative studies will be assessed using the ROBIS checklist, whilst risk of bias of individual quantitative studies will be assessed using the Cochrane RoB tool, v.2 as described in Developing NICE guidelines: the manual. The quality assessment will be performed by one reviewer and this will be quality assessed by a senior reviewer.
Strategy for data synthesis	• Depending on the availability of the evidence, the findings will be summarised narratively or quantitatively. Where possible, meta-analyses will be conducted using Cochrane's Review Manager software. A fixed effect meta-analysis will be conducted and data will be presented as risk ratios or odds ratios for dichotomous outcomes, and mean differences or standardised mean differences for continuous outcomes. • Heterogeneity in the effect estimates of the individual studies will be assessed using the I^2 statistic. I^2 values of greater than 50% and 80% will be considered as serious and very serious heterogeneity, respectively. Heterogeneity will be explored as appropriate using sensitivity analyses and pre-

Field	Content		
	specified subgroup analyses. If heterogeneity cannot be explained through subgroup analysis then a random effects model will be used for meta-analysis, or the data will not be pooled. • The confidence in the findings across all available evidence will be evaluated for each outcome using an adaptation of the 'Grading of Recommendations Assessment, Development and Evaluation (GRADE) toolbox' developed by the international GRADE working group: http://www.gradeworkinggroup.org/		
Analysis of sub-groups	If there is sufficient data, views and experiences will be analysed separately by the following age ranges: • <1 year-old (i.e. 364 days-old or less) • ≥1 to <12 years-old (i.e. 365 days-old to 11 years and 364 days-old • ≥12 to <18 years-old (i.e. 12 years and 0 days-old to 17 years and 364 days-old) The committee are aware that children can experience substantial cognitive and developmental change during the ages of 1 and 12, and that there may be (though not necessarily) substantive differences between children in this group depending on the topic about which they are being asked. The committee will therefore be consulted regarding whether data regarding further subgroups within this age range (e.g. 1-5, 6-11) should be used. Subgroup analysis according to any of the groups listed in the Equality Considerations section of the scope will be conducted if there is sufficient data.		
Type and method of review	☒	Intervention	
	☐	Diagnostic	
	☐	Prognostic	
	☐	Qualitative	
	☐	Epidemiologic	
	☐	Service Delivery	
	☐	Other (please specify)	
Language	English		
Country	England		
Anticipated or actual start date			
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	☑	☑

Field	Content		
	Formal screening of search results against eligibility criteria	☑	☑
	Data extraction	☑	☑
	Risk of bias (quality) assessment	☑	☑
	Data analysis	☑	☑
Named contact	**5a. Named contact** National Guideline Alliance **5b. Named contact e-mail** Infant&younghealth@nice.org.uk **5c. Organisational affiliation of the review** National Institute for Health and Care Excellence (NICE) and National Guideline Alliance		
Review team members	NGA Technical Team		
Funding sources/sponsor	This systematic review is being completed by the National Guideline Alliance, which receives funding from NICE.		
Conflicts of interest	All guideline committee members and anyone who has direct input into NICE guidelines (including the evidence review team and expert witnesses) must declare any potential conflicts of interest in line with NICE's code of practice for declaring and dealing with conflicts of interest. Any relevant interests, or changes to interests, will also be declared publicly at the start of each guideline committee meeting. Before each meeting, any potential conflicts of interest will be considered by the guideline committee Chair and a senior member of the development team. Any decisions to exclude a person from all or part of a meeting will be documented. Any changes to a member's declaration of interests will be recorded in the minutes of the meeting. Declarations of interests will be published with the final guideline.		
Collaborators	Development of this systematic review will be overseen by an advisory committee who will use the review to inform the development of evidence-based recommendations in line with section 3 of Developing NICE guidelines: the manual. Members of the guideline committee are available on the NICE website: https://www.nice.org.uk/guidance/indevelopment/gid-ng10119/documents		
Other registration details	-		
Reference/URL for published protocol	https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=145600		
Dissemination plans	NICE may use a range of different methods to raise awareness of the guideline. These include standard approaches such as: • notifying registered stakeholders of publication • publicising the guideline through NICE's newsletter and alerts		

Field	Content	
	- issuing a press release or briefing as appropriate, posting news articles on the NICE website, using social media channels, and publicising the guideline within NICE.	
Keywords	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	

CCTR: Cochrane Controlled Trials Register (also known as CENTRAL); CDSR: Cochrane Database of Systematic Reviews; GRADE: Grading of Recommendations Assessment, Development and Evaluation; NGA: National Guideline Alliance; NHS: National health service; NICE: National Institute for Health and Care Excellence; RCT: randomised controlled trial; RoB: risk of bias; ROBIS: Risk of bias in systematic reviews.

Appendix B – Literature search strategies

Literature search strategies for review question: How can the experience of babies, children and young people be measured so as to improve their experience of healthcare?

Databases: Embase/Medline/PsycINFO

Date searched: 30/07/2020

#	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/ or attitude to death/) use emez
33	(adverse childhood experience/ or exp attitude to health/ or exp Patient satisfaction/) use ppez
34	(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/) use ppez
35	(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 Preferences/) use psyh
36	(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.
37	((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.
38	or/32-37
39	10 and 31 and 38
40	(*Questionnaire/ or health care survey/ or health survey/ or short survey/) use emez
41	(*"surveys and questionnaires"/ or health care surveys/ or health surveys/ or patient health questionnaire/) use ppez
42	(surveys/ or online surveys/ or telephone surveys/ or mail surveys/ or questionnaires/ or general health questionnaire/) use psyh
43	(questionnaire* or survey*).ti.
44	structured interview/ use emez
45	(structured adj interview*).ti.
46	(satisfaction adj3 (indicator* or measure* or assess*)).tw.
47	((satisfaction or measure*) adj3 scale).tw.
48	(care adj5 (indicator* or measure* or assess*)).tw.
49	(experience* adj3 (measure* or indicator* or assess*)).tw.
50	health care quality indicators/ use ppez
51	(rating adj2 (instrument* or scale*)).tw.
52	or/40-51
53	39 and 52
54	exp United Kingdom/
55	(national health service* or nhs*).ti,ab,in,ad,cq.
56	(english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab.
57	(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.
58	(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.
59	(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.

#	Searches
60	(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.
61	(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.
62	or/54-61
63	((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
64	((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
65	63 or 64
66	62 not 65
67	53 and 66
68	limit 67 to yr="2009-current"
69	Letter/ use ppez
70	letter.pt. or letter/ use emez
71	note.pt.
72	editorial.pt.
73	Editorial/ use ppez
74	News/ use ppez
75	news media/ use psyh
76	exp Historical Article/ use ppez
77	Anecdotes as Topic/ use ppez
78	Comment/ use ppez
79	Case Report/ use ppez
80	case report/ or case study/ use emez
81	Case report/ use psyh
82	(letter or comment*).ti.
83	or/69-82
84	randomized controlled trial/ use ppez
85	randomized controlled trial/ use emez
86	random*.ti,ab.
87	cohort studies/ use ppez
88	cohort analysis/ use emez
89	cohort analysis/ use psyh
90	case-control studies/ use ppez
91	case control study/ use emez
92	or/84-91
93	83 not 92
94	animals/ not humans/ use ppez
95	animal/ not human/ use emez
96	nonhuman/ use emez
97	"primates (nonhuman)"/
98	exp Animals, Laboratory/ use ppez
99	exp Animal Experimentation/ use ppez
100	exp Animal Experiment/ use emez
101	exp Experimental Animal/ use emez
102	animal research/ use psyh
103	exp Models, Animal/ use ppez
104	animal model/ use emez
105	animal models/ use psyh
106	exp Rodentia/ use ppez
107	exp Rodent/ use emez
108	rodents/ use psyh
109	(rat or rats or mouse or mice).ti.
110	or/93-109
111	68 not 110

#	Searches
112	**remove duplicates from 111**
113	meta-analysis/
114	meta-analysis as topic/
115	systematic review/
116	meta-analysis/
117	(meta analy* or metanaly* or metaanaly*).ti,ab.
118	((systematic or evidence) adj2 (review* or overview*)).ti,ab.
119	((systematic* or evidence*) adj2 (review* or overview*)).ti,ab.
120	(reference list* or bibliograph* or hand search* or manual search* or relevant journals).ab.
121	(search strategy or search criteria or systematic search or study selection or data extraction).ab.
122	(search* adj4 literature).ab.
123	(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.
124	cochrane.jw.
125	((pool* or combined) adj2 (data or trials or studies or results)).ab.
126	113 or 114 or 117 or 119 or 120 or 121 or 122 or 123 or 124
127	126 use ppez
128	115 or 116 or 117 or 118 or 120 or 121 or 122 or 123 or 124 or 125
129	128 use emez
130	((comprehensive* or integrative or systematic*) adj3 (bibliographic* or review* or literature)).ti,ab,id.
131	(meta-analy* or metaanaly* or "research synthesis").ti,ab,id.
132	(((information or data) adj3 synthesis) or (data adj2 extract*)).ti,ab,id.
133	(review adj5 (rationale or evidence)).ti,ab,id. and "Literature Review".md.
134	(cinahl or (cochrane adj3 trial*) or embase or medline or psyclit or pubmed or scopus or "sociological abstracts" or "web of science").ab.
135	("systematic review" or "meta analysis").md.
136	or/130-135
137	136 use psyh
138	127 or 129 or 137
139	53 and 138
140	limit 139 to yr=”2009 – current”
141	**remove duplicates from 140**

Database: Cochrane Library

Date searched: 30/07/2020

#	Searches
1	MeSH descriptor: [Adolescent] this term only
2	MeSH descriptor: [Minors] this term only
3	(adolescen* or teen* or youth* or young or juvenile* or minors or highschool*):ti,ab,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] this term only
15	MeSH descriptor: [Community Health Services] this term only
16	MeSH descriptor: [Community Pharmacy Services] this term only

#	Searches
17	MeSH descriptor: [Community Health Centers] this term only
18	MeSH descriptor: [Community Mental Health Centers] this term only
19	MeSH descriptor: [Delivery of Health Care] this term only
20	MeSH descriptor: [Dental Care for Children] this term only
21	MeSH descriptor: [Dental Health Services] explode all trees
22	MeSH descriptor: [Dentists] this term only
23	MeSH descriptor: [Dental Facilities] this term only
24	MeSH descriptor: [Emergency Medical Services] this term only
25	MeSH descriptor: [Emergency Service, Hospital] this term only
26	MeSH descriptor: [General Practice] this term only
27	MeSH descriptor: [Health Facilities] this term only
28	MeSH descriptor: [Health Services] this term only
29	MeSH descriptor: [Home Care Services] this term only
30	MeSH descriptor: [Home Care Services, Hospital-Based] this term only
31	MeSH descriptor: [Home Nursing] this term only
32	MeSH descriptor: [Hospice Care] this term only
33	MeSH descriptor: [Hospices] this term only
34	MeSH descriptor: [Hospitals] explode all trees
35	MeSH descriptor: [Intensive Care Units] this term only
36	MeSH descriptor: [Intensive Care Units, Pediatric] this term only
37	MeSH descriptor: [Intensive Care Units, Neonatal] this term only
38	MeSH descriptor: [Mental Health Services] explode all trees
39	MeSH descriptor: [Nutritionists] this term only
40	MeSH descriptor: [Occupational Therapy] this term only
41	MeSH descriptor: [Orthodontists] this term only
42	MeSH descriptor: [Pediatric Nursing] this term only
43	MeSH descriptor: [Pharmacies] this term only
44	MeSH descriptor: [Primary Health Care] this term only
45	MeSH descriptor: [Respite Care] this term only
46	MeSH descriptor: [School Health Services] explode all trees
47	MeSH descriptor: [School Nursing] this term only
48	MeSH descriptor: [Secondary Care] this term only
49	MeSH descriptor: [Telemedicine] this term only
50	MeSH descriptor: [Tertiary Healthcare] this term only
51	MeSH descriptor: [Transportation of Patients] this term only
52	MeSH descriptor: [Adolescent, Hospitalized] this term only
53	MeSH descriptor: [Child, Hospitalized] this term only
54	MeSH descriptor: [Hospitalization] this term only
55	MeSH descriptor: [Inpatients] this term only
56	MeSH descriptor: [Outpatients] this term only
57	(hospital* or inpatient* or outpatient*):ti,ab,kw
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

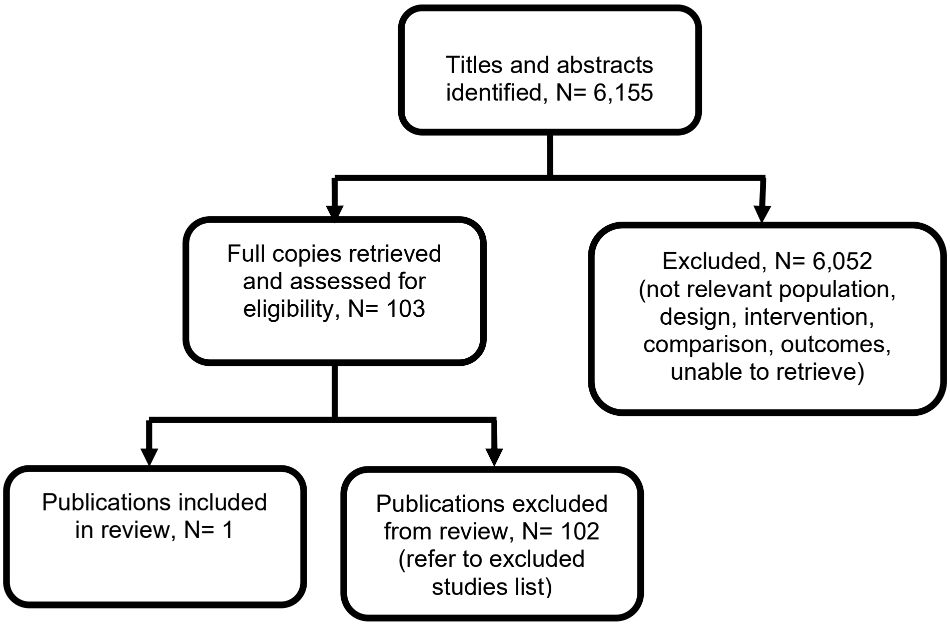
#	Searches
69	(respite near/2 care):ti,ab,kw
70	(foster care or looked after children or children in care):ti,ab,kw
71	#12 OR #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20 OR #21 OR #22 OR #23 OR #24 OR #25 OR #26 OR #27 OR #28 OR #29 OR #30 OR #31 OR #32 OR #33 OR #34 OR #35 OR #36 OR #37 OR #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: [Consumer Behavior] explode all trees
78	MeSH descriptor: [Patient Preference] this term only
79	MeSH descriptor: [Attitude to Death] this term only
80	MeSH descriptor: [Health Knowledge, Attitudes, Practice] this term only
81	(attitude* or choice* or dissatisf* or expectation* or experienc* or inform* or opinion* or perceive* or perception* or perspective* or preferen* or priorit* or satisf* or thought* or view*):ti,ab,kw
82	((adolescen* or baby or babies or child* or infant* or patient* or teen* or young person*) near/4 (decisi* or decid* or involv* or participat*)):ti,ab,kw
83	#72 OR #73 OR #74 OR #75 OR #76 OR #77 OR #78 OR #79 OR #80 OR #81 OR #82
84	MeSH descriptor: [Surveys and Questionnaires] this term only
85	MeSH descriptor: [Health Care Surveys] this term only
86	MeSH descriptor: [Health Surveys] this term only
87	MeSH descriptor: [Patient Health Questionnaire] this term only
88	(questionnaire* or survey*):ti
89	(structured near interview*):ti
90	(satisfaction near/3 (indicator* or measure* or assess*)):ti,ab,kw
91	((satisfaction or measure*) near/3 scale):ti,ab,kw
92	(care near/5 (indicator* or measure* or assess*)):ti,ab,kw
93	(experience* near/3 (measure* or indicator* or assess*)):ti,ab,kw
94	MeSH descriptor: [Quality Indicators, Health Care] this term only
95	(rating near/2 (instrument* or scale*)):ti,ab,kw
96	#84 OR #85 OR #86 OR #87 OR #88 OR #89 OR #90 OR #91 OR #92 OR #93 OR #94 OR #95
97	**#11 AND #71 AND #83 AND #96 with Cochrane Library publication date Between Jan 2009 and Aug 2020**
98	MeSH descriptor: [United Kingdom] explode all trees
99	(national health service* or nhs*):ti,ab,kw
100	(english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) near/5 english)):ti,ab,kw
101	(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
102	(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
103	(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

#	Searches
	("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
104	(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
105	(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
106	(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
107	#98 OR #99 OR #100 OR #101 OR #102 OR #103 OR #104 OR #105 OR #106
108	MeSH descriptor: [Africa] explode all trees
109	MeSH descriptor: [Americas] explode all trees
110	MeSH descriptor: [Antarctic Regions] explode all trees
111	MeSH descriptor: [Arctic Regions] explode all trees
112	MeSH descriptor: [Asia] explode all trees
113	MeSH descriptor: [Oceania] explode all trees
114	#108 OR #109 OR #110 OR #111 OR #112 OR #113
115	MeSH descriptor: [United Kingdom] explode all trees
116	MeSH descriptor: [Europe] this term only
117	#115 OR #116
118	#114 not #117
119	#107 not #118
120	**#97 AND #119**

Appendix C – Clinical evidence study selection

Study selection for: How can the experience of babies, children and young people be measured so as to improve their experience of healthcare?

Figure 1: Clinical evidence study selection flow chart



Appendix D – Clinical evidence tables

Evidence tables for review question: How can the experience of babies, children and young people be measured so as to improve their experience of healthcare?

Table 6: Evidence tables

Study details	Participants	Interventions	Methods	Outcomes and results	Comments
Full citation Horn, Rachel, Jones, Steve, Warren, Kate, The Cost-Effectiveness of Postal and Telephone Methodologies in Increasing Routine Outcome Measurement Response Rates in CAMHS, Child and Adolescent Mental Health, 15, 60-63, 2010 **Ref Id** 1111795 **Country/ies where the study was carried out** UK **Study type**	**Sample size** N (clusters) = 3 CAMHS teams randomised to 3 different treatment arms, including outcomes from N = 178 children, out of N = 268 eligible to participate. - n = 56 in CAMHS Team A (control) - n = 48 in CAMHS Team B (intervention) - n = 74 in CAMHS Team C (intervention) **Characteristics** Age of children and young people: not reported Gender of children and young people (M/F): not reported	**Interventions** - General improvement to system + Postal reminder (CAMHS Team B, intervention) Same as CAMHS Team A plus both reminder letter and questionnaires sent to non-responders after 2 weeks. - General improvement to system + Postal reminder + Telephone reminder (CAMHS Team C, intervention) Same as CAMHS Team B plus telephone call to non-responders 2 weeks after postal reminder.	**Details** Community CAMHS composed of broadly equivalent staff mix of mental health nurses, psychologists, psychiatrists and other therapists, weighted in proportion to population and referrals to each team. Crude case mix of three CAMHS similar although Team A served less 'deprived' population. Baseline return rate over 3 months established from January-March 2008. Interventions attempting to improve return rates implemented from May-July 2008. Families sent Strength and Difficulties Questionnaire (SDQ) and Experience of Service Questionnaire (ESQ) during both baseline and intervention periods. Surveys could either be completed over the telephone with CAMHS staff, or sent in to the service after reminder conversation. 'Return' defined as returning either the SDQ or the ESQ; 'Return rate' calculated as proportion of families seen by service who were 6-months post-	**Results** **Number of questionnaires returned/eligible to be sent during 3-mo baseline period (response rate)** CAMHS Team A: 7/25 (28%) CAMHS Team B: 6/25 (24%) CAMHS Team C: 10/40 (25%) Reports no significant difference in baseline response rates between three CAMHS teams, chi-square (2) =0.12, p=0.94 **Number of questionnaires returned/eligible to be sent during 3-mo intervention period (response rate):** CAMHS Team A: 22/56 (39%)	**Limitations** **Limitations (assessed using the Revised Cochrane risk of bias tool for cluster-randomized trials [RoB 2.0])** **Bias arising from the randomization process: Low risk** 1a.1 Was the allocation sequence random? No information, reports methods randomised to community CAMHS but not clear how nor when randomised. 1a.2: Is it likely that the allocation sequence was subverted? Probably not, reports similar crude case mix although Team A reported to serve less 'deprived population'. 1a.3: Were there baseline imbalances that suggest a problem with the randomization process? No information. **Bias arising from the timing of identification and recruitment of individual participants in relation to timing of randomization: Some concerns** 1b.1 Were all the individual participants identified before randomization of clusters (and if the trial

Study details	Participants	Interventions	Methods	Outcomes and results	Comments
Cluster-randomised controlled trial **Aim of the study** To investigate the cost-effectiveness of different administration methods to improve return rates of a 6-month post-assessment service questionnaire **Study dates** 01/2008 to 07/2008 **Source of funding** Not reported	**Inclusion criteria** • Attending 1 of 3 community CAMHS **Exclusion criteria** Not reported	• General improvement to system (CAMHS Team A, control group) Centralisation of questionnaire administration, quality improvements to questionnaires, covering letters and information sheet, and increased presentation of feedback in patient waiting areas.	assessment and had not been discharged. Time and other resource costs recorded for each method of administration; families in Team C who were telephoned were asked how they felt about being telephoned. Methods of improving return rates for questionnaires randomly allocated to one of three CAMHS.	CAMHS Team B: 19/48 (40%) CAMHS Team C: 44/74 (59%) **Percentage increase in response rate from baseline to intervention period** CAMHS Team A: 11% CAMHS Team B: 16% CAMHS Team C: 34% Reports no significant difference between baseline and intervention periods for CAMHS Teams A and B, but chi-squared (1)=12.37, p<0.001 for CAMHS Team C. **Adjusted results during 3-mo intervention period (response rate) for number of questionnaires returned/eligible to be sent during 3-mo intervention period (calculated assuming ICC=0.3, see 'Other information' below):** CAMHS Team A: 1/3; CAMHS Team B: 1/3; CAMHS Team C: 2/4 CAMHS Team B vs CAMHS Team A,	specifically recruited patients were they all recruited before randomization of clusters)? No information, not clear when randomisation occurred. 1b.2 If N/PN/NI to 1b.1: Is it likely that selection of individual participants was affected by knowledge of the intervention? No. 1b.3 Were there baseline imbalances that suggest differential identification or recruitment of individual participants between arms? Possibly yes, Team C had almost twice as many participants as Teams A and B at baseline although similar response rates. **Bias due to deviations from intended interventions: Some concerns** 2.1a: Were participants aware that they were in a trial? No information. 2.1b: If Y/PY/NI to 2.1a: Were participants aware of their assigned intervention during the trial? No information. 2.2: Were carers and trial personnel aware of participants' assigned intervention during the trial? No information regarding what families knew during trial period. Yes for trial personnel. 2.3. If Y/PY/NI to 2.1 or 2.2: Were there deviations from the intended intervention beyond what would be expected in usual practice? Probably not. 2.4: If Y/PY to 2.3: Were these deviations from intended intervention unbalanced between groups and likely to have affected the outcome? Not applicable.

Study details	Participants	Interventions	Methods	Outcomes and results	Comments
				RR=1.0 (95% CI 0.1 - 9.61) CAMHS Team C vs CAMHS Team A, RR=1.5 (95% CI 0.23 - 9.8) CAMHS Team C vs CAMHS Team B, RR=1.5 (95% CI 0.23 - 9.8) CAMHS Team B + CAMHS Team C vs CAMHS Team A, RR=1.2 (95% CI 0.25 - 5.71) **Adjusted results during 3-mo intervention period (response rate) for number of questionnaires returned/eligible to be sent during 3-mo intervention period (calculated assuming ICC=0.15, see 'Other information' below):** CAMHS Team A: 2/6; CAMHS Team B: 2/5; CAMHS Team C: 5/8 CAMHS Team B vs CAMHS Team A, RR=1.2 (95% CI 0.25 - 5.71) CAMHS Team C vs CAMHS Team A, RR=1.88 (95% CI 0.54 - 6.56)	2.5a Were any clusters analysed in a group different from the one to which they were assigned? No information. 2.5b Were any participants analysed in a group different from the one to which their original cluster was randomized? No information. 2.6 If Y/PY/NI to 2.5: Was there potential for a substantial impact (on the estimated effect of intervention) of analysing participants in the wrong group? No information. **Bias due to missing outcome data: Low risk** 3.1a: Were outcome data available for all, or nearly all, clusters randomized? Yes. 3.1b Were outcome data available for all, or nearly all, participants within clusters? Yes. 3.2 If N/PN/NI to 3.1a or 3.1b: Are the proportions of missing outcome data and reasons for missing outcome data similar across intervention groups? Not applicable. 3.3 If N/PN/NI to 3.1a or 3.1b: Is there evidence that results were robust to the presence of missing outcome data? Not applicable. **Bias in measurement of the outcome: Low risk** 4.1a: Were outcome assessors aware that a trial was taking place? Yes, CAMHS staff would have known that trial was being conducted.

Study details	Participants	Interventions	Methods	Outcomes and results	Comments
				CAMHS Team C vs CAMHS Team B, RR=1.56 (95% CI 0.47 - 5.19) CAMHS Team B + CAMHS Team C vs CAMHS Team A, RR=1.62 (95% CI 0.47 - 5.57)	4.1b: If Y/PY/NI to 4.1: Were outcome assessors aware of the intervention received by study participants? Yes, as above. 4.2: Was the assessment of the outcome likely to be influenced by knowledge of intervention received? No. **Bias in the selection of the reported result: Low risk** Are the reported outcome data likely to have been selected, on the basis of the results, from... 5.1: ... multiple outcome measurements (e.g. scales, definitions, time points) within the outcome domain? No. 5.2:... multiple analyses of the data? No. **Overall judgement of bias:** Study judged to have 'Some concerns' for two domains, which lowers confidence in the results. Authors inappropriately use chi-square test as if participants were unit of randomisation/analysis. **Other information** *Analyses conducted for calculating effect sample size of intervention and control groups were as follows:* Average cluster size (total number of participants/number of clusters), M= 178/3=59.33 **Response rate outcome:**

Study details	Participants	Interventions	Methods	Outcomes and results	Comments
					No relevant ICC identified in database of ICCs, available at https://www.abdn.ac.uk/hsru/what-we-do/tools/#panel177, so conservative ICCs of 0.3 and 0.15 chosen in line with https://pubmed.ncbi.nlm.nih.gov/10787581/. *Assuming ICC=0.3* Design effect = 1 + (M-1) x ICC = 1 + (59.33-1) x 0.3 = 17.8 Effective sample size in CAMHS Team A = 56/17.8 = 3; Adjusted results = 22/17.8 = 1 Effective sample size in CAMHS Team B = 48/17.8 = 3; Adjusted results = 19/17.8 = 1 Effective sample size in CAMHS Team C = 74/17.8 = 4; Adjusted results = 44/17.8 = 2 *Assuming ICC=0.15* Design effect = 1 + (M-1) x ICC = 1 + (59.33-1) x 0.15 = 8.9 Effective sample size in CAMHS Team A = 56/8.9 = 6; Adjusted results = 22/8.9 = 2 Effective sample size in CAMHS Team B = 48/8.9 = 5; Adjusted results = 19/8.9 = 2 Effective sample size in CAMHS Team C = 74/8.9 = 8; Adjusted results = 44/8.9 = 5

CAMHS: Child and Adolescent Mental Health Service; N: number; NA: not applicable; NI: no information; RCT: randomised controlled trial; PN: probably not; PY: probably yes; Y: yes

Appendix E – Forest plots

Forest plots for review question: How can the experience of babies, children and young people be measured so as to improve their experience of healthcare?

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

Appendix F – GRADE tables

GRADE tables for review question: How can the experience of babies, children and young people be measured so as to improve their experience of healthcare?

Table 7: Clinical evidence profile for comparison of postal reminder versus control (general administration improvement) on response rate to 6-month post assessment questionnaire

Quality assessment							Number of returns		Effect			
Number of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Postal reminder**	**General improvements**	**Relative (95% CI)**	**Absolute**	**Quality**	**Importance**
Response rate (assessed with: Number questionnaires returned/number questionnaires eligible to be sent)												
1 (Horn 2010)	Cluster RCT	serious[1]	no serious inconsistency	serious[2]	very serious[3]	none	1/3 (33.3%)	1/3 (33.3%)	RR 1 (0.1 to 9.61)[4]	0 fewer per 1000 (from 300 fewer to 1000 more)	VERY LOW	CRITICAL

1 Serious risk of bias in the evidence contributing to the outcomes as per RoB 2 for cluster randomized trials
2 Population is indirect because target population is babies, children and young people and study is on children and young people using mental health services
3 95% CI crosses 2 MIDs (0.8 and 1.25)
4 Reported results from study adjusted for sample size. Average cluster size=59.33. Assuming an intra-class correlation of 0.3, design effect = 17.8

Table 8: Clinical evidence profile for comparison of telephone reminder versus control (general administration improvement) on response rate to 6-month post assessment questionnaire

Quality assessment							Number of returns		Effect			
Number of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Telephone reminder**	**Postal reminder**	**Relative (95% CI)**	**Absolute**	**Quality**	**Importance**
Response rate (assessed with: Number questionnaires returned/number questionnaires eligible to be sent)												
1 (Horn 2010)	Cluster RCT	serious[1]	no serious inconsistency	serious[2]	very serious[3]	none	2/4 (50%)	1/3 (33.3%)	RR 1.5 (0.23 to 9.8)[4]	167 more per 1000 (from 257 fewer to 1000 more)	VERY LOW	CRITICAL

1 Serious risk of bias in the evidence contributing to the outcomes as per RoB 2 for cluster randomized trials
2 Population is indirect because target population is babies, children and young people and study is on children and young people using mental health services
3 95% CI crosses 2 MIDs (0.8 and 1.25)
4 Reported results from study adjusted for sample size. Average cluster size=59.33. Assuming an intra-class correlation of 0.3, design effect = 17.8

Table 9: Clinical evidence profile for comparison of telephone reminder versus postal reminder on response rate to 6-month post assessment questionnaire

Quality assessment							Number of returns		Effect			
Number of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Telephone reminder**	**Postal reminder**	**Relative (95% CI)**	**Absolute**	**Quality**	**Importance**
Response rate (assessed with: Number questionnaires returned/number questionnaires eligible to be sent)												
1 (Horn 2010)	Cluster RCT	serious[1]	no serious inconsistency	serious[2]	very serious[3]	none	2/4 (50%)	1/3 (33.3%)	RR 1.5 (0.23 to 9.8)4	167 more per 1000 (from 257 fewer to	VERY LOW	CRITICAL

Quality assessment							Number of returns		Effect			
Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Telephone reminder	Postal reminder	Relative (95% CI)	Absolute	Quality	Importance
										1000 more)		

1 Serious risk of bias in the evidence contributing to the outcomes as per RoB 2 for cluster randomized trials
2 Population is indirect because target population is babies, children and young people and study is on children and young people using mental health services
3 95% CI crosses 2 MIDs (0.8 and 1.25)
4 Reported results from study adjusted for sample size. Average cluster size=59.33. Assuming an intra-class correlation of 0.3, design effect = 17.8

Table 10: Clinical evidence profile for comparison of reminder versus control (general administration improvement) on response rate to 6-month post assessment questionnaire

Quality assessment							Number of returns		Effect			
Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Reminder	General improvement	Relative (95% CI)	Absolute	Quality	Importance
Response rate (assessed with: Number questionnaires returned/number questionnaires eligible to be sent)												
1 (Horn 2010)	Cluster RCT	serious[1]	no serious inconsistency	serious[2]	very serious[3]	none	2/5 (40%)	2/6 (33.3%)	RR 1.2 (0.25 to 5.71)[4]	67 more per 1000 (from 250 fewer to 1000 more)	VERY LOW	CRITICAL

1 Serious risk of bias in the evidence contributing to the outcomes as per RoB 2 for cluster randomized trials
2 Population is indirect because target population is babies, children and young people and study is on children and young people using mental health services
3 95% CI crosses 2 MIDs (0.8 and 1.25)
4 Reported results from study adjusted for sample size. Average cluster size=59.33. Assuming an intra-class correlation of 0.3, design effect = 17.8

Appendix G – Economic evidence study selection

Economic evidence study selection for review question: How can the experience of babies, children and young people be measured so as to improve their experience of healthcare?

One global search was conducted for this review question. See supplementary material 6 for further information

Appendix H – Economic evidence tables

Economic evidence tables for review question: How can the experience of babies, children and young people be measured so as to improve their experience of healthcare?

Table 11: Economic evidence tables for review question: How can the experience of babies, children and young people be measured so as to improve their experience of healthcare?

Study country and type	Intervention and comparator	Study population, design and data sources	Costs and outcomes (descriptions and values)	Results	Comments
Horn 2010 UK Cost-effectiveness analysis Conflict of interest: NR Source of funding: NR	Mailing only (6-month questionnaire with general improvements) Mailing plus postal reminder (6-month questionnaire with general improvements plus a reminder letter and questionnaire to non-responders 2 weeks after initial mailing) Mailing plus postal reminder plus telephone reminder (6-month questionnaire with general improvements, a reminder letter and questionnaire to non-responders 2 weeks after initial mailing plus a telephone call to non-responders 2 weeks after postal reminder)	Families who had used Child and Adolescent Mental Health Services (CAMHS) Source of baseline data: RCT (N=268) Source of effectiveness data: RCT (N=268) Source of cost data: RCT (N=268) Source of unit cost data: National sources	Costs: administration time, calls, stamps, business reply envelopes Mean cost per participant: Mailing only: £1.95 Mailing plus postal reminder: £3.90 Mailing plus postal reminder plus telephone reminder: £6.58 Primary measure of outcome: returned completed questionnaires Mean completed questionnaires returned: Mailing only: 33% Mailing plus postal reminder: 42% Mailing plus postal reminder plus telephone reminder: 77%	Mailing plus postal reminder extendedly dominated ICER of mailing plus postal reminder plus telephone reminder (vs. mailing only): £10.52 per additional completed questionnaire returned Sensitivity analysis: none undertaken	Perspective: NHS Currency: UK£ Cost year: likely 2008 Time horizon: 4 weeks Discounting: N/A Applicability: directly applicable Limitations: potentially serious limitations

N: number; NR: not reported; N/A: not applicable; RCT: Randomised controlled trial

Appendix I – Economic evidence profiles

Economic evidence profiles for review question: How can the experience of babies, children and young people be measured so as to improve their experience of healthcare?

Table 12: Economic evidence profile for comparison of mailing only, mailing plus postal reminder, mailing plus postal reminder plus telephone reminder

Study and country	Limitations	Applicability	Other comments	Incremental costs	Incremental effects	ICER	Uncertainty
Horn 2010 UK	Potentially serious limitations[a]	Directly applicable[b]	Cost-effectiveness analysis Time horizon: 4 weeks Primary measure of outcome: percent of completed questionnaires returned	Versus mailing only - Mailing plus postal reminder: £1.95 - Mailing plus postal reminder plus telephone reminder: £4.63 Mailing plus postal reminder plus telephone reminder (vs. mailing only): £2.68	Versus mailing only - Mailing plus postal reminder: 9.38% - Mailing plus postal reminder plus telephone reminder: 44% Mailing plus postal reminder plus telephone reminder (vs. mailing only): 35%	Mailing plus postal reminder extendedly dominated ICER of mailing plus postal reminder plus telephone reminder (vs. mailing only): £10.52 per additional completed questionnaire returned	Deterministic sensitivity analyses: none undertaken PSA: NR Bootstrapping not undertaken

ICER: incremental cost-effectiveness ratio; NR: not reported; PSA: probabilistic sensitivity analysis; QALY: quality-adjusted life year

(a) No sensitivity analysis; no QALYs; small sample size; there were two Mailing plus postal reminder plus telephone reminder groups, as one group had a large proportion of incorrect participant data, the committee made a decision to not include this comparator in this analysis as it is not representative of practice in their centres

(b) UK study

Appendix J – Economic analysis

Economic evidence analysis for review question: How can the experience of babies, children and young people be measured so as to improve their experience of healthcare?

No economic analysis was conducted for this review question.

Appendix K – Excluded studies

Excluded studies for review question: How can the experience of babies, children and young people be measured so as to improve their experience of healthcare?

Clinical studies

Table 13: Excluded studies and reasons for their exclusion

Study	Reason for Exclusion
Abrol, E., Groszmann, M., Pitman, A., Hough, R., Taylor, R. M., Aref-Adib, G., Exploring the digital technology preferences of teenagers and young adults (TYA) with cancer and survivors: a cross-sectional service evaluation questionnaire, Journal of cancer survivorship : research and practice, 11, 670-682, 2017	Study design not in PICO - Cross-sectional
AlSaud, A. M., Taddese, H. B., Filippidis, F. T., Trends and correlates of the public's perception of healthcare systems in the European Union: a multilevel analysis of Eurobarometer survey data from 2009 to 2013, BMJ open, 8, e018178, 2018	Study design not in PICO - Cross-sectional
Amari, E., Vandebeek, C., Montgomery, C. J., Skarsgard, E., Ansermino, J. M., Telephone and web-based pediatric day surgery questionnaires, International Journal of Health Care Quality Assurance, 23, 339-351, 2010	Country: Canada
Ambresin, A. E., Bennett, K., Patton, G. C., Sanci, L. A., Sawyer, S. M., Assessment of youth-friendly health care: A systematic review of indicators drawn from young people's perspectives, Journal of Adolescent Health, 52, 670-681, 2013	Outcomes of included studies not in PICO. Included studies checked for inclusion.
Anonymous,, Development of more focused questionnaires improves results, Nursing children and young people, 28, 13, 2016	Editorial article
Barber, S., Bekker, H., Marti, J., Pavitt, S., Khambay, B., Meads, D., Development of a Discrete-Choice Experiment (DCE) to Elicit Adolescent and Parent Preferences for Hypodontia Treatment, Patient, 12, 137-148, 2019	Study design not in PICO - Cross-sectional
Bennett, K. E., Ambresin, A. E., Patton, G. C., Sawyer, S. M., Development of the 'adolescent friendly hospital survey', Turk Pediatri Arsivi, 2), 97, 2013	Conference abstract
Beresford, B., Clarke, S., Greco, V., Referrers' use and views of specialist mental health services for deaf children and young people in England, Journal of Mental Health, 19, 193-201, 2010	Population not in PICO - Healthcare professionals
Bikker, A. P., Fitzpatrick, B., Murphy, D., Mercer, S. W., Measuring empathic, person-centred communication in primary care nurses: validity and reliability of the Consultation and Relational Empathy (CARE) Measure, BMC family practice, 16, 149, 2015	Study design not in PICO - No comparison
Blasche, G., Marktl, W., Eisenwort, B., Skolka, A., Pichlhofer, O., The treatment experience questionnaire: development and validation of a questionnaire assessing the individual's emotional, perceptual, and cognitive reactions to alternative, physical, and dental treatments, Forschende Komplementarmedizin (2006), 20, 205-12, 2013	Study design not in PICO - No comparison
Boss, R. D., Kinsman, H. I., Donohue, P. K., Health-related quality of life for infants in the neonatal intensive care unit, Journal of Perinatology, 32, 901-906, 2012	Narrative review. Included studies checked for inclusion.
Bowling, A., Rowe, G., McKee, M., Patients' experiences of their healthcare in relation to their expectations and satisfaction: a population survey, Journal of the Royal Society of Medicine, 106, 143-9, 2013	Population not in PICO - Participants not under 18, or data not presented

Study	Reason for Exclusion
	separately for target population
Bravery, K., Cabrera, A. M., Gibson, F., Harding, V., Martins, A., Oldreive, N., Polly, S., Jaffrey, M., Usability testing of a digital child experience measure for children with cancer, Pediatric Blood and Cancer, 63 (Supplement 3), S223, 2016	Conference abstract
Bravery, K., Cabrera, A., Harding, V., Martins, A., Oldreive, N., Smithson, D., Snowdon, P., Sweet, R., Gibson, F., Development of a child experience measure for children with cancer, Pediatric Blood and Cancer, 62 (Supplement 4), S345-S346, 2015	Conference abstract
Brown, A., Ford, T., Deighton, J., Wolpert, M., Satisfaction in child and adolescent mental health services: translating users' feedback into measurement, Administration and policy in mental health, 41, 434-446, 2014	Study design not in PICO - No comparison
Brown, J., Aladangady, N., Measuring the quality of care: using patient experience trackers in a neonatal unit, Nursing Times, 106, 10-11, 2010	Study design not in PICO - No comparison
Burger, S. A., Tallett, A., Maconochie, I., Pall, K., Children's care pathway and parental experiences following use of NHS 111, a non-emergency medical helpline in England, International Journal for Quality in Health Care, 28 (Supplement 1), 31, 2016	Conference abstract
Butt, M. L., Pinelli, J., Boyle, M. H., Thomas, H., Hunsberger, M., Saigal, S., Lee, D. S., Fanning, J. K., Austin, P., Development and Evaluation of an Instrument to Measure Parental Satisfaction With Quality of Care in Neonatal Follow-Up, Journal of Developmental and Behavioral Pediatrics, 30, 57-65, 2009	Outcome not in PICO - Validity of new measurement
Cahill, Paul, O'Reilly, Ken, Carr, Alan, Dooley, Barbara, Stratton, Peter, Validation of a 28-item version of the Systemic Clinical Outcome and Routine Evaluation in an Irish context: The score-28, Journal of Family Therapy, 32, 210-231, 2010	Intervention not in PICO - Measurement of progress in therapy, not healthcare experience
Canaway, A. G., Frew, E. J., Measuring preference-based quality of life in children aged 6-7 years: a comparison of the performance of the CHU-9D and EQ-5D-Y--the WAVES pilot study, Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation, 22, 173-183, 2013	Intervention not in PICO - Measurement of health-related quality of life, not healthcare experience
Chakravorty, S., Tallett, A., John, W., Using a new patient feedback survey to explore experiences of living with Sickle Cell Disease in the UK, British Journal of Haematology, 176 (Supplement 1), 15, 2017	Conference abstract
Chakravorty, S., Tallett, A., Sathyamoorthy, G., James, J., Using a new patient feedback survey to explore experiences of living with sickle cell disease in the UK, International Journal for Quality in Health Care, 28 (Supplement 1), 60-61, 2016	Conference abstract
Challenor, R., Perry, R., Measuring patient satisfaction: three years' data and experience of using a validated patient questionnaire, International Journal of STD and AIDS, 26, 667-671, 2015	Study design not in PICO - Cross-sectional
Chow, M. Y., Morrow, A. M., Cooper Robbins, S. C., Leask, J., Condition-specific quality of life questionnaires for caregivers of children with pediatric conditions: a systematic review, Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation, 22, 2183-2200, 2013	Intervention of included studies not in PICO. Included studies checked for inclusion.
Cohen, W., Wynne, D. M., Parent and Child Responses to the Pediatric Voice-Related Quality-of-Life Questionnaire, Journal of Voice, 29, 299-303, 2015	Intervention not in PICO - Measurement of health related quality of life, not healthcare experience.
Cole, J. A., Gillespie, P., Smith, S. M., Byrne, M., Murphy, A. W., Cupples, M. E., Using postal questionnaires to evaluate physical	Outcome not in PICO - All related to physical activity

Study	Reason for Exclusion
activity and diet behaviour change: case study exploring implications of valid responder characteristics in interpreting intervention outcomes, BMC research notes, 7, 725, 2014	
Dall'Oglio, I., Mascolo, R., Gawronski, O., Tiozzo, E., Portanova, A., Ragni, A., Alvaro, R., Rocco, G., Latour, J. M., A systematic review of instruments for assessing parent satisfaction with family-centred care in neonatal intensive care units, Acta Paediatrica, International Journal of Paediatrics, 107, 391-402, 2018	Population of included studies not in PICO. Included studies checked for inclusion.
Davies, F. C., Clancy, M., Surveying child patients in emergency care is possible, Emergency Medicine Journal, 31, 262, 2014	Commentary article
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	Outcomes of included studies not in PICO. Included studies checked for inclusion.
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	Study design not in PICO - Cross-sectional
Day, L. A., Brice, P., Development and initial validation of a questionnaire to measure hearing parents' perceptions of health care professionals' advice, Journal of Deaf Studies and Deaf Education, 18, 123-137, 2013	Population not in PICO - Parental views
De Stefani, A., Bruno, G., Irlandese, G., Barone, M., Costa, G., Gracco, A., Oral health-related quality of life in children using the child perception questionnaire CPQ11-14: a review, European Archives of Paediatric Dentistry: Official Journal of the European Academy of Paediatric DentistryEur Arch Paediatr Dent, 14, 14, 2019	Population of included studies not in PICO. Included studies checked for inclusion.
Desai, A. D., Popalisky, J., Simon, T. D., Mangione-Smith, R. M., The effectiveness of family-centered transition processes from hospital settings to home: A review of the literature, Hospital Pediatrics, 5, 219-231, 2015	Outcomes of included studies not in PICO. Included studies checked for inclusion.
Down, C., Waldron, B., Maini, R., Williams, F. L. R., Brown, A., Notghi, L., Martin, K., Chin, R., Basu, H., Kirkpatrick, M., Ferrie, C., Whitehouse, W. P., Dunkley, C., Epilepsy12-United Kingdom collaborative clinical audit of health care for children and young people with suspected epileptic seizures, Archives of disease in childhood, 3), A118-A119, 2015	Conference abstract
Dunkley, C., Waldron, B., Maini, R., Williams, F., Brown, A., Ranmal, R., Flower, D., Colaco, F., Bowyer, K., Notghi, L., Martin, K., Chin, R., Basu, H., Paton, J., Kirkpatrick, M., Ferrie, C., Whitehouse, W. P., Epilepsy12 - United Kingdom collaborative clinical audit of health care for children and young people with suspected epileptic seizures, Epilepsia, 5), 16, 2012	Conference abstract
Espinel, A. G., Shah, R. K., McCormick, M. E., Krakovitz, P. R., Boss, E. F., Patient satisfaction in pediatric surgical care: A systematic review, Otolaryngology - Head and Neck Surgery (United States), 150, 739-749, 2014	Intervention of included studies not in PICO. Included studies checked for inclusion.
Espinel, A. G., Shah, R. K., McCormick, M. E., Krakovitz, P. R., Boss, E. F., Patient satisfaction in pediatric surgical care: A systematic review, Otolaryngology - Head and Neck Surgery (United States), 150, 739-749, 2014	Outcomes of included studies not in PICO. Included studies checked for inclusion.
Espinel, A. G., Shah, R., McCormick, M. E., Boss, E. F., Patient satisfaction as a quality indicator in pediatric surgical care: A systematic review, Otolaryngology - Head and Neck Surgery (United States), 1), P34, 2013	Outcomes of included studies not in PICO. Included studies checked for inclusion.

Study	Reason for Exclusion
Evans, J., Rose, D., Flach, C., Csipke, E., Glossop, H., McCrone, P., Craig, T., Wykes, T., VOICE: developing a new measure of service users' perceptions of inpatient care, using a participatory methodology, Journal of Mental Health, 21, 57-71, 2012	Outcome not in PICO - Validity of new measurement
Foster, T., Maillardet, V., Surveying young patients, Emergency Medicine Journal, 27, 221-223, 2010	Outcome not in PICO - Validity of new measurement
Glenny, A. M., Worthington, H. V., Milsom, K. M., Rooney, E., Tickle, M., Strategies for maximizing consent rates for child dental health surveys: a randomised controlled trial, BMC medical research methodology, 13, 108, 2013	Outcome not in PICO - Consent for survey participation
Gore, C., Griffin, R., Rothenberg, T., Tallett, A., Hopwood, B., Sizmur, S., O'Keeffe, C., Warner, J. O., New patient-reported experience measure for children with allergic disease: development, validation and results from integrated care, Archives of Disease in Childhood, 101, 935-43, 2016	Outcome not in PICO - Validity of new measurement
Gore, C., Rothenberg, T., Griffin, R., Tallett, A., O'Keeffe, C., Warner, J. O., Patient reported experience measures - Development and validation of an allergic disease specific tool for children and young people, Clinical and Experimental Allergy, 43 (12), 1467, 2013	Conference abstract
Griffin, R., Gore, C., Rothenberg, T., Tallett, A., O'Keeffe, C., Makrinioti, C. N., Warner, J. O., Allergy-specific patient reported experience measures - The views of children, young people and their families on their care, Clinical and Experimental Allergy, 43 (12), 1434, 2013	Conference abstract
Gurung, G., Richardson, A., Wyeth, E., Edmonds, L., Derrett, S., Child/youth, family and public engagement in paediatric services in high-income countries: A systematic scoping review, Health expectations : an international journal of public participation in health care and health policy, 23, 261-273, 2020	Scoping review. Included studies checked for inclusion.
Hargreaves, D. S., Viner, R. M., McDonagh, J. E., What do young people value in health services? Validation of the you're welcome quality criteria against data from 2 national inpatient surveys in england, Archives of disease in childhood, 1), A77, 2012	Conference abstract
Harley, C., Adams, J., Booth, L., Selby, P., Brown, J., Velikova, G., Patient experiences of continuity of cancer care: Development of a new medical care questionnaire (MCQ) for oncology outpatients, Value in Health, 12, 1180-1186, 2009	Outcome not in PICO - Validity of new measurement
Hindmarsh, P., Wright, A., Diabetes Patient Experience Project with Children, Young People and Parents: Developing a standard toolkit to guide regional paediatric diabetes networks in the ongoing collection of quantitative and qualitative patient experience feedback from children and young people as well as parental opinion, Diabetic medicine, 1), 87, 2012	Conference abstract
Holley, S., Knibb, R., Latter, S., Liossi, C., Mitchell, F., Radley, R., Roberts, G., Development and validation of the Adolescent Asthma Self-Efficacy Questionnaire (AASEQ), The European respiratory journal., 02, 2019	Outcome is validity of new measurement
Homa, K., Sabadosa, K. A., Nelson, E. C., Rogers, W. H., Marshall, B. C., Development and validation of a cystic fibrosis patient and family member experience of care survey, Quality Management in Health Care, 22, 100-16, 2013	Outcome not in PICO - Validity of new measurement
Hopwood, B., Lloyd, K., Tallett, A., Chow, C., Warner, J., Developing an allergy specific patient reported experience measure (PREM), Archives of Disease in Childhood, 96, A48, 2011	Conference abstract

Study	Reason for Exclusion
Hopwood, B., Tallett, A., Little voice: giving young patients a say, Nursing times, 107, 18-20, 2011	Study design not in PICO - Cross-sectional
Hutchings, A., Grosse Frie, K., Neuburger, J., van der Meulen, J., Black, N., Late response to patient-reported outcome questionnaires after surgery was associated with worse outcome, Journal of clinical epidemiology, 66, 218-25, 2013	Population not in PICO - Participants not under 18, or data not presented separately for target population
Ishaque, S., Roberts, R., Karnon, J., Salter, A., Thomas, D., Adaptation/content validation of measure yourself medical outcomes profile (MYMOP) questionnaire for 7-11 year old children, Quality of Life Research, 27 (Supplement 1), S114-S115, 2018	Conference abstract
Jenkins, P. J., Sng, S., Brooksbank, K., Brooksbank, A. J., Socioeconomic deprivation and age are barriers to the online collection of patient reported outcome measures in orthopaedic patients, Annals of the Royal College of Surgeons of England, 98, 40-44, 2016	Population not in PICO - Participants not under 18, or data not presented separately for target population
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	International (passed through UK only filter)
Johal, A., Fleming, P. S., Al Jawad, F. A., A prospective longitudinal controlled assessment of pain experience and oral health-related quality of life in adolescents undergoing fixed appliance treatment, Orthodontics & craniofacial research, 17, 178-186, 2014	Intervention not in PICO - Fixed appliance treatment
John, Mary, Jeffries, Fiona W., Acuna-Rivera, Marcela, Warren, Fiona, Simonds, Laura M., Development of measures to assess personal recovery in young people treated in specialist mental health services, Clinical psychology & psychotherapy, 22, 513-524, 2015	Intervention not in PICO - Designed to assess perception of mental health progress rather than healthcare experiences
Joy, R., Smith, D. P., Mannion, J. F., Using an electronic tablet to survey patient satisfaction in an adolescent transitional diabetes clinic at York, UK, Pediatric Diabetes, 19), 132-133, 2014	Poster presentation
Kappesser, J., de Laffolie, J., Faas, D., Ehrhardt, H., Hermann, C., Comparison of two neonatal pain assessment tools (Children and Infant's Postoperative Pain Scale and the Neonatal Facial Coding System-Revised) and their relations to clinicians' intuitive pain estimates, European Journal of Pain (United Kingdom), 23, 708-718, 2019	Intervention not in PICO - Measuring clinicians ability to discern pain in neonates
Kemp, K. A., Chan, N., McCormack, B., Douglas-England, K., Drivers of Inpatient Hospital Experience Using the HCAHPS Survey in a Canadian Setting, Health Services Research, 50, 982-97, 2015	Comparisons of included studies not in PICO. Included studies checked for inclusion.
Khangah, H. A., Jannati, A., Imani, A., Assessment of healthcare providers' performance considering three healthcare quality indicators: A review article, Shiraz E Medical Journal, 17 (4-5) (no pagination), 2016	Population of included studies not in PICO. Included studies checked for inclusion.
Kjell, O. N. E., Kjell, K., Garcia, D., Sikstrom, S., Semantic measures: Using natural language processing to measure, differentiate, and describe psychological constructs, Psychological methods, 24, 92-115, 2019	Study designs of included studies not in PICO. Included studies checked for inclusion.
Latour, J. M., Measuring parent satisfaction with nursing care, Archives of Disease in Childhood, 99, A16, 2014	Conference abstract
Lorenc, A., Robinson, N., Community use of traditional and complementary healthcare approaches (TCA) for children-Comparing internet and face to face survey methods, European Journal of Integrative Medicine, 2 (4), 229, 2010	Conference abstract

Study	Reason for Exclusion
MacKenzie, H., Thavaneswaran, A., Chandran, V., Gladman, D. D., Patient-reported outcome in psoriatic arthritis: a comparison of Web-based versus paper-completed questionnaires, Journal of Rheumatology, 38, 2619-24, 2011	Population not in PICO - Participants not under 18, or data not presented separately for target population
Maguire, L., Aventin, A., Lohan, M., Clarke, M., What do young people really understand when completing questionnaires? Lessons learnt from developing a questionnaire to measure behavioural outcomes in a sexual health trial, Trials. Conference: 3rd International Clinical Trials Methodology Conference. United Kingdom, 16, 2015	Poster presentation
Maini, Rishma, Kirkpatrick, Martin, McCafferty, Aileen, Dunkley, Colin, Ogston, Simon, Williams, Fiona, Evaluation of a questionnaire to measure parent/carer and child/young person experience of NHS epilepsy services, Seizure, 63, 71-78, 2018	Study design not in PICO - Cross-sectional
Marshman, Z., Eddaiki, A., Bekker, H. L., Benson, P. E., Development and evaluation of a patient decision aid for young people and parents considering fixed orthodontic appliances, Journal of Orthodontics, 43, 276-287, 2016	Intervention not in PICO - Questionnaire measuring shared-decision making, not healthcare experience
McMurray, J., McNeil, H., Lafortune, C., Black, S., Prorok, J., Stolee, P., Measuring patients' experience of rehabilitation services across the care continuum. Part I: A systematic review of the literature, Archives of Physical Medicine and Rehabilitation, 97, 104-120, 2016	Population of included studies not in PICO. Included studies checked for inclusion.
McMurray, J., McNeil, H., Lafortune, C., Black, S., Prorok, J., Stolee, P., Measuring patients' experience of rehabilitation services across the care continuum. Part I: A systematic review of the literature, Archives of Physical Medicine and Rehabilitation, 97, 104-120, 2016	Population of included studies not in PICO. Included studies checked for inclusion.
McNair, A., Drage, K. J., Ireland, A. J., Sandy, J. R., Williams, A. C., Piloting a patient-based questionnaire to assess patient satisfaction with the process of orthodontic treatment, Angle Orthodontist, 79, 759-765, 2009	Outcome not in PICO - Validity of new measurement
Morgan, A. J., Rapee, R. M., Bayer, J. K., Increasing response rates to follow-up questionnaires in health intervention research: randomized controlled trial of a gift card prize incentive, Clinical trials (london, england), 14, 381â 386, 2017	Population not in PICO - Parental views
Morley, D., Dummett, S., Kelly, L., Dawson, J., Fitzpatrick, R., Jenkinson, C., Pretesting the Oxford participation and activities questionnaire: Results from an expert review, Movement Disorders, 1), S419, 2015	Conference abstract
Noyes, J., Edwards, R. T., EQ-5D for the assessment of health-related quality of life and resource allocation in children: A systematic methodological review, Value in health, 14, 1117-1129, 2011	Intervention of included studies not in PICO. Included studies checked for inclusion.
O'Cathain, A., Knowles, E., Nicholl, J., Measuring patients' experiences and views of the emergency and urgent care system: psychometric testing of the urgent care system questionnaire, BMJ Quality & Safety, 20, 134-40, 2011	Population not in PICO - Participants not under 18, or data not presented separately for target population
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
Patalay, P., Hayes, D., Deighton, J., Wolpert, M., A Comparison of Paper and Computer Administered Strengths and Difficulties Questionnaire, Journal of Psychopathology and Behavioral Assessment, 38, 242-250, 2016	Intervention not in PICO - Measurement of mental health only, not healthcare experience

Study	Reason for Exclusion
Patalay, Praveetha, Deighton, Jessica, Fonagy, Peter, Wolpert, Miranda, Equivalence of paper and computer formats of a child self-report mental health measure, European Journal of Psychological Assessment, 31, 54-61, 2015	Intervention not in PICO - Measurement of mental health only, not healthcare experience
Perry, Sarah, Carpenter, Simon, Preliminary development and piloting of a user-generated routine outcome measure in a children and young people's counselling service, Counselling & Psychotherapy Research, 16, 171-182, 2016	Study design not in PICO - Cross-sectional
Quigley, D. D., Palimaru, A., Lerner, C., Hays, R. D., A review of best practices for monitoring and improving inpatient pediatric patient experiences, Hospital Pediatrics, 10, 277-285, 2020	Interventions of included studies not in PICO. Included studies checked for inclusion.
Rahi, J. S., Tadi, V., Keeley, S., Lewando-Hundt, G., Capturing children and young people's perspectives to identify the content for a novel vision-related quality of life instrument, Ophthalmology, 118, 819-824, 2011	Study design not in PICO - Qualitative study
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	Intervention not in PICO - Measurement of specific disease symptoms only, not healthcare experience
Richards, S. H., Campbell, J. L., Dickens, A., Does the method of administration influence the UK GMC patient questionnaire ratings?, Primary health care research & development, 12, 68-78, 2011	Study design not in PICO - Cross-sectional
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
Riley, A. R., Walker, B. L., Hall, T. A., Development and initial validation of a measure of parents' preferences for behavioral counseling in primary care, Families, systems & health : the journal of collaborative family healthcare, 2020	Country: USA
Robertson, S., Pryde, K., Evans, K., Patient involvement in quality improvement: Is it time we let children, young people and families take the lead?, Archives of Disease in Childhood: Education and Practice Edition, 99, 23-27, 2014	Outcomes of included studies not in PICO. Included studies checked for inclusion.
Rosenberg, A. R., Bona, K., Wharton, C. M., Bradford, M., Shaffer, M. L., Wolfe, J., Baker, K. S., Adolescent and Young Adult Patient Engagement and Participation in Survey-Based Research: A Report From the "Resilience in Adolescents and Young Adults With Cancer" Study, Pediatric Blood and Cancer, 63, 734-736, 2016	Population not in PICO - Participants not under 18, or data not presented separately for target population
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
Sadler-Williams, E., Wang, L., Carmichael, S., McSkimming, P., Patient perceptions of IMPs: An international perspective, Pharmaceutical Engineering, 36, 50-58, 2016	Study design not in PICO - No comparison
Sadlo, A., Altevers, J., Peplies, J., Kaltz, B., Classen, M., Bauer, A., Koletzko, S., Timmer, A., Measuring satisfaction with health care in young persons with inflammatory bowel disease--an instrument development and validation study, BMC health services research, 14, 97, 2014	Outcome not in PICO - Validity of new measurement
Sakonidou, S., Andrzejewska, I., Webbe, J., Modi, N., Bell, D., Gale, C., Interventions to improve quantitative measures of parent	Outcomes of included studies not in PICO.

Study	Reason for Exclusion
satisfaction in neonatal care: A systematic review, BMJ Paediatrics Open, 4, e000613, 2020	Included studies checked for inclusion.
Sanford, K., Rivers, A. S., Braun, T. L., Schultz, K. P., Buchanan, E. P., Medical Consultation Experience Questionnaire: Assessing perceived alliance and experienced confusion during medical consultations, Psychological AssessmentPsychol Assess, 30, 1499-1511, 2018	Population not in PICO - Parental views
Sizmur, S., Graham, C., Walsh, J., Influence of patients' age and sex and the mode of administration on results from the NHS friends and family test of patient experience, Journal of Health Services Research and Policy, 20, 5-10, 2015	Study design not in PICO - Cross-sectional
Sousa, V. E. C., Dunn Lopez, K., Towards Usable E-Health. A Systematic Review of Usability Questionnaires, Applied clinical informatics, 8, 470-490, 2017	Outcomes of included studies not in PICO. Included studies checked for inclusion.
Starr, K., McPherson, G., Forrest, M., Cotton, S. C., SMS text pre-notification and delivery of reminder e-mails to increase response rates to postal questionnaires in the SUSPEND trial: a factorial design, randomised controlled trial, Trials, 16, 295, 2015	Population not in PICO - Participants not under 18, or data not presented separately for target population
Tallett, A., Hopwood, B., Using a child-friendly survey to obtain feedback about the hospital experience of young inpatients, Archives of Disease in Childhood: Education and Practice Edition, 1), A67, 2013	Conference abstract
Weston, R. L., Hopwood, B., Harding, J., Sizmur, S., Ross, J. D. C., Development of a validated patient satisfaction survey for sexual health clinic attendees, International Journal of STD and AIDS, 21, 584-590, 2010	Population not under 18, or unable to calculate proportions
Wiebe, Natalie, Fiest, Kirsten M., Dykeman, Jonathan, Liu, Xiaorong, Jette, Nathalie, Patten, Scott, Wiebe, Samuel, Patient satisfaction with care in epilepsy: How much do we know?, Epilepsia, 55, 448-455, 2014	Interventions of included studies not in PICO. Included studies checked for inclusion.
Willems, D. C. M., Joore, M. A., Nieman, F. H. M., Severens, J. L., Wouters, E. F. M., Hendriks, J. J. E., Using EQ-5D in children with asthma, rheumatic disorders, diabetes, and speech/language and/or hearing disorders, International Journal of Technology Assessment in Health Care, 25, 391-399, 2009	Intervention not in PICO - Measurement of health status only, not healthcare experience
Wolpert, M., Cheng, H., Deighton, J., Measurement issues: Review of four patient reported outcome measures: SDQ, RCADS, C/ORS and GBO - their strengths and limitations for clinical use and service evaluation, Child and Adolescent Mental Health, 20, 63-70, 2015	Intervention not in PICO - Measurement of health status only, not healthcare experience
Wray, J., Hobden, S., Knibbs, S., Oldham, G., Hearing the voices of children and young people to develop and test a patient-reported experience measure in a specialist paediatric setting, Archives of disease in childhood, 103, 272-279, 2018	Study design not in PICO - No comparison

Economic studies

Table 14: Excluded studies and reasons for their exclusion

Study	Reason for exclusion
Cohen, W., Wynne, D. M., Parent and Child Responses to the Pediatric Voice-Related Quality-of-Life Questionnaire, Journal of Voice, 29, 299-303, 2015	Intervention does not fit the inclusion criteria: Adapting an adult related Quality of Life questionnaire

Study	Reason for exclusion
Hamilton, M. P., Hetrick, S. E., Mihalopoulos, C., Baker, D., Browne, V., Chanen, A. M., Pennell, K., Purcell, R., Stavely, H., McGorry, P. D., Identifying attributes of care that may improve cost-effectiveness in the youth mental health service system, Medical Journal of Australia, 207, S27-S37, 2017	Intervention does not fit the inclusion criteria: Examining different types of therapeutic treatments for mental health problems
Knapp, M., Evers, S., Health economic aspects of child and adolescent mental health, Psychiatrische Praxis, 38, 2011	This is a conference abstract and not a fully published study
Montgomery, S., Hassan, M., Kusel, J., Economic orphans? The prevalence of child-specific utilities in nice appraisals for paediatric indications, Value in Health, 17 (7), A326-A327, 2014	This is a conference abstract and not a fully published study
Noyes, J., Edwards, R. T., Hastings, R. P., Hain, R., Totsika, V., Bennett, V., Hobson, L., Davies, G. R., Humphreys, C., Devins, M., Spencer, L. H., Lewis, M., Evidence-based planning and costing palliative care services for children: novel multi-method epidemiological and economic exemplar, BMC Palliative Care, 12, 18, 2013	Intervention does not fit the inclusion criteria: Not using Health Economics to compare different palliative care options
Ougrin, D., Corrigall, R., Poole, J., Zundel, T., Sarhane, M., Slater, V., Stahl, D., Reavey, P., Byford, S., Heslin, M., Ivens, J., Crommelin, M., Abdulla, Z., Hayes, D., Middleton, K., Nnadi, B., Taylor, E., Comparison of effectiveness and cost-effectiveness of an intensive community supported discharge service versus treatment as usual for adolescents with psychiatric emergencies: a randomised controlled trial, The Lancet Psychiatry, 5, 477-485, 2018	Intervention does not fit the inclusion criteria: Treatments for mental health
Rennie, L., Porteous, T., Ryan, M., Preferences for managing symptoms of differing severity: a discrete choice experiment, Value in Health, 15, 1069-76, 2012	Intervention does not fit the inclusion criteria: Population only adults
Revill, P., Ryan, P., McNamara, A., Normand, C., A cost and outcomes analysis of alternative models of care for young children with severe disabilities in Ireland, Alter, 7, 260-274, 2013	Intervention does not fit the inclusion criteria: Parental opinion of care
Thorrington, D., Eames, K., Measuring health utilities in children and adolescents: A systematic review of the literature, PLoS ONE, 10 (8) (no pagination), 2015	Intervention does not fit the inclusion criteria: Evaluating the ways of measuring BCYP health states not BCYP experience of healthcare
Trepel, D., Ali, S., Health-related quality of life measures in economic evaluations of child and adolescence mental health interventions: A systematic review, Journal of Mental Health Policy and Economics, 1), S22, 2012	This is a conference abstract and not a fully published study
Wray, J., Oldham, G., Using patient reported experience measures (PREMs) as quality improvement tools in paediatric cardiothoracic services: Making it happen, European journal of pediatrics, 175 (11), 1520-1521, 2016	This is a conference abstract and not a fully published study
Yu, A. P., Ben-Hamadi, R., Wu, E. Q., Kaltenboeck, A., Bergman, R., Xie, J., Blum, S., Erder, M. H., Impact of initiation timing of SSRI or SNRI on depressed adolescent healthcare utilization and costs, Journal of Medical Economics, 14, 508-515, 2011	Intervention does not fit the inclusion criteria: Timing of treating Major Depressive Disorder not Babies, Children and Young people’s experience of healthcare

Appendix L – Research recommendations

Research recommendations for review question: How can the experience of babies, children and young people be measured so as to improve their experience of healthcare?

Research question

How can the experience of babies, children and young people be measured so as to improve their experience of healthcare?

Why this is important

The experiences that babies, children and young people have of their healthcare are important in themselves and also for the potential impact on outcomes and future uptake of services as well as compliance with treatment or other recommendations. While much information can be gained from careful observation by healthcare providers, only service users can give complete information about their experiences. Babies, children and young people may be less able than adults to provide this information, however, and there is also a need for measurement approaches that go beyond the anecdotal to allow comparisons between different approaches and evaluations of changes. Although grey literature suggested many promising approaches, the systematic review for this question found very little quantitative evidence supporting ways to gather information about babies, children and young people's experiences of healthcare.

Table 15: Research recommendation rationale

Research question	**How can the experience of babies, children and young people be measured so as to improve their experience of healthcare?**
Why is this needed	
Importance to 'patients' or the population	It is essential to measure the healthcare experience of babies, children and young people. This allows for the identification of areas of weakness and therefore allows their experience to be improved.
Relevance to NICE guidance	The purpose of the research is to enable recommendations to be made about the best way to measure children and young people's experience, that can ultimately improve the healthcare experiences of babies, children and young.
Relevance to the NHS	The NHS is an organisation that develops and improves by continuously measuring and acting on feedback from its service users, and this is important for services provided to babies, children and young people, as well as adults.
National priorities	The findings from this research would support the priorities of the NHS Long Term Plan with respect to children and young people by supporting the workforce to listen, respond and meet their needs.
Current evidence base	Although the grey literature suggested many promising approaches to measuring children and young people's healthcare experience, the systematic review for this question found very little quantitative evidence supporting ways to

Research question	**How can the experience of babies, children and young people be measured so as to improve their experience of healthcare?**
	gather information about babies, children and young people's experiences of healthcare.
Equality	Methods for measuring experiences of healthcare would need to include children and young people with protected characteristics or from disadvantaged or marginalised groups.
Feasibility	As this research would not impact on children and young people's healthcare, and only on how their experiences were measured, it would be feasible to recruit from a variety of healthcare settings and across all ages.

Table 16: Research recommendation modified PICO table

Criterion	**Explanation**
Population	Babies, children and young people in receipt of healthcare (ages 0 to 17)
Intervention	Methods of measuring of experiences of healthcare
Comparator	Different methods and modes of measuring experiences of healthcare, different timing, different populations
Outcomes	**Critical** • Acceptability to respondent • Response rate **Important** • Mode effect: phenomenon when a particular survey administration mode causes different data to be collected. • Data accuracy (proportion of number of errors to amount of missing data) • Data equivalence (proportion of missing data to total possible data) • Time taken to complete survey
Study design	Randomised controlled trial
Timeframe	3 years
Additional information	If appropriate, age groups should be stratified to align with WHO and ONS bands: • (Parents or carers of) 0-4 years • 5-9 years • 10-14 years • 15-17 years

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

Appendix M – Evidence from reference groups and focus groups

Reference group and focus group evidence for review question: How can the experience of babies, children and young people be measured so as to improve their experience of healthcare?

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

Table 17: Evidence from reference groups and focus groups

Age < 7 years	Age 7-11 Years	Age 11-14 years	Overall quality of the evidence
There was no evidence from this group for this question	There was no evidence from this group for this question	**Methods to obtain feedback:** • Verbal/face-to-face • Computers are good - like tech and feel comfortable with it • Token box voting could be misused – would need to hand out the tokens • Token boxes – adopted into a wall-vote system • Some text is too talky/intimidating • Have surveys on iPads – cuts down on writing – some people can't write/press buttons – need audio/speech options • Surveys delivered by people same age = easier to communicate – cuts out jargon. Better communication • Tech/button surveys are easily manipulated • Tick box questionnaires can be inaccurate – need explanation of why you've ticked that box • Ask/give survey whilst patient is still in services' care – if you leave it until later it may not be done	• Low
		Questions to include: • 'Do you think you are getting enough care?' • 'Did you like your treatment?' • 'What could we do differently?' • 'What is your perfect hospital experience?' • Rate you care/treatment 1-10	

Age < 7 years	Age 7-11 Years	Age 11-14 years	Overall quality of the evidence
		• Keep it simple – people don't want to spend a lot of time on it • Make it easy/smooth • Make it positive – not upsetting • Use symbols – easy for people who have English as an additional language • Have option for someone to talk through + fill it in with you – they have to be honest and record what you actually said	

Appendix N – Evidence from national surveys

Evidence from national surveys for review question: How can the experience of babies, children and young people be measured so as to improve their experience of healthcare?

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

Table 18: 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	COMPLAINTS: • 60% of young people wanted to make a complaint or a suggestion but had not done so • 19% had made a complaint but over 50% of these reported that nothing happened as a result. • 3 young people had had positive experiences of making a complaint: in 1 case the service had explained how they planned to address the complaint; in 1 case the service had explained that changes had been made as a result; in 1 case the young person could see that obvious changes had been made to improve the service. REASONS FOR NOT MAKING A COMPLAINT: • The most common reasons given for not making a complaint was that nothing would change, thinking nobody will listen, fear of repercussions, or not knowing how to complain. Quotes: 'I've already been treated like rubbish by people in power of the service I've complained about' 'I think I will be stereotyped as a complainer and that they think I don't appreciate the NHS and my care' 'Raised concern and told if raised another concern wouldn't be allowed to use service again' 'Nothing would stop me giving feedback' MAKING IT EASIER TO GIVE FEEDBACK OR MAKE A COMPLAINT:	• Low

Survey	Findings	Overall quality of the evidence
	• Being able to complain anonymously, clear information about the right to complain and how to complain, belief that feedback and responses will be received about complaints, and assurance that they won't be treated differently for making a complaint were all given as factors that would make it easier for young people to make a complaint. Quotes: 'Having people actually read and take complaints seriously!' 'Having people who actually would or have used the service being in positions to make changes and take complaints, rather than someone who is just guessing what is actually needed' 'Most people won't speak up because they don't' want to make a fuss, it isn't worth it. There needs to be a mass change. A change in the way we read and interpret opinions. Not seeing the individual as someone who just wants to complain. But someone who would like to see genuine, positive change.'	
Care Quality Commission. Children and young people's inpatient and day case survey 2018	CONCERNS: • 64% of parents of 0-15 year olds said they could have told hospital staff if they had a concern	• Low
Child Outcomes Research Consortium. Child- and Parent-reported Outcomes and Experience from Child and Young People's Mental Health Services 2011-2015	• No relevant findings were identified for this question	• N/A
Health and Social Care Information Centre. Children's Dental Health Survey 2013. (Country 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

Survey	Findings	Overall quality of the evidence
National Children's Bureau. Listening to children's views on health provision 2012	- No relevant findings were identified for this question	- N/A
Opinion Matters. Declare your care survey 2018	CONCERNS/ COMPLAINTS: - 34% of young people had voiced concerns or made an official complaint - 15% had wanted to complain but didn't - The remaining 52% had never felt the need to raise a concern or make a complaint REASONS FOR NOT RAISING CONCERN / MAKING COMPLAINT: - Of 19 young people who did not raise concerns the reasons that prevented them from doing this were: o Didn't know how (21%) o Didn't know who is best person to raise it with (42%) o Didn't want to be seen as a trouble-maker (42%) o Didn't think it would be taken seriously (21%) o Didn't think it would make any difference (26%) o Staff are busy and it doesn't help (5%) o Worried care would get worse if I complained (21%) o I have complained before and it didn't make any difference (5%) o The issue was resolved without me needing to make a complaint (11%) RESULT OF RAISING CONCERN/ MAKING COMPLAINT: - Of 43 young people who had raised a concern or made a complaint, 65% wanted it to improve their care; 65% wanted it to improve the service for everyone and 37% wanted an apology or an explanation. - 33% said the issue was resolved quickly; 19% were happy with the outcome; 42% had to complain multiple times, didn't feel like they were taken seriously, or no action was taken as a result of their concern/complaint	- Low

Survey	Findings	Overall quality of the evidence
	ENCOURAGEMENT TO RAISE CONCERNS: • Of 128 young people, factors that would encourage them to express concerns would be: ○ More information about expected standards of care (34%) ○ A more open culture encouraging feedback (34%) ○ Receiving regular feedback on actions taken (37%) ○ Having an advocate or third party who could raise concerns (19%) ○ Being able to report concerns anonymously (34%) ○ Knowing which staff (36%) or services (24%) to raise concerns with	
Picker Institute. Children and Young People's Patient Experience Survey 2018.	• No relevant findings were identified for this question	• N/A
Picker Institute. Paediatric Emergency Department Survey 2015 and Children and Young People's Outpatient Survey 2015	• No relevant findings were identified for this question	• N/A
Picker Institute/NHS England/Bliss. Neonatal Survey 2014 *Results for individual questions were converted into scores on a scale of 1 to 100, with 100 representing the best possible outcome (the scores are not percentages).*	• 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 (13-17 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 (13-17 years) felt that it was important for the local services to collect information about the experiences of patients they treated through a series of regular qualitative approaches (group	• Low

Survey	Findings	Overall quality of the evidence
	discussions and/or individual interviews with children and young people with cancer), and that these should be supplemented with a survey that was sent to all patients (over a certain age). Quotes: ‘I think it’s really important that you can influence things that affect your care, because some things affect you but not others. I think it’s important to take into consideration what each person wants.’ (F15) ‘I think it’s important to ask about all the places where people are seen. Personally, I’ve had good experiences everywhere, but I know some people haven’t and I think it’s important to ask about all the places where we are seen.’ (M16) METHODS TO GATHER FEEDBACK: • Children under 11 years: ○ Prefer handheld electronic device, iPad or tablet ○ Prefer symbols (smiley/sad faces) rather than text • Young people 13-17 years: ○ Liked both surveys and interviews (individual face to face or groups), but thought surveys would be easier if you were very ill. ○ 2 young people preferred pen and paper surveys sent to their home address, but all the others preferred an online survey as easy to administer, cheap and simple to complete, and would like to receive the invitation by email not by text. Quotes: ‘I feel that a group would be good for support rather than to give information. If I was invited to one now, I wouldn’t mind going to it. But when I was ill I wouldn’t have done it. I would prefer a survey. And I think that for me, when I was in hospital, for a lot of the time I was just too ill to engage with a group discussion or anything like that. The advantage of a survey is that you can look at it when you want and fill it in when you feel you can. And it should have open questions as well so that you can write in your feelings about questions.’ (F15)	

Survey	Findings	Overall quality of the evidence
	'I guess it's most convenient to do it online really. And then you just send it off to them. I definitely think most people nowadays have a tablet or a phone or a computer. I think it should be sent by email. Because knowing myself, I reckon I would ignore random texts, and email is a bit more official.' (F15) WHEN TO GATHER FEEDBACK: • Young people (13-17 years) thought surveys were best conducted after the end of treatment, but qualitative data should be collected at different points in the journey. Quotes: 'My experience has been very long (from August 2015 to January 2018) so I think it should be done at regular intervals. I think patients would be happy with that, every few of months or so. If I'd been asked say 3 months into it, I'd have been able to comment on the diagnosis part and the early part of the treatment. But then a few months later, things were different, and it would be best if I'd been asked again at that point.' (F15) 'I think the group discussion would be a good idea – both at the end but also half way through.' (F13) WHAT QUESTIONS TO ASK: • Young people (13-17 years) said the questions should include: ○ Whether you felt you were treated with respect ○ Quality of communication with medical and other staff ○ Friendliness of staff ○ Whether you felt fully informed about your care and treatment, including side effects of medications ○ Whether you felt you were fully involved in decision making ○ Whether the environment was clean and hygienic ○ Whether young people felt they were treated as an autonomous and independent person, or whether medical staff spoke about them (with parents etc. or other healthcare professionals) rather than to them ○ Whether young people were able to see family and friends whenever they wanted ○ Whether there were other children/young people of a similar age (and opportunities for socialising and making friends)	

Survey	Findings	Overall quality of the evidence
	○ Whether there were adequate facilities to alleviate the boredom/tedium of being on treatment, including electronic gaming/devices and WIFI etc. as well as DVDs/books and traditional games ○ Views on the school hospital service and on the support provided b by the hospital with education more broadly (including working with respondents' schools to address uninformed 'teasing' and bullying related to cancer) ○ Views on the quality of food provided ○ Whether there was sufficient privacy (including noise) ○ Whether they were able to regulate the temperature of their room/ environment. RAISING CONCERNS OR COMPLIMENTS: Quotes: 'Now when I go as an outpatient I see comments cards, but at the time when I was inpatient, I never really did any of that – I wasn't really well enough to do anything like that. I don't remember anyone saying, 'if things aren't good, here's how you can let us know'.' (F15) 'I filled in the cards on the ward quite a few times. If you had a good experience. There's a box for any room for improvement. You write what ward you're on. I wrote how helpful and cheerful the staff were and how nice they were and how much they do to cheer you up. You can write about a particular member of staff and put their name down and the message gets passed on and then the hospital praises them I think.' (F13)	

N/A: not applicable