National Institute for Health and Care Excellence

FINAL

Babies, children and young people's experience of healthcare

[H] Empowering children and young people to advocate for themselves

NICE guideline NG204

Evidence reviews underpinning recommendations 1.5.14 to 1.5.17 in the NICE guideline

August 2021

Final

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

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Review question

How can children and young people be empowered to advocate for themselves?

Introduction

It is a right enshrined in the UN Convention on the Rights of the Child that, wherever possible, healthcare decisions should be made in consultation with the children and young people they affect. Unfortunately, a range of barriers can prevent this happening, such as the individual beliefs of healthcare professionals or parents or carers, logistical factors such as time and space, or service-related barriers such as service design or local policies. This guideline aims to put children and young people at the centre of decision-making about their healthcare. While some children and young people may feel they are able to express their views and make decisions, others may feel they do not have the confidence, power or ability to do this and so their voices are not heard.

The aim of this review is to identify evidence-based methods to empower children and young people to be effective self-advocates, and make recommendations on how children and young people can be supported to advocate for themselves.

Summary of the protocol

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

Table 1: Summary of the protocol

Population	• People <18 years-old who have experience of healthcare • Studies that use the views of parents or carers as proxies will be included only if they are responding on behalf of their child or charge, and ○ The baby or child of the parent or carer is under 5 years old, or ○ There is a clear rationale provided as to why the study is using parents' or carers' views on and experiences of healthcare as proxies for their child.
Phenomenon of interest	Experience of healthcare, in particular how children and young people can be empowered to advocate for themselves – i.e. represent their views and interests - with respect to their healthcare and related decisions.
Primary outcome	Themes will be identified from the literature. The committee identified the following potential themes (however, not all of these themes may be found in the literature, and additional themes may be identified): • Having developmentally-appropriate opportunities to learn about self-advocacy and one's rights with respect to healthcare • Involving child or young person in the measurement of relevant healthcare outcomes (e.g. blood glucose level), record-keeping or treatment decisions • Opportunities to gain knowledge about and understand changing advocacy needs throughout healthcare journey relative to the individual child or young person • Providing encouragement or support to a child or young person to express themselves • Signposting to sources of information and help (e.g. support groups, websites), and providing support to facilitate understanding and use of this.

For further details, see the review protocol in appendix A.

Methods and process

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

Clinical evidence

Included studies

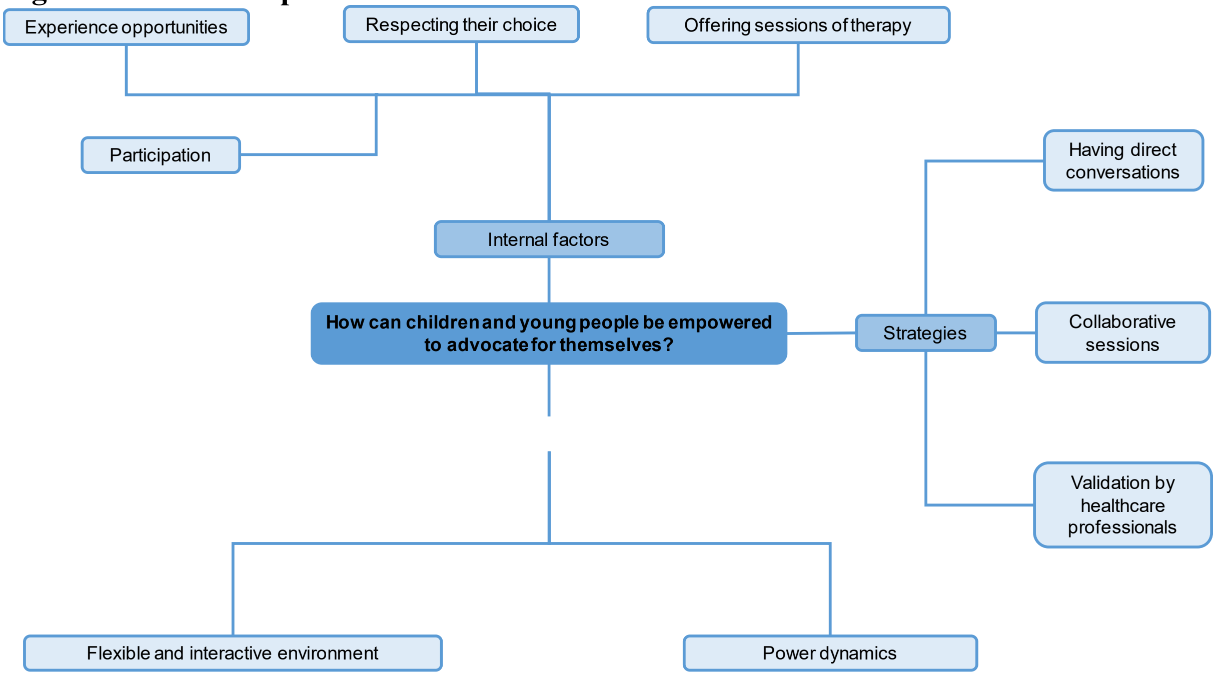
This was a qualitative review with the aim of:

- Understanding how children and young people can be empowered to advocate for themselves with respect to their healthcare and related decisions.

A systematic review of the literature was conducted using a combined search. Ten studies were included in this evidence review: 4 qualitative studies used semi-structured interviews (Alderson 2019, Grealish 2013, Harper 2014, Mitchell 2012), there was 1 mixed-methods study (Edbrooke-Childs 2019), 1 cross-sectional study (Lowes 2015), and 2 qualitative studies used semi-structured interviews and focus groups (Holley 2018 and Nightingale 2017). In addition, 2 of the studies were systematic reviews (Lerch 2019 and Robards 2018). For the systematic review by Lerch 2019, parent-child opinions were explored to understand the transition process to self-management. Of the 9 studies included in the systematic review by Lerch 2019, 1 was conducted in the UK and 8 were conducted in the US. The systematic review by Robards 2018 included 7 studies conducted in the UK and 59 studies conducted in the US, Australia, Canada, New Zealand and Portugal.
The included studies are summarised in Table 2.

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

Figure 1: Theme map



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

Excluded studies

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

Summary of studies included in the evidence review

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

Table 2: Summary of included studies

Study	Participants	Methods	Themes
Alderson 2019 **Study design** Semi-structured interview and co-produced group **Aim of the study** To explore the experiences and views of members of a PPI group for looked-after children set in the context of an ongoing health service intervention trial North East England, UK	N=16 young people and adults • n=11 young people with care experience • n=1 participation officer • n=4 researchers o Only the views of young people have been included in this review. *Semi-structured interview* N=12 young people and adults • n=7 young people with care experience • n=1 participation officer • n=4 researchers *Co-produced group* N=15 young people and adults • n=11 young people with care experience • n=1 participation officer • n=3 researchers **Characteristics** Age (range): 15-19 years Gender (M/F): 6/5	**Recruitment** Convenience sample of the 11 young people participating in a Patient Public Involvement group and attending a Children in Care Council session **Data collection** Two rounds of semi-structured interviews with topic guide, plus 9 co-produced group sessions with last session to determine 'top tips' for working with looked after children, care leavers, and other marginalised children **Analysis** Thematic analysis using constant comparison	• External factors: Flexible and interactive environment • External factors: Power dynamic • Internal factors: Respecting their choice
Edbrooke-Childs 2019 **Study design** Mixed method including semi-structured interview **Aim of the study** To determine the effectiveness, usage and acceptability of a new	N=11 children and young people **Characteristics** Age (mean; range): 15.55 years; 11-17 years Gender (M/F): not reported	**Recruitment** Participants invited to participate in interviews from parent RCT. Initial recruitment from CAMHS and schools **Data collection** As part of mixed-methods feasibility study, semi-structured interviews covering participant's	• Strategies: Collaborative sessions

Study	Participants	Methods	Themes
smartphone/tablet app, Power Up UK (no further details reported)		experiences of using Power Up **Analysis** Thematic analysis	
Grealish 2013 **Study design** Semi-structured interview **Aim of the study** To examine how the concept of empowerment applies to young people and their parents with psychosis, using qualitative methods Manchester, UK	N=9 young people **Characteristics** Age (mean; range): 16.4 years; 14-18 years Gender (M/F): 5/4	**Recruitment** CAMHS **Data collection** Semi-structured interviews **Analysis** Interpretative phenomenological analysis	• External factors: Flexible and interactive environment • Internal factors: Independence • Strategies: Validation by healthcare professionals • Strategies: Having direct conversations • Strategies: Collaborative sessions
Harper 2014 **Study design** Semi-structured interview **Aim of the study** To explore young people's experiences of the newly established 16-18 mental health services North West England, UK	N=10 young people **Characteristics** Age (range): 16-18 • 16 years-old, n=1 • 17 years-old, n=5 • 18 years-old, n=4 Gender (M/F): 3/7	**Recruitment** Purposive sampling identified by key workers at 16-18 mental health services **Data collection** Semi-structured interviews **Analysis** Interpretative phenomenological analysis	• Internal factors: Independence • Internal factors: Offering sessions of therapy • Strategies: Collaborative sessions
Holley 2018 **Study design** Focus group and semi-structured interview **Aim of the study** To gain a broader insight into self-reported barriers and facilitators to adolescent asthma self-management Southampton and Isle of Wight, UK	N=54 young people, parents and healthcare professionals • n=28 young people • n=12 parents • n=14 healthcare professionals o Only the views of young people have been included in this review. **Characteristics** Age (range): 12-18 years Gender (M/F): 14/14	**Recruitment** Purposive sampling of patient lists from GP surgeries and hospital paediatric outpatient wards **Data collection** Focus group or semi-structured interview at hospital or participant's home **Analysis** Inductive thematic analysis	• External factors: Flexible and interactive environment • Strategies: Having direct conversations

Study	Participants	Methods	Themes
Lerch 2019 **Study design** Systematic review **Aim of the study** To assess impact of parent-adolescent relationships on illness adherence behaviours during the transition to self-management UK and US	K=9 studies **Characteristics** Type of study (k): • Qualitative=3 • Quantitative=5 • Mixed method=1 o This study incorporated all their results (qualitative and quantitative) into a narrative summary, which was then used in the findings of this review. Range of sample size of included studies: • Adolescents, n=11 – 200 • Adolescent-parent dyads, n=10 – 150 • Parents, n=15 – 62 o Parent-child opinions were included to understand the process adolescents underwent as they transitioned to self-management for chronic illness Study country (k): • US=8 • UK=1	Review does not appear to have been prospectively registered **Search strategy** Systematic search of PubMed, Cumulative Index to Nursing and Allied Health Literature, and Web of Science was conducted from the earliest database records to early June 2017. **Data extraction** The following details were extracted from included studies: • Study purpose • Intervention or measures • Outcomes • Study design, • Sample including sexes and ages of participants • Illness diagnosis • Key findings and clinical significance **Quality assessment of included studies** No quality assessment reported **Analysis** Data were extracted according to PRISMA guidelines. No critical appraisal of included studies was performed.	• Strategies: Collaborative sessions
Lowes 2015 **Study design** Mixed methods including free-text questionnaire **Aim of the study** To explore experiences of living	N=518 children and young people at baseline • Intervention group, n=259 • Control group, n=259	**Recruitment** Participants taking part in DEPICTED cluster-RCT study, who were recruited from paediatric diabetes services **Data collection** Questionnaire including age-appropriate free-text	• Strategies: Having direct conversations

Study	Participants	Methods	Themes
with and managing Type 1 diabetes in children and adolescents, as well as attending specialist paediatric diabetic services Cardiff, UK	N=390 children and young people at 12-month follow-up • Intervention group, n=185 • Control group, n=205 **Characteristics** Age (range): 7-15 years Gender (M/F): not reported	questions at baseline and 1-year follow-up **Analysis** Qualitative descriptive analysis	
Mitchell 2012 **Study design** Semi-structured interview **Aim of the study** To explore parental perspectives on their and their child's role in choice-making their son/daughter's life York, UK	N=14 parental proxies (11 mothers and 3 fathers) representing 11 families o Parental proxies were included because children had learning disabilities and life-limiting conditions **Characteristics** Age of children: not reported Gender of children (M/F): not reported	**Recruitment** Purposive sampling of children and young people with learning difficulties and their parents from two children's hospices **Data collection** Semi-structured interview **Analysis** Thematic (Framework) analysis	• Internal factors: Experience opportunities
Nightingale 2017 **Study design** Semi-structured interview and focus group **Aim of the study** To explore the views of children with Chronic Kidney Disease, their parents, and key professionals to inform the future development of a digital care-management app Leeds and London, UK	N=36 children, young people, parents and healthcare professionals • n=17 children and young people • n=10 parents • n=9 healthcare professionals o Only the views of children and young people are included in this review. **Characteristics** Age (range): 5-18 years • 5-10 years-old, n=6 • 11-14 years-old, n=6 • 15-18 years-old, n=5	**Recruitment** Participants were purposively sampled from 2 paediatric kidney units **Data collection** Semi-structured interview and focus group **Analysis** Framework analysis in context of behaviour change theories	• External factors: Flexible and interactive environment

Study	Participants	Methods	Themes
	Gender (M/F): 9/8		
Robards 2018 **Study design** Systematic review **Aim of the study** To access engagement with and navigation through healthcare systems for marginalised young people in the digital age. Multiple countries	K=68 studies Range of sample size: N=3 to 1388 **Characteristics** Type of study (k) • Qualitative=44 • Quantitative=16 • Mixed-methods=8 ○ This study incorporated all their results (qualitative and quantitative) into a narrative summary, which was then used in the findings of this review. Participants (k): • Young people=61 • Professionals=11 • Parents=7 Although the study notes that their themes were identified by all the participants in their population (marginalised young people up to age 24 years old, parents and healthcare professionals), views of people > 18 years old, parents and health professionals will also have been included in their results. Our findings have been downgraded for relevance where applicable.	**Recruitment** Not applicable **Data collection** Systematic literature search **Analysis** Data extraction, quality appraisal of studies, and thematic analysis	• Internal factors: Participation

CAMHS: Child and Adolescent Mental Health Service; F: Female; GP: general practitioner; K: Number of studies; M: male; N: number; PPI: Patient and Public Involvement; 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).

Quality assessment of studies included in the evidence review

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

Main theme 1: External factors

- Sub-theme 1.1: Flexible and interactive environment. The overall confidence in this sub-theme was judged to be moderate.
- Sub-theme 1.2: Power dynamics. The overall confidence in this sub-theme was judged to be very low.

Main theme 2: Internal factors

- Sub-theme 2.1: Independence. The overall confidence in this sub-theme was judged to be moderate.
- Sub-theme 2.2: Respecting their choice. The overall confidence in this sub-theme was judged to be low.
- Sub-theme 2.3: Offering sessions of therapy. The overall confidence in this sub-theme was judged to be moderate.
- Sub-theme 2.4: Participation. The overall confidence in this sub-theme was judged to be high.
- Sub-theme 2.5: Experience opportunities. The overall confidence in this sub-theme was judged to be moderate.

Main theme 3: Strategies

- Sub-theme 3.1: Collaborative sessions. The overall confidence in this sub-theme was judged to be moderate.
- Sub-theme 3.2: Having direct conversations. The overall confidence in this sub-theme was judged to be low.
- Sub-theme 3.3: Validation by healthcare professionals. The overall confidence in this sub-theme was judged to be low.

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

Evidence from reference groups and focus groups

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

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

Age groups	• < 7 years • 7-11 years • 11-14 years
Areas covered	• Asking questions • Decision making and choice • Supporting children's and young people's participation
Illustrative quotes	• 'I like to talk to the doctor because it is my body.' • What would help you be involved in decisions about your own health and speak up for yourself? o 'Communication skills' o 'Giving it a go and if it doesn't work out it doesn't matter'

	o ‘I don’t know, I’m not a confident speaker’ (several young people felt they just weren’t confident and there wasn’t much that would change that) • What could a doctor do or say to make you feel more confident advocating for yourself? o ‘Ask me ‘are you ok’ or ‘what do you think’’ o ‘Explaining what’s going on o ‘Tell you what’s happening’

See the evidence summary in appendix M.

Evidence from national surveys

There was no evidence from the grey literature review of national surveys so there is no evidence summary in appendix N.

Economic evidence

Included studies

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

Excluded studies

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

Summary of studies included in the economic evidence review

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

Economic model

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

The committee’s discussion of the evidence

Interpreting the evidence

The outcomes that matter most

This review focused on how children and young people can be empowered to advocate for themselves with respect to their healthcare and related decisions. To address this issue, the review was designed to include qualitative data and, as a result, the committee could not specify in advance the data that would be located. Instead, they identified the following main themes to guide the review.

- Having developmentally-appropriate opportunities to learn about self-advocacy and one’s rights with respect to healthcare.
- Involving children and young people in the measurement of relevant healthcare outcomes, record-keeping or treatment decisions.
- Opportunities to gain knowledge about and understand changing advocacy needs throughout healthcare journey relative to the individual child or young person
- Providing encouragement or support to a child or young person to express themselves.
- Signposting to sources of information and help, as well as providing support to facilitate understanding and use of these opportunities.

The evidence review provided data relating to most, but not all, of the themes set out in the protocol. There was a lack of evidence surrounding education of children and young people around self-advocacy and rights with respect to healthcare. Additionally, extra themes emerged from the evidence that had not been anticipated in the protocol. These were related to having flexible and interactive environments, being mindful of power dynamics, involving children and young people in the development of healthcare services, and experiencing opportunities to make decisions and therefore develop the skills required.

The quality of the evidence

The evidence was assessed using GRADE-CERQual methodology, and the overall confidence in the findings ranged from very low to high quality. The review findings were generally downgraded because of methodological limitations of the included studies, assessed using the Critical Appraisal Skills Programme (CASP) checklist for qualitative reviews or systematic reviews. Concerns included lack of researcher reflexivity and inadequate rigour during data analysis. The evidence was also downgraded due to the adequacy of data and coherence in the study findings. The evidence was also downgraded due to relevance. For example, 1 of the systematic reviews included parents and non-UK participant views as well as participants from 16 up to 48 years (Lerch 2019). These data were included because the themes identified and extracted were clearly supported by evidence from the participants under 18 years old.

Benefits and harms

Based on the evidence from the sub-theme of a flexible and interactive environment, the committee discussed the factors that may help children and young people advocate for themselves. This included a suitable environment which encourages them to engage in discussions, a private space, and allowing enough consultation time to give children and young people an opportunity to speak about their views and opinions. The committee emphasised that it is imperative that clinicians are aware of the way the child or young person communicates before the consultation takes place as establishing effective communication gives children and young people more opportunities to express themselves, encouraging their independence and ability to self-advocate. This is particularly relevant in those who are nonverbal or have communication difficulties, so the committee made a recommendation about ensuring the preferred method of communication was identified.

The evidence on power dynamics was discussed by the committee, who agreed that there was wide diversity in healthcare professionals' practice with respect to encouraging children and young people to speak up for themselves. In particular, healthcare professionals may have preconceived ideas, particularly about children and young people who do not communicate verbally, or those with disabilities. Evidence from the systematic review showed that children and young people did not want healthcare professionals to make assumptions about their ability to express their views and opinions. This was particularly common in looked after children and homeless children and young people, so the committee made a recommendation that all children and young people should be given the opportunity to advocate for themselves to ensure that they are actively encouraged to express what matters to them.

The committee discussed that children and young people cannot advocate for themselves unless they have adequate information about their condition. This was shown in the evidence about direct conversations and validation by healthcare professionals, which indicated that education from healthcare providers, and having things explained in a jargon-free, non-patronising manner enables children and young people to make decisions, which in turn leads to a more positive experience. In addition, children and young people felt that healthcare professionals tried to protect them from certain aspects and details related to their healthcare and so they might not have all the information they required.

The committee noted that, even with the best of intentions, the roles of parents or carers can sometimes create barriers that reduce the scope for children and young people to express their views and opinions. The committee acknowledged that involving parents or carers in healthcare discussions is important, but they noted that promoting the over-involvement of parents can result in prioritising parents' or carers' needs over children and young people, which tends to invalidate the child's or young person's wishes, feelings or independence.

There was evidence on independence that showed that sometimes children and young people may prefer to have conversations without their parents or carers present, and evidence that children and young people liked to work collaboratively with healthcare professionals. The committee identified some ways to overcome this barrier, such as making the child or young person the focus of discussions and deferring to parents only when the child or young person asks for it. There was also evidence that children and young people liked working with healthcare professionals who had an awareness of their circumstances and experiences. The committee therefore made recommendations encompassing all these factors, to empower children to advocate for themselves.

The committee discussed that one of the studies included in the review (Edbrooke-Childs 2019) used a smartphone app called PowerUp, and members of the committee were aware of a number of different apps that allowed children and young people to be involved in managing their own condition more independently and therefore made a recommendation about the use of such apps, and some guidance on the standards these apps should attain to be recommended for use within the NHS.

The evidence on participation showed that engaging young people in service design and improvement contributes to engagement and increases involvement. Children and young people particularly liked seeing the impact that their feedback had in the way services are designed and identifying solutions for themselves and the community. The committee therefore made a recommendation that involving children in this way could help develop their skills in advocating for themselves.

The committee noted that a limitation of the systematic literature review was that all the evidence was from young people, with no evidence from children.

In addition to the evidence from the systematic literature review, the committee reviewed the evidence from the focus groups and reference groups. This showed that some children and young people felt as if they needed permission from healthcare professionals to speak about what matters to them, and the committee agreed that some approaches to empower children and young people to advocate for themselves in their recommendations would help overcome this.

Empowering children and young people to advocate for themselves allows them to make decisions and choices about their life, however the committee identified some possible harms, such as pressuring children and young people to advocate for themselves even if they don’t wish to, or raising unrealistic expectations about the influence they could have over healthcare choices, if there are not options available.

Cost effectiveness and resource use

No economic studies were identified which were applicable to this review question. The committee discussed that more time from healthcare professionals may be required to facilitate self-advocacy. In practice, this may require longer consultation times. The overall view was that the recommendations in this area reflect current practice for most services and would have only modest resource implications, if any, which are justifiable as such care is likely to lead to improvements in children and young people’s experience of healthcare.

Recommendations supported by this evidence review

This evidence review supports recommendations 1.5.14 to 1.5.17 in the NICE guideline.

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Appendices

Appendix A – Review protocol

Review protocol for review question: How can children and young people be empowered to advocate for themselves?

Table 4: Review protocol

Field	**Content**
PROSPERO registration number	CRD42019152563
Review title	Empowering children and young people to self-advocate in their healthcare
Review question	How can children and young people be empowered to advocate for themselves?
Objective	To establish how children and young people can be empowered to represent their own views and interests, for example in the course of general healthcare discussions or in light of what healthcare staff or parents and carers deem to be the recommended course of action.
Searches	The following databases will be searched: • CCTR • CDSR • Embase • MEDLINE • MEDLINE IN-Process • PsycINFO One broad, guideline-wide, search will be conducted for qualitative questions, capturing the population and the settings. A UK filter will be applied to identify relevant UK studies and a systematic review filter will be applied to the remainder of the results to identify relevant reviews that include evidence from non-UK high-income countries. If no systematic reviews of this type are identified, then a more focused search may be conducted to identify studies conducted in the following high-income countries: Australia, Austria, Belgium, Canada Denmark, Finland, France, Germany, Greece, Iceland, Ireland, Italy, Liechtenstein, Luxembourg, Malta, Monaco, Netherlands, New Zealand, Norway, Portugal, Spain, Sweden, Switzerland, and USA. Searches will be restricted by: • Date: 2009 • Language of publication: English language only • Publication status: Conference abstracts will be excluded because these do not typically provide sufficient information to fully assess risk of bias • Standard exclusions filter (animal studies/low level publication types) will be applied

Field	Content
	For each search (including economic searches), the principal database search strategy is quality assured by a second information specialist using an adaption of the PRESS 2015 Guideline Evidence-Based Checklist
Condition or domain being studied	• Babies, children's and young people's experience of healthcare
Population	• People <18 years-old who have experience of healthcare • Studies that use the views of parents or carers as proxies will be included only if they are responding on behalf of their child or charge, and o The baby or child of the parent or carer is under-5 years-old, or o There is a clear rationale provided as to why the study is using parents' or carers' views on and experiences of healthcare as proxies for their child. Note: Studies where part of the population is <18 years-old and part of the population is ≥18 years-old will only be included if it is clear that the themes are supported by evidence from the former group only.
Intervention/Exposure/Test	• Experience of healthcare, in particular how children and young people can be empowered to advocate for themselves – i.e. represent their own views and interests - with respect to their healthcare and related decisions.
Comparator/Reference standard/Confounding factors	Not applicable
Types of study to be included	• Systematic reviews of qualitative studies • Studies using qualitative methods: focus groups, semi-structured and structured interviews, observations • Surveys conducted using open-ended questions and a qualitative analysis of responses Note: Mixed methods studies will be included, but only qualitative data will be extracted, and risk of bias assessed. Systematic reviews that include evidence from countries not listed in the search strategy will be excluded if the sources of the themes and evidence from high-income countries cannot be clearly established. Evidence from individual qualitative studies conducted in the high-income countries listed in the search strategy will be included only if no relevant systematic review evidence is identified.
Other exclusion criteria	STUDY DESIGN • Studies using quantitative methods only (including surveys that report only quantitative data) • Surveys using mainly closed questions or which quantify open-ended answers for analysis TOPIC OF STUDY Studies on the following topics will also be excluded: • Accessing non-NHS commissioned health promotion interventions • Views and experiences of healthcare professionals and service managers • Views and experiences of people reporting only on social care planning and shared decision making

Field	Content
	Studies that focus explicitly on the following topics rather than focussing on the views on and experiences of babies, children and young people in healthcare will be excluded as they are covered by the following NICE guidelines: • Child abuse and maltreatment: o Child abuse and neglect (NG76) o Child maltreatment: when to suspect maltreatment in under 18s (CG89) • Community engagement o Community engagement (NG44) • Drug misuse in children and young people: o Alcohol: school-based interventions (PH7) o Alcohol-use disorders: diagnosis, assessment and management of harmful drinking and alcohol dependence (CG115) o Alcohol-use disorders: prevention (PH24) o Drug misuse prevention: targeted interventions (NG64) • End of life care for infants, children and young people with life-limiting conditions: planning and management (NG61) • Immunisations: reducing differences in uptake in under 19s (PH21) • Oral health promotion: general dental practice (NG30) • Physical activity and weight management: o Maternal and child nutrition (PH11) o Obesity prevention (CG43) o Physical activity for children and young people (PH17) o Weight management: lifestyle services for overweight or obese children and young people (PH47) • Pregnancy, including routine antenatal, intrapartum or postnatal care: o Antenatal and postnatal mental health: clinical management and service guidance (CG192) o Antenatal care for uncomplicated pregnancies (CG62) o Intrapartum care for healthy women and babies (CG190) o Intrapartum care for women with existing medical conditions or obstetric complications and their babies (NG121) o Multiple pregnancy: antenatal care for twin and triplet pregnancies (CG129) o Postnatal care up to 8 weeks after birth (CG37) o Pregnancy and complex social factors: a model for service provision for pregnant women with complex social factors (CG110) • Self-harm: o Self-harm in over 8s: long-term management (CG133)

Field	Content
	o Self-harm in over 8s: short-term management and prevention of recurrence (CG16) • Sexual health and contraception o Contraceptive services for under 25s (PH51) o Sexually transmitted infections and under-18 conceptions: prevention (PH3) o Harmful sexual behaviour among children and young people (NG55) • Smoking prevention: o Smoking: preventing uptake in children and young people (PH14) o Smoking prevention in schools (PH23) o Stop smoking interventions and services (NG92) • The transition from children's to adults' services for young people using health or social care services (NG43)
Context	UK studies from 2009 onwards will be prioritised for decision making by the committee as those conducted in other countries may not be representative of current expectations about either services or current attitudes and behaviours of healthcare professionals. The committee presumes that due to their development, particular circumstances and/or condition, there are some topics that babies, children and young people may not be in a position to pronounce on and that in these circumstances, it may be necessary to treat the 'indirect' views of their parents or carers as proxies for their own views on and experiences of healthcare in order to make recommendations. The guideline committee will be consulted on whether a study should be included if it is unclear why parents' or carer's views are being reported instead of their child or charge, and reasons for exclusion if appropriate will be documented. The topic about which the BCYP are talking about should be generalizable to the wider healthcare context (e.g. a study on the views on and experience of communication with healthcare professionals whilst receiving chemotherapy would be included, whilst a study on experience of chemotherapy would be too narrow and not generalizable to wider healthcare context and therefore excluded). Recommendations will apply to those receiving care in all settings where NHS- or local authority- commissioned healthcare is provided (including home, school, community, hospital, specialist and transport settings). Specific recommendations for groups listed in the Equality Considerations section of the scope may be also be made as appropriate.
Primary outcomes (critical outcomes)	• Having developmentally-appropriate opportunities to learn about self-advocacy and one's rights with respect to healthcare • Involving child or young person in measurement of relevant healthcare outcomes (e.g. blood glucose level), recordkeeping or treatment decisions • Opportunities to gain knowledge about and understand changing advocacy needs throughout healthcare journey relative to individual child or young person • Providing encouragement or support to child or young person to express themselves • Signposting to sources of information and help (e.g. support groups, websites), and providing support to facilitate understanding and use of this

Field	Content
	The following themes will not be covered in this review despite relating to healthcare planning and shared decision making: • Access to healthcare information (reviewed in RQ 2.1) • Barriers to, and facilitators of, access to healthcare information (reviewed in RQ 8.1) • Barriers to, and facilitators of, continuity of care (will be covered in RQ 8.2) • Communication with healthcare staff (reviewed in RQ 1.2) • Confidentiality, privacy and consent for children and young people in healthcare (reviewed in RQ 1.3) • Involvement in health care and shared-decision making (reviewed in RQ 1.1)
Secondary outcomes (important outcomes)	Not applicable
Data extraction (selection and coding)	• All references identified by the searches and from other sources will be uploaded into STAR and de-duplicated. Titles and abstracts of the retrieved citations will be screened to identify studies that potentially meet the inclusion criteria outlined in the review protocol. • Duplicate screening will not be undertaken for this question. • Full versions of the selected studies will be obtained for assessment. Studies that fail to meet the inclusion criteria once the full version has been checked will be excluded at this stage. Each study excluded after checking the full version will be listed, along with the reason for its exclusion. A standardised form will be used to extract data from studies, including study reference, research question, theoretical approach, data collection and analysis methods used, participant characteristics, second-order themes, and relevant first-order themes (i.e. supporting quotes). One reviewer will extract relevant data into a standardised form, and this will be quality assessed by a senior reviewer.
Risk of bias (quality) assessment	Risk of bias of individual qualitative studies will be assessed using the CASP (Critical Skills Appraisal Programme) Qualitative checklist. Risk of bias of systematic reviews of qualitative studies will be assessed using the CASP (Critical Skills Appraisal Programme) Systematic Review checklist. See Appendix H in Developing NICE guidelines: the manual for further details. The quality assessment will be performed by one reviewer and this will be quality assessed by a senior reviewer.
Strategy for data synthesis	• Extracted second-order study themes and related first-order quotes will be synthesised by the reviewer into third-order themes and related sub-themes. • The GRADE-CERQual (Confidence in the Evidence from Reviews of Qualitative research; Lewin 2015) approach will be used to summarise the confidence in the third-order theme or sub-theme from the qualitative evidence. The overall confidence in evidence about each theme or sub-theme will be rated on four dimensions: methodological limitations, coherence, adequacy, and relevance. • Methodological limitations refer to the extent to which there were problems in the design or conduct of the studies and will be assessed with the CASP checklist for qualitative studies or systematic reviews as appropriate. Coherence of findings will be assessed by examining the clarity of the data. Adequacy of data will be assessed by looking at the degree of richness and quantity of findings. Relevance of evidence will be assessed by determining

Field	Content		
	the extent to which the body of evidence from the primary studies are applicable to the context of the review question.		
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	13 January 2020		
Anticipated completion date	07 April 2021		
Stage of review at the time of this submission	Review stage	Started	Completed
	Preliminary searches		☑
	Piloting of the study selection process		☑
	Formal screening of search results against eligibility criteria		☑
	Data extraction		☑

Field	Content		
	Risk of bias (quality) assessment		☑
	Data analysis		☑
Named contact	**5a. Named contact** National Guideline Alliance **5b. Named contact e-mail** Infant&younghealth@nice.org.uk **5c Organisational affiliation of the review** National Institute for Health and Care Excellence (NICE) and National Guideline Alliance		
Review team members	NGA Technical Team		
Funding sources/sponsor	This systematic review is being completed by the National Guideline Alliance, which receives funding from NICE.		
Conflicts of interest	All guideline committee members and anyone who has direct input into NICE guidelines (including the evidence review team and expert witnesses) must declare any potential conflicts of interest in line with NICE's code of practice for declaring and dealing with conflicts of interest. Any relevant interests, or changes to interests, will also be declared publicly at the start of each guideline committee meeting. Before each meeting, any potential conflicts of interest will be considered by the guideline committee Chair and a senior member of the development team. Any decisions to exclude a person from all or part of a meeting will be documented. Any changes to a member's declaration of interests will be recorded in the minutes of the meeting. Declarations of interests will be published with the final guideline.		
Collaborators	Development of this systematic review will be overseen by an advisory committee who will use the review to inform the development of evidence-based recommendations in line with section 3 of Developing NICE guidelines: the manual. Members of the guideline committee are available on the NICE website: https://www.nice.org.uk/guidance/indevelopment/gid-ng10119/documents		
Other registration details	-		
Reference/URL for published protocol	https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42019152563		
Dissemination plans	NICE may use a range of different methods to raise awareness of the guideline. These include standard approaches such as: • notifying registered stakeholders of publication • publicising the guideline through NICE's newsletter and alerts • issuing a press release or briefing as appropriate, posting news articles on the NICE website, using social media channels, and publicising the guideline within NICE.		
Keywords	Access; accessibility; babies; children; experience; healthcare; infants; qualitative; services; views; young people.		
Details of existing review of same topic by same authors	Not applicable		

Field	**Content**	
Current review status	☒	Ongoing
	☒	Completed but not published
	☐	Completed and published
	☐	Completed, published and being updated
	☐	Discontinued
Additional information	[Provide any other information the review team feel is relevant to the registration of the review.]	
Details of final publication	www.nice.org.uk	

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

Appendix B – Literature search strategies

Literature search strategies for review question: How can children and young people be empowered to advocate for themselves?

Databases: Embase/Medline/PsycINFO

Date searched: 29/07/2020

#	**Searches**
1	(ADOLESCENT/ or MINORS/) use ppez
2	exp ADOLESCENT/ use emez
3	(adolescen$ or teen$ or youth$ or young or juvenile? or minors or highschool$).ti,ab,jw,nw.
4	exp CHILD/
5	(child$ or schoolchild$ or "school age" or "school aged" or preschool$ or toddler$ or kid? or kindergar$ or boy? or girl?).ti,ab,jw,nw.
6	exp INFANT/
7	(infan$ or neonat$ or newborn$ or baby or babies).ti,ab,jw,nw.
8	exp PEDIATRICS/ or exp PUBERTY/
9	(p?ediatric$ or pubert$ or prepubert$ or pubescen$ or prepubescen$).ti,ab,jx,ec.
10	or/1-9
11	(Ambulance/ or Ambulance Transportation/ or Child Health Care/ or Community Care/ or Day Care/ or Dentist/ or Dental Facility/ or Pediatric Dentist/ or Dietitian/ or Emergency Care/ or Emergency Health Service/ or Emergency Ward/ or General Practice/ or Health Care/ or Health Care Delivery/ or Health Care Facility/ or Health Service/ or exp Home Care/ or Home Mental Health Care/ or Hospice/ or Hospice Care/ or exp Hospital/ or Hospital Care/ or Intensive Care Unit/ or Mental Health Care/ or Mental Health Service/ or Nursing Care/ or Newborn Care/ or Newborn Intensive Care/ or Neonatal Intensive Care Unit/ or Occupational Therapy/ or Ophthalmology/ or Orthodontics/ or Pediatric Intensive Care Unit/ or Pharmacy/ or exp Primary Health Care/ or Physiotherapy/ or Respite Care/ or School Health Nursing/ or exp School Health Service/ or Secondary Care Center/ or Secondary Health Care/ or "Speech and Language Rehabilitation"/ or Telemedicine/ or Tertiary Care Center/ or Tertiary Health Care/) use emez
12	(Ambulances/ or Adolescent Health Services/ or exp Child Health Services/ or Community Health Services/ or Community Pharmacy Services/ or Community Health Centers/ or Community Mental Health Centers/ or "Delivery of Health Care"/ or Dental Care for Children/ or exp Dental Health Services/ or Dentists/ or Dental Facilities/ or Emergency Medical Services/ or Emergency Service, Hospital/ or General Practice/ or Health Facilities/ or Health Services/ or Home Care Services/ or Home Care Services, Hospital-Based/ or Home Nursing/ or Hospice Care/ or Hospices/ or exp Hospitals/ or Intensive Care Units/ or Intensive Care Units, Pediatric/ or Intensive Care Units, Neonatal/ or exp Mental Health Services/ or Nutritionists/ or Occupational Therapy/ or Orthodontists/ or Pediatric Nursing/ or Pharmacies/ or Primary Health Care/ or Respite Care/ or exp School Health Services/ or School Nursing/ or Secondary Care/ or Telemedicine/ or Tertiary Healthcare/ or "Transportation of Patients"/) use ppez
13	(Adolescent Psychiatry/ or Community Health/ or Community Services/ or Dentists/ or Dental Health/ or Educational Psychology/ or Health Care Delivery/ or Health Care Services/ or Home Care/ or Home Visiting Programes/ or Hospice/ or exp Hospitals/ or Intensive Care/ or Language Therapy/ or exp Mental Health Services/ or Neonatal Intensive Care/ or Occupational Therapy/ or Outreach Programs/ or Pharmacy/ or Physical Therapy/ or Primary Health Care/ or Psychiatric Clinics/ or Psychiatric Units/ or Respite Care/ or Speech Therapy/ or Telemedicine/ or Telepsychiatry/ or Telepsychology/ or Walk In Clinics/) use psyh
14	(hospital patient/ or hospitalized adolescent/ or hospitalized child/ or hospitalized infant/ or hospitalization/ or hospital patient/ or outpatient/) use emez
15	(adolescent, hospitalized/ or child, hospitalized/ or Hospitalization/ or inpatients/ or outpatients/) use ppez
16	(hospitalized patients/ or exp hospitalization/ or outpatients/) use psyh
17	(hospital* or inpatient* or outpatient*).tw.
18	(health* adj3 (care or center* or centre* or clinic* or facility or facilities or service* or setting* or specialist*)).tw.

#	**Searches**
19	((dental or communit* or emergency or hospital* or home or intensive or high-dependen* or mental* or primary or secondary or tertiary) adj3 (care or health*)).tw.
20	(emergency adj2 room*).tw.
21	(ambulance* or CAMHS or dentist* or dietics or dieti?ian or hospice* or NICU or nutritionist* or orthodont* or ophthalmolog* or (outreach adj2 team*) or pharmacy or pharmacies or physio* or SCBU or SENCO or telemedicine*).tw.
22	((virtual* or online) adj2 (physician* or clinician* or doctor*)).tw.
23	(communit* adj3 (p?ediatric* or nurs*)).tw.
24	(home adj3 visit*).tw.
25	((walk-in or "urgent care") adj2 (centre* or center* or clinic* or service*)).tw.
26	"speech and language therap*".tw.
27	general practice*.tw.
28	(health* and (nursery or nurseries or school*)).tw.
29	(respite adj2 care).tw.
30	(foster care or "looked after children" or "children in care").tw.
31	or/11-30
32	(Experience/ or personal experience/ or attitude to health/ or patient attitude/ or patient preference/ or patient satisfaction/) use emez
33	(attitude to death/ or patient advocacy/ or consumer advocacy/ or professional-patient relationship/) use emez
34	(adverse childhood experience/ or exp attitude to health/ or exp Patient satisfaction/) use ppez
35	(exp Consumer Participation/ or "Patient Acceptance of Health Care"/ or *exp consumer satisfaction/ or patient preference/ or Attitude to Death/ or health knowledge, attitudes, practice/ or Patient Advocacy/ or consumer advocacy/ or narration/ or focus groups/ or Patient-Centered Care/ or exp Professional-Patient Relations/) use ppez
36	(exp Client Attitudes/ or exp Client Satisfaction/ or exp Attitudes/ or exp Health Attitudes/ or exp Preferences/ or exp Client Satisfaction/ or exp Death Attitudes/ or exp Advocacy/ or exp Preferences/ or client centered therapy/) use psyh
37	(attitude* or choice* or dissatisf* or expectation* or experienc* or inform* or opinion* or perceive* or perception* or perspective* or preferen* or priorit* or satisf* or thought* or view*).tw.
38	((adolescen* or baby or babies or child* or infant* or patient* or teen* or young person*) adj4 (decisi* or decid* or involv* or participat*)).tw.
39	("informed choice" or "shared decision making").tw.
40	empowerment.tw.
41	(patient-focused or patient-cent?red).tw.
42	(advocate or advocacy).tw.
43	((aversion or barrier* or facilitat* or hinder* or obstacle* or obstruct*) adj2 (care or health* or intervention* or pathway* or program* or service* or therap* or treat*)).ti,ab.
44	or/32-43
45	10 and 31 and 44
46	Qualitative Research/
47	exp interview/ use emez
48	interview/ use ppez
49	interviews/ use psyh
50	interview*.tw.
51	thematic analysis/ use emez
52	(theme$ or thematic).mp.
53	qualitative.af.
54	questionnaire$.mp.

#	**Searches**
55	ethnological research.mp.
56	ethnograph$.mp.
57	ethnonursing.af.
58	phenomenol$.af.
59	(life stor$ or women* stor$).mp.
60	(grounded adj (theor$ or study or studies or research or analys?s)).af.
61	((data adj1 saturat$) or participant observ$).tw.
62	(field adj (study or studies or research)).tw.
63	biographical method.tw.
64	theoretical sampl$.af.
65	((purpos$ adj4 sampl$) or (focus adj group$)).af.
66	open ended questionnaire/ use emez
67	(account or accounts or unstructured or openended or open ended or text$ or narrative$).mp.
68	(life world or life-world or conversation analys?s or personal experience$ or theoretical saturation).mp.
69	((lived or life) adj experience$).mp.
70	narrative analys?s.af.
71	or/46-70
72	45 and 71
73	limit 72 to (yr="2009 - current" and english language)
74	exp United Kingdom/
75	(national health service* or nhs*).ti,ab,in,ad,cq.
76	(english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab.
77	(gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*).ti,ab,jx,in,ad,cq.
78	(bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))).ti,ab,in,ad,cq.
79	(bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's").ti,ab,in,ad,cq.

#	**Searches**
80	(aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's").ti,ab,in,ad,cq.
81	(armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's").ti,ab,in,ad,cq.
82	or/74-81
83	((exp africa/ or exp americas/ or exp antarctic regions/ or exp arctic regions/ or exp asia/ or exp oceania/) not (exp united kingdom/ or europe/)) use ppez
84	((exp "arctic and antarctic"/ or exp oceanic regions/ or exp western hemisphere/ or exp africa/ or exp asia/ or exp "australia and new zealand"/) not (exp united kingdom/ or europe/)) use emez
85	83 or 84
86	82 not 85
87	73 and 86
88	Letter/ use ppez
89	letter.pt. or letter/ use emez
90	note.pt.
91	editorial.pt.
92	Editorial/ use ppez
93	News/ use ppez
94	news media/ use psyh
95	exp Historical Article/ use ppez
96	Anecdotes as Topic/ use ppez
97	Comment/ use ppez
98	Case Report/ use ppez
99	case report/ or case study/ use emez
100	Case report/ use psyh
101	(letter or comment*).ti.
102	or/88-101
103	randomized controlled trial/ use ppez
104	randomized controlled trial/ use emez
105	random*.ti,ab.
106	cohort studies/ use ppez
107	cohort analysis/ use emez
108	cohort analysis/ use psyh
109	case-control studies/ use ppez
110	case control study/ use emez
111	or/103-110
112	102 not 111
113	animals/ not humans/ use ppez
114	animal/ not human/ use emez
115	nonhuman/ use emez
116	"primates (nonhuman)"/
117	exp Animals, Laboratory/ use ppez
118	exp Animal Experimentation/ use ppez
119	exp Animal Experiment/ use emez
120	exp Experimental Animal/ use emez
121	animal research/ use psyh

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

Database: Cochrane Library

Date searched: 29/07/2020

#	Search
1	MeSH descriptor: [Adolescent] this term only
2	MeSH descriptor: [Minors] this term only
3	(adolescen* or teen* or youth* or young or juvenile* or minors or highschool*):ti,ab,kw
4	MeSH descriptor: [Child] explode all trees
5	(child* or schoolchild* or "school age" or "school aged" or preschool* or toddler* or kid* or kindergar* or boy* or girl*):ti,ab,kw

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

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

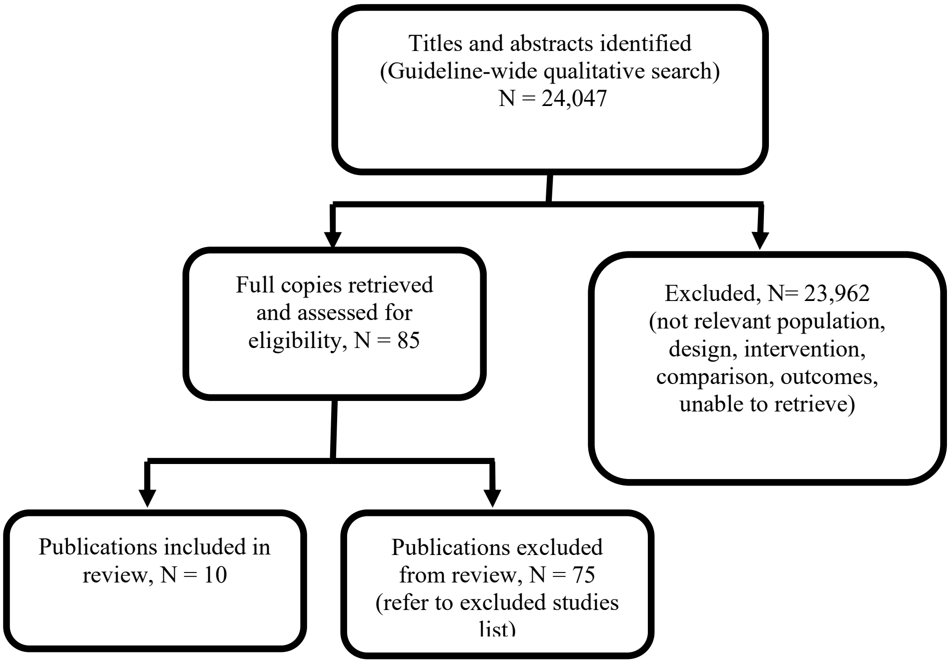
#	Search
90	(advocate or advocacy):ti,ab,kw
91	((aversion or barrier* or facilitat* or hinder* or obstacle* or obstruct*) near/2 (care or health* or intervention* or pathway* or program* or service* or therap* or treat*)):ti,ab,kw
92	#72 OR #73 OR #74 OR #75 OR #76 OR #77 OR #78 OR #79 OR #80 OR #81 OR #82 OR #83 OR #84 OR #85 OR #86 OR #87 OR #88 OR #89 OR #90 OR #91
93	MeSH descriptor: [Qualitative Research] this term only
94	MeSH descriptor: [Interview] this term only
95	(interview*):ti,ab,kw
96	(theme* or thematic):ti,ab,kw
97	(qualitative):ti,ab,kw
98	(questionnaire*):ti,ab,kw
99	(ethnological research):ti,ab,kw
100	(ethnograph*):ti,ab,kw
101	(ethnonursing):ti,ab,kw
102	(phenomenol*):ti,ab,kw
103	(life stor* or women* stor*):ti,ab,kw
104	(grounded near (theor* or study or studies or research or analys*s)):ti,ab,kw
105	((data near/1 saturat*) or participant observ*):ti,ab,kw
106	(field near (study or studies or research)):ti,ab,kw
107	(biographical method):ti,ab,kw
108	(theoretical sampl*):ti,ab,kw
109	((purpos* near/4 samp**) or (focus near group*)):ti,ab,kw
110	(account or accounts or unstructured or openended or open ended or text* or narrative*):ti,ab,kw
111	(life world or life-world or conversation analys*s or personal experience* or theoretical saturation):ti,ab,kw
112	((lived or life) near experience*):ti,ab,kw
113	(narrative analys*s):ti,ab,kw
114	#93 OR #94 OR #95 OR #96 OR #97 OR #98 OR #99 OR #100 OR #101 OR #102 OR #103 OR #104 OR #105 OR #106 OR #107 OR #108 OR #109 OR #110 OR #111 OR #112 OR #113
115	#11 AND #71 AND #92 AND #114 with Cochrane Library publication date Between Jan 2009 and Aug 2020
116	MeSH descriptor: [United Kingdom] explode all trees
117	(national health service* or nhs*):ti,ab,kw
118	(english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) near/5 english)):ti,ab,kw
119	(gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*):ti,ab,kw
120	(gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*):so
121	(bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or

#	**Search**
	ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))):ti,ab,kw
122	(bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's"):ti,ab,kw
123	(aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's"):ti,ab,kw
124	armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's":ti,ab,kw
125	#116 OR #117 OR #118 OR #119 OR #120 OR #121 OR #122 OR #123 OR #124
126	MeSH descriptor: [Africa] explode all trees
127	MeSH descriptor: [Americas] explode all trees
128	MeSH descriptor: [Antarctic Regions] explode all trees
129	MeSH descriptor: [Arctic Regions] explode all trees
130	MeSH descriptor: [Asia] explode all trees
131	MeSH descriptor: [Oceania] explode all trees
132	#126 OR #127 OR #128 OR #129 OR #130 OR #131
133	MeSH descriptor: [United Kingdom] explode all trees
134	MeSH descriptor: [Europe] this term only
135	#133 OR #134
136	#132 not #135
137	#125 not #136
138	#115 AND #137 with Cochrane Library publication date Between Jan 2009 and Aug 2020

Appendix C – Clinical evidence study selection

Study selection for review question: How can children and young people be empowered to advocate for themselves?

Figure 2: Study selection flow chart



Appendix D – Clinical evidence tables

Evidence tables for review question: How can children and young people be empowered to advocate for themselves?

Table 5: Evidence tables

Study details	Participants	Methods	Themes and findings	Limitations
Full citation Alderson, H., Brown, R., Smart, D., Lingam, R., Dovey-Pearce, G., 'You've come to children that are in care and given us the opportunity to get our voices heard': The journey of looked after children and researchers in developing a Patient and Public Involvement group, Health expectations: an international journal of public participation in health care and health policy., 21, 2019 **Ref Id** 1052635 **Country/ies where the study was carried out** North-East England, UK **Study type** Semi-structured interview and co-produced group **Aim of the study**	**Sample size** N=16 young people and adults • n=11 young people with care experience • n=1 participation officer • n=4 researchers o Only the views of young people have been included in this review. *Semi-structured interview* N=12 young people and adults • n=7 young people with care experience • n=1 participation officer • n=4 researchers *Co-produced group* N=15 young people and adults • n=11 young people with care experience	**Setting** North-East England Children in Care Council (CICC) meeting, CICC is an organisation designed to allow looked after children (LAC) and care leavers to have an input in how councils should run their Children's Services. **Sample selection** Researchers contacted the CICC Participation Officer to arrange to attend a CICC meeting. LAC volunteered their interest with the Participation Officer (no information given on how they were informed of the patient and public involvement (PPI) group initially), who then arranged mutually convenient times for researchers and LAC to meet. **Data collection** Semi-structured interviews with topic guide set up and conducted at 2 time points (before CICC sessions and in final CICC session) with collaboration of young people/CICC participation officer. Seven of the 11 young people participating in PPI group participated in interviews, conducted by researchers involved in the Patient Public Involvement project, at first	**Author's themes:** • Involvement as a fluid and evolving process • Awareness of power • Respecting everyone's knowledge and skills **Findings** Face-to-face interaction with researchers was essential in engaging participants. Doing this over a long period of time allowed young people to become comfortable in the situation, allowing a relaxed rapport building. Due to the perceived vulnerability of LAC by society, they routinely miss out on opportunities to be involved in healthcare research. Author's tried to engage LAC on an 'equal' footing, encouraging participants to lead discussions and directing the content of the video aid. Despite this, not all participants were comfortable taking this active role and preferred traditional teacher-student dynamics. LAC wanted feedback on how their PPI project influenced the larger research study. They were not happy with tokenistic consultations where they are not given any follow-up information. Sessions should be	**Limitations (assessed using the CASP checklist for qualitative studies).** *Q1: Was there a clear statement of the aims of the research?* Yes. *Q2: Was a qualitative methodology appropriate?* Yes. *Q3: Was the research design appropriate to address the aims of the research?* Yes. *Q4: Was the recruitment strategy appropriate to the aims of the research?* Yes. Convenience sampling was used to recruit interested young people. However, incentives could have created bias. Looked after children and care leavers were given a £10 voucher for each session they engaged which may have led to bias. *Q5: Were the data collected in a way that addressed the research issue?* Yes. LAC were identified using appropriate channel and data was audio-recorded and transcribed verbatim.

Study details	Participants	Methods	Themes and findings	Limitations
To explore the experiences and views of members of a PPI group for looked after children set in the context of an ongoing health service intervention trial. **Study dates** Not reported. **Source of funding** This study received funding from the Catherine Cookson Foundation and National Institute for Health Research.	• n=1 participation officer • n=3 researchers **Characteristics** Age (range): 15-19 years Gender (M/F): 6/5 Ethnicity: All participants were White British All living in North-East England in • Foster placements • Residential children home • Independent living **Inclusion criteria** • Looked after child or care leaver attending Children In Care Council (CICC) sessions **Exclusion criteria** Not reported	time point, exploring their views on understanding of the term 'research', how they felt they could contribute to research project, and expectations and feelings about working with researchers. Interview occurred in different room than CICC session. Researchers also interviewed twice by independent researcher. After completion of PPI work, second round of interviews conducted with 4 of the 7 young people, CICC's participation officer and PPI researchers (2 of the 7 had relocated; 1 was not well enough to attend) within CICC session. In this round, participants were asked about their involvement in the PPI research, if expectations had been met, and whether there was need for any change to facilitate improved involvement in future research. Interviews audio-recorded and transcribed verbatim. Transcripts anonymised and participant key stored separately. A list of 10 'top tips' for working with looked after children and care leavers, and other marginalised children and young people, was co-produced by the young people in a group exercise in which they wrote down their tips individually and then worked together to agree on them. **Analysis** Thematic analysis using iterative constant comparative method.	interactive. This not only engages LAC but tailors them to the differing literacy and behavioural needs of participants. A familiar person helps LAC to maintain contact with the research programme. This can be support in person (for example during sessions) or via technology (for example by sending reminder text messages). LAC wanted session researchers that had experience and were therefore aware of the challenges encountered in the care system. Researchers should be empathetic, non-judgement and sensitive. PPI should endeavour to teach a new skill to LAC.	*Q6: Has the relationship between researcher and participants been adequately considered?* Can't tell. Researchers involved in the PPI project were interviewed twice by an independent researcher. However, details of the impact of this interviews were not provided. *Q7: Have ethical issues been taken into consideration?* Yes. Informed consent obtained (from guardians for under 16s) and ethical approval obtained from Newcastle and North Tyneside NRES. *Q8: Was the data analysis sufficiently rigorous?* Yes. Themes were developed in an iterative manner to in cooperate evolving ideas during the semi-structured interviews and allow for input from an independent researcher to ensure rigour. *Q9: Is there a clear statement of findings?* Yes. The authors discuss findings for supporting looked after children within research, as well as supporting this within contrary evidence from literature. Q10: *Is the research valuable for the UK?* Yes. Detailed recommendations for PPI, LAC or groups of under-represented young people were provided that are applicable to the UK and future research linked to

Study details	Participants	Methods	Themes and findings	Limitations
				policymaking. 2. Yes. Findings are generalizable to other situations but may require tailoring to non-research contexts within the UK. *Overall judgement of quality:* Minor concerns **Other information** Participants given £10 voucher for each session attended to demonstrate that their contributions are valued and their expertise respected. Children in Care Council (CICC) sessions are run by each UK local authority and are intended to give children in care and care leavers opportunity to have voice and give opinions on how council should run children's services. Three researchers involved in both interviews and focus groups at any one time but one researcher was replaced for second round of interviews.
Full citation Edbrooke-Childs, J., Edridge, C., Averill, P., Delane, L., Hollis, C., Craven, M. P., Martin, K., Feltham, A., Jeremy, G., Deighton, J., Wolpert, M., A Feasibility Trial of Power Up: Smartphone App to Support Patient Activation and Shared Decision Making for Mental Health in Young	**Sample size** N=11 children and young people **Characteristics** Age (Mean; range): 15.55 years; 11-17 years Gender (M/F) not reported Specialist services, n=6 Schools, n=5	**Setting** Specialist child and adolescent mental health services **Sample selection** Recruited from the parent RCT in which participants were recruited from specialist CAMHS centres and 2 schools. Clinicians in the CAMHS centres identified individual patients aged 11-19 for possible inclusion. 2 schools were randomised into 12 clusters. Participants in both	**Author's themes:** • Impact of use **Findings** Young people highlighted that Power Up mediated communication with important people in their support network, facilitating conversation and helping them to share things with others, which they might not have	**Limitations (assessed using the <u>CASP checklist for qualitative studies</u>).** *Q1: Was there a clear statement of the aims of the research?* Yes. *Q2: Was a qualitative methodology appropriate?* Yes. *Q3: Was the research design appropriate to address the aims of the*

Study details	Participants	Methods	Themes and findings	Limitations
People, JMIR MHealth and UHealth, 7, e11677, 2019 **Country/ies where the study was carried out** UK **Study type** Mixed method including semi-structured interview **Aim of the study** To determine the effectiveness, usage and acceptability of a new smartphone/tablet app, Power Up. **Study dates** January 2017 - February 2018 **Source of funding** This study received support from National Institute for Health Research, Invention for Innovation Programme.	**Inclusion criteria** - 11-19 years-old - In their initial assessment sessions for recruitment to the parent randomised controlled trial **Exclusion criteria** Not reported although authors mentioned the following: - Not meeting inclusion criteria - Declined to participate - No time to take part - No consent	intervention arms were then invited to complete interviews on the acceptability of the application. **Data collection** As part of mixed methods feasibility study, semi-structured interviews conducted covering young people's experiences of using Power Up and its impact on their self-management of their mental health, acceptability, and possible improvements. Interviews audio-recorded and transcribed verbatim. **Analysis** Thematic analysis	otherwise. This provided much-needed support.	*research?* Yes. Mixed methods feasibility study. *Q4: Was the recruitment strategy appropriate to the aims of the research?* Can't tell. No description of how participants were chosen from initial RCT, beyond the fact they were asked to participate. No information on how/if there was a criterion beyond that. *Q5: Were the data collected in a way that addressed the research issue?* Can't tell. Data collected through interviews and content well described. No justification is given, the setting described or mention of an interview guide. Recruitment expanded from specialist centres to include secondary schools as well due to an expansion of the target audience for the application. However, no mention at what time in the trial that this happened. *Q6: Has the relationship between researcher and participants been adequately considered?* No. No description of potential bias/influence between researcher and participants. *Q7: Have ethical issues been taken into consideration?* Yes. Consent process described and consent obtained. Study was approved by Health Research Authority Research

Study details	**Participants**	**Methods**	**Themes and findings**	**Limitations**
				ethics committee (RCT) and University College London Research Ethics Committee (cluster RCT). *Q8: Was the data analysis sufficiently rigorous?* Can't tell. Very descriptive findings presented with multiple quotes for each finding. No information given regarding the analysis method, the number of researchers involved or consideration of bias. *Q9: Is there a clear statement of findings?* No. Findings very detailed in results. There is a detailed discussion relating the results back to the whole feasibility trial, rather than simply the qualitative aspect of the trial. No discussion on evidence, surroundings findings or credibility of findings. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* Yes. 1. Yes. Results of the feasibility trial will go on to inform a full-scale RCT on mobile applications in self-management. 2. Can't tell. No data reported on who elected to participate in the interviews from the effectiveness study. *Overall judgement of quality:* Moderate concerns

Study details	Participants	Methods	Themes and findings	Limitations
				Other information None.
Full citation Grealish, A., Tai, S., Hunter, A., Morrison, A. P., Qualitative exploration of empowerment from the perspective of young people with psychosis, Clinical Psychology & Psychotherapy, 20, 136-148, 2013 **Country/ies where the study was carried out** Manchester, UK **Study type** Semi-structured interview **Aim of the study** The aim of this project was to examine how the concept of empowerment applies to young people (understanding and experience of the concept of empowerment from the perspective of young people and their parents) with psychosis, using qualitative methods.	**Sample size** N=9 young people **Characteristics** Mean (mean; range): 16.4 years; 14-18 years Gender (M/F): 5/4 Ethnicity: • White British, n=8 • Asian, n=1 Duration of symptoms (mean; range): 5 years; 3-8 years **Inclusion criteria** Not specifically reported but paper states that participants were: • In recovery (defined as a period where young people were coping with psychiatric symptoms) • Had ongoing contact with CAMHS for a minimum of 6 months at recruitment	**Setting** CAMHS **Recruitment** CAMHS **Data collection** Semi-structured interviews with young people, lasting 60-90 minutes. A choice was given to have parents involved in the interview process - all chose to have their guardians present. Interviews began with a discussion surrounding the concept of empowerment. The interview schedule was designed to use open-ended, neutral questions to prompt a flowing narrative from the participants with minimal input from researchers. **Analysis** Interpretative phenomenological analysis (designed to produce a rich idiographic analysis). Data were transcribed verbatim and read/re-read a minimum of 5 times by 1 researcher who was experienced in mental health nursing. Initial ideas and common themes were noted on transcripts, which were then grouped and condensed into a master list for each	**Author's themes:** • Individual control and choices versus inflexibility • Lifestyle within institutions • Being listened to and understood • Communication • Information about treatment • Talking about symptoms • Coping mechanisms • Emotional support from clinicians **Findings** Young people and their parents placed high value of having a sense of choice, even when this potentially increased attempts at coercion from others. Young people mentioned the frustration they experienced with clinicians who appeared to favour their own or institutional priorities over the wishes or capabilities of young people and their families. This approach was disempowering, rather opportunities to maintain control and choice were regarded as facilitators. Participants viewed rule-based approaches as restrictive rather than empowering. They identified staff responses as blocking their ability to access their own coping mechanisms	**Limitations (assessed using the CASP checklist for qualitative studies).** *Q1: Was there a clear statement of the aims of the research?* Yes. To examine how the concept of empowerment applies to young people with psychosis. *Q2: Was a qualitative methodology appropriate?* Yes. Semi-structured interviews. *Q3: Was the research design appropriate to address the aims of the research?* Yes. Qualitative design using interviews were used to explore their experiences. *Q4: Was the recruitment strategy appropriate to the aims of the research?* Can't tell. Participants were purposely selected from only one NHS clinical environment. While there was no dropout, the nature of the recruitment - using links with attending consultant - may have led to coercion. *Q5: Were the data collected in a way that addressed the research*

Study details	Participants	Methods	Themes and findings	Limitations
Study dates Not reported. **Source of funding** Not reported.	• Able to provide informed consent as determined by consultant psychiatrist **Exclusion criteria** Not reported	interview. These were then compared between participants, creating sub-themes and higher-order categories. Themes were checked by 2 other authors and modified if needed. The final findings were presented to a 4th researcher who confirmed the reliability of the analysis.	or perceived self-control which was detrimental to their own recovery. Young people and their parents identified that being listened to facilitated empowerment through a process of being made to feel understood. Participants specified that if clinicians can communicate in a jargon-free and non-patronizing manner, this has the effect of making them feel respected, heard and understood. YPs mentioned that HPs were sometimes ignored their experiences / stories, which could be insightful in designing interventions. Clinicians who validated personal distress and experiences were regarded as facilitators of empowerment. Young people and their parents found direct communication with clinicians empowering, both through direct conversations between clinicians and young people, and indirectly through their parents. Poor collaboration, and no explanation or justification of decision outcomes was provided was considered as disempowering young people or parents. The opportunity to talk to and discuss symptoms with clinicians was seen as empowering as this process enabled participants to increase their understanding of symptoms and facilitate their ability to seek help, reduced anxiety and fear. Young people valued opportunities to develop their own coping mechanisms for symptoms and an understanding of when and how to utilize them was	*issue?* Yes. Authors provide a detailed description of the ethical approval with adequate time before consent. Participants were interviewed in with parents and offered lone interviews. Semi-structured interviews were used, developed using current literature and flexible to allow for the natural evolution of evidence. *Q6: Has the relationship between the researcher and participants been adequately considered?* Can't tell. The influence of the researcher on the data was mentioned but not adequately addressed. *Q7: Have ethical issues been taken into consideration?* Yes. Consent was obtained before the interview and described within the methods, and ethical approval was sought from the local research ethics committee. *Q8: Was the data analysis sufficiently rigorous?* Yes. Themes were developed iteratively to incorporate contrary ideas and input from a research team to ensure rigour as well as triangulation. *Q9: Is there a clear statement of findings?* Yes. The authors discuss of findings of the experience of empowerment among patients with psychosis, identifying gaps in research grounded in the relevant literature and

Study details	Participants	Methods	Themes and findings	Limitations
			considered crucial to achieving empowerment. Young people particularly valued having strategies they developed themselves recognized by clinicians. They described this as empowering as the fostering of new ways of coping allowed them to be less dependent on the health service and to recover. Participants reported how important it was to receive emotional support from staff in order to achieve empowerment. This created the perception of clinicians being approachable, friendly, fun and with a sense of humour. They perceived these clinicians to be listening, engaging and helping them to understand their problems. These clinicians were also able to give reassurance.	using broader UK evidence to support their findings as well as recommendations for future research. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* Yes. 1. Details how the study findings fit in with current literature and the UK population were provided, and how they can be used to inform best practice. Ideas and directions for future research presented. 2. Probably. Good mixed of population (children, young people and parents), size for qualitative study and data collection processes; but perhaps less generalizable to other clinical populations. *Overall judgement of quality:* Minor concerns **Other information** None.
Full citation Harper, B., Dickson, J. M., Bramwell, R., Experiences of young people in a 16-18 Mental Health Service, Child and Adolescent Mental Health, 19, 90-96, 2014 **Country/ies where the study was carried out**	**Sample size** N=10 young people **Characteristics** Age (range): 16-18 years • 16 years-old, n=1 • 17 years-old, n=5 • 18 years-old, n=4 Gender (M/F): 3/7	**Setting** 2 specialist mental health services for 16-18-year-old **Sample selection** Purposive sampling of 13 participants (but 3 did not complete interview due to deteriorating mental health). Potential participants were identified by key workers at 2 NHS 16-18 MHS. The study wanted to recruit a small,	**Author's themes:** • Developmentally attuned services • Power differentials • Developing self-expression in services • Continuity and loss in therapeutic relationships **Findings** Participants described as an 'us-and-them' dynamic between professionals	**Limitations (assessed using the CASP checklist for qualitative studies).** *Q1: Was there a clear statement of the aims of the research?* Yes. *Q2: Was a qualitative methodology appropriate?* Yes. *Q3: Was the research design appropriate to address the aims of the*

Study details	Participants	Methods	Themes and findings	Limitations
North-West England, UK **Study type** Semi-structured interview **Aim of the study** To explore young people's experiences of the newly established 16-18 mental health services (16-18 MHS). **Study dates** Not reported. **Source of funding** First author received support from the NHS as part of their Clinical Psychology training. No other funding reported.	Ethnicity: All White-British **Inclusion criteria** - Prior experience of CAMHS - Suitable current mental health status - Available to participate - Mental capacity to consent **Exclusion criteria** Not reported	homogeneous sample in order to obtain rich data source. **Data collection** Individual semi-structured interviews lasting an average of 48 minutes (ranged from 25-80 minutes). The interview schedule was designed according to prior literature on young people's experiences of 16-18MHS and modified from another study that investigated the transition from childhood to adulthood. Questions focused on encouraging young people to reflect on their experiences of using 16-18 MHS, and the schedule was used flexibly to allow the young people to talk about areas that were important to them. Researchers used limited prompts in an effort to expand views and experiences. The schedule was piloted with 2 study participants to ensure relevance and ease of understanding. After reviewing, data from these interviews was included with the final results **Analysis** Interpretative phenomenological analysis (designed to produce a rich idiographic analysis). Data was transcribed, and researchers were familiarised with the data by reading and re-reading. During this process, preliminary analytical findings were noted before line-by-line coding occurred to summarise findings and	and service-users in CAMHS. This experience of being treated ‘like a child’ in CAMHS was paralleled by feeling unheard and powerless. Young people expressed the desire for deeper collaboration at this stage in their lives and recognition of their desire for increased independence, which facilitated engagement and reduced feelings of being controlled by services and service dynamics. Children and young people valued having the choice to see their therapist ‘alone’ in 16–18 MHS, which enabled them to disclose more information without the fear of parental involvement. Being dominated by parental over-involvement was perceived to prioritise parent’s needs over children and young people, and limited opportunities to address his mental health concerns and appeared to invalidate his feelings or independence. The use of therapy to facilitate self-expression was mentioned as participants matured from childhood to adolescence.	*research?* Yes. Interpretive phenomenological analysis used in order to deeply explore participants' personal experiences and views of a particular event. This approach does not make objective statements about analysed data. *Q4: Was the recruitment strategy appropriate to the aims of the research?* Yes. Researchers wanted to recruit a small number of homogenous participants. Key workers from 2 NHS 16-18MHS identified potential participants. Reasons for non-participation given. *Q5: Were the data collected in a way that addressed the research issue?* Yes. Data collected via semi-structured interviews. A topic guide developed using previous literature and was piloted with 2 initial participants. Examples of questions are provided. The guide was applied flexibly to allow participants to introduce novel views and experiences. However, no mention of data saturation. *Q6: Has the relationship between researcher and participants been adequately considered?* No. No description of potential bias/influence between researcher and participants. *Q7: Have ethical issues been taken*

Study details	Participants	Methods	Themes and findings	Limitations
		higher-order codes were identified. Emergent themes were used to determine emergent cluster themes for each participant. Throughout this process, original quotes from transcripts were identified. After themes had been determined for each participant, superordinate themes were identified across all participant interviews while continually being checked for coherence against the evolving analysis. .		*into consideration?* Yes. Study obtained ethical approval from National Research Ethics Service. Informed consent obtained before interviews with a 2-week cooling-off period to give participants chance to change their mind. *Q8: Was the data analysis sufficiently rigorous?* Yes. A very detailed description of analysis and how themes were derived from the raw transcripts. A section detailing the techniques used to mitigate bias in the analysis, including group discussion of themes, the independent researcher conducted an analysis audit at each stage. Contradictory data is presented and discussed where appropriate, and a good amount of data is presented to support the reported findings. However, no explanation of how the data presented were chosen from the original sample. *Q9: Is there a clear statement of findings?* Yes. Good, detailed explanation of findings within the identified themes, with regular referral back to the original research question. Adequate discussion surrounding evidence both for and against the study's findings, as well as the credibility of findings. *Q10: Is the research valuable for the UK? (1. Contribution to literature and*

Study details	Participants	Methods	Themes and findings	Limitations
				2. Transferability) Can't tell. 1. Yes. Details how the study findings fit in with current literature and the UK population, and how they can be used to inform best practice. Ideas and directions for future research presented. 2. No. Interpretative phenomenological analysis is designed to produce rich data on a homogeneous sample. It is not designed to be generalizable. *Overall judgement of quality:* Minor concerns **Other information** None.
Full citation Holley, S., Walker, D., Knibb, R., Latter, S., Liossi, C., Mitchell, F., Radley, R., Roberts, G., Barriers and facilitators to self-management of asthma in adolescents: An interview study to inform development of a novel intervention, Clinical and Experimental Allergy, 48, 944-956, 2018 **Ref Id** 989694	**Sample size** N=54 young people, parents and healthcare professionals • n = 28 young people • n = 12 parents • n = 14 healthcare professionals ○ Only the views of young people have been included in this review. **Characteristics** Age (range): 12-18 years • 12-13 years-old, n=9 • 14-15, n=7	**Setting** Primary and secondary care sites (GP surgeries and hospital paediatric outpatient) **Sample collection** Eligible participants were identified by searching patient lists of general practitioner (GP) surgeries and hospital paediatric outpatients for adolescents aged 12-18 years with doctor-diagnosed asthma, prescribed regular prophylactic medication for asthma, and with no other significant long-term medical condition. The initial approach was by letter or in person from their usual doctor or nurse. Older participants (16- to 18-year-olds) were given the option to	**Author's themes:** • Barriers to self-management of asthma ○ Lack of knowledge about asthma and treatments ○ Difficult communication with healthcare professional • Facilitators to self-management of asthma ○ Knowledge about asthma and treatments ○ Good communication and support from healthcare professional **Findings** Young people discussed how being confused about diagnosis and treatments, not understanding how medications worked and different	**Limitations (assessed using the <u>CASP checklist for qualitative studies</u>).** *Q1: Was there a clear statement of the aims of the research?* Yes. To address these issues by utilizing robust, contemporary qualitative research methods to gain a broader insight into self-reported barriers and facilitators to adolescent asthma self-management, not just adherence to treatment. *Q2: Was a qualitative methodology appropriate?* Yes. Semi-structured interviews.

Study details	Participants	Methods	Themes and findings	Limitations
Country/ies where the study was carried out Southampton and Isle of Wight, UK **Study type** Semi-structured interview and focus group **Aim of the study** To gain a broader insight into self-reported barriers and facilitators to adolescent asthma self-management, not just adherence to treatment. **Study dates** October 2014 and March 2015 **Source of funding** Asthma UK—Joanna Martin Project	• 16-18, n=12 Gender of child (M/F): 14/14 **Inclusion criteria** • Aged 12-18 years • Attended paediatric outpatient clinic for adolescents with doctor-diagnosed asthma • Prescribed regular prophylactic medication for asthma • No other significant long-term medical condition **Exclusion criteria** Not reported	take part in either a focus group or a 1:1 interview; younger participants were asked to take part in a 1:1 interview only. Purposive sampling was used to ensure a range of ages, gender and asthma severity. Parents (or guardians) and HCPs of the adolescents who agreed to participate in the study were approached in person to take part in focus groups, although 1:1 interviews were conducted where participants were unable to take part in a focus group. Twelve parent/guardians agreed to take part ranging in age from 34-55 years, 10 were female, 2 were male. The HCPs included three respiratory paediatricians, an adult respiratory physician, a general paediatrician, three secondary care asthma nurse specialists, two primary care nurses, community asthma nurse, a school nurse and a GP. **Data collection** A semi-structured interview schedule informed by a review of the literature was used with input from experts in the area; this included psychologists with expertise in asthma, allergy and self-efficacy for management of long-term conditions, and a paediatric asthma consultant. The interview guide was flexible, piloted in the first interview, no changes were deemed necessary and data were therefore included in this analysis. Focus groups took place at a hospital; individual	healthcare professionals issuing conflicting information were barriers to self-management. The amount of information ranged from too much to too little, with both being problematic. Healthcare professionals were negatively described as rude, condescending, poor listeners and officious. BCYP said that they gave incorrect information, contradicting information or not enough information. Young people did not feel as though they were able to ask questions to their healthcare workers. They did not feel comfortable being honest with healthcare professionals regarding their symptoms or medication regimes, or avoided answering questions. However, when a good relationship was established, healthcare professionals were described as nice and supportive, using language that they could understand and gave out understandable information.	*Q3: Was the research design appropriate to address the aims of the research?* Yes. Qualitative design using interviews were used to explore their experiences *Q4: Was the recruitment strategy appropriate to the aims of the research?* Yes. Participants were purposely selected from general practitioner (GP) surgeries and paediatric hospital outpatients. *Q5: Were the data collected in a way that addressed the research issue?* Yes. Written informed consent was sought from all participants as well as parental consent for adolescents. All participants were assured of confidentiality. Semi-structured interviews were used, developed using current literature and flexible to allow for. *Q6: Has the relationship between researcher and participants been adequately considered?* Yes. A description of the influence of the researcher on the data was provided. *Q7: Have ethical issues been taken into consideration?* Yes. Written informed consent was sought from all participants as well as parental consent for adolescents. All participants were assured of confidentiality. Ethical approval obtained from the East of

Study details	Participants	Methods	Themes and findings	Limitations
		interviews were conducted either at a hospital or in participants' homes. A psychologist (SH) with experience in conducting focus groups and interviews with adolescents conducted the interviews and facilitated focus groups using a semi-structured interview guide— parent or guardian supervision. An interim analysis of adolescent transcripts was conducted by SH and GR to assess whether data saturation had been achieved. Although it was clear at this point that no new themes were emerging, further interviews were conducted to ensure an even spread of ages and asthma severity. Interviews and focus groups were audio-recorded and transcribed verbatim. **Analysis** Inductive thematic analysis approach with independent interim analysis for data saturation. Adolescent transcripts were analysed first and the early-phases involved independently reading (and re-reading) a selection of the adolescent transcripts to become familiar with the data and generating initial codes. The two investigators met to discuss the initial codes and review the transcripts developed in NVivo. The same procedure was conducted with the parent and HCP transcripts, which were reviewed and discussed in tandem. The final stage—triangulation—involved comparing		England National Research Ethics Committee—Cambridge Central (study reference 14/EE/0172). *Q8: Was the data analysis sufficiently rigorous?* Yes. Themes were developed in an iterative manner to incorporate contrary ideas and input from a research team to ensure rigour. *Q9: Is there a clear statement of findings?* Yes. The authors discuss findings on self-managing asthma among children and young people using broader UK evidence to support their findings. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* 1. Yes. Details how the study findings fit in with current literature and the UK population were provided, and how they can be used to inform best practice. Ideas and directions for future research presented. 2. Probably. Good population size for qualitative study and data collection processes. *Overall judgement of quality:* Minor concerns **Other information** Study also involved parents and healthcare professionals. However, these participants are outside the

Study details	Participants	Methods	Themes and findings	Limitations
		and reviewing the themes from the three participant groups to determine if they were complementary or contradictory. Triangulation, multiple perspectives and reflexivity were employed.		protocol population and data not extracted.
Full citation Lerch, Matthew F., Thrane, Susan E., Adolescents with chronic illness and the transition to self-management: A systematic review, Journal of Adolescence, 72, 152-161, 2019 **Country/ies where the study was carried out** No restriction **Study type** Systematic review **Aim of the study** To assess the impact of parent-adolescent relationships on illness adherence behaviours during the transition to self-management. **Study dates** Search conducted to June 2017	**Sample size** K=9 included studies • Qualitative, k=3 • Quantitative, k=5 • Mixed method, k=1 **Characteristics** Range of sample size (n) in included studies: • Adolescents, n=11 – 200 • Adolescent-parent dyads, n=10 – 150 • Parents, n=15 – 62 ○ Parent-child opinions were included to understand the process adolescents underwent as they transitioned to self-management for chronic illness Study country (k): • USA, k=8 • UK, k=1	**Search strategy** A systematic literature search of 3 online databases was conducted to create a synthesis of existing qualitative and quantitative data on this topic with results organized into themes. A systematic search of PubMed, Cumulative Index to Nursing and Allied Health Literature, and Web of Science was conducted from the earliest database records to early June 2017. Authors collaborated conducted abstract reviews and a full-text review if an abstract review was inconclusive. Abstracts were screened, with 2 researchers performing an initial 200 paper pilot and achieving more than 95% inter-rater agreement. Any disagreements were discussed, and an agreement reached. Out of 1241 abstracts screen, 235 full texts were read and 68 were included for the final review. **Data extraction** Following details were extracted from included studies: • Study purpose • Intervention or measures	**Features of included studies** One study collected input from an adolescent population (Babler & Strickland, 2015), all others engaged adolescent-parent dyads, with the parent being typically the mother. Some dyads were more truly a triad, with adolescent-mother-father participation. Six of the dyadic studies collected input from adolescents and parents separately (Dashiff et al., 2013; Gaston et al., 2012; Knopf et al.,2008; Sawicki et al., 2015). Two studies relied upon mail-in responses and did not specify cooperative or non-cooperative dyadic data completion. The first survey did not report response rate, the second reported a response rate of 43% (King et al., 2014; Polfuss et al., 2015). Finally, one study did not clarify the question of independent survey completion (Hilliard et al., 2013). Two studies conducted one-time interviews (Babler & Strickland, 2015; Sawicki et al., 2015) and two studies collected one-time questionnaires (Gaston et al., 2012; Knopf et al., 2008). One study paired a one-time questionnaire with a	**Limitations (assessed using the <u>CASP checklist for systematic reviews</u>).** Q1: *Did the review address a clearly focused question?* Yes Q2: *Did the authors look for the right type of papers?* Yes Q3: *Do you think all the important, relevant studies were included?* Can't tell. 3 online key databases were used, and the search strategy was devised by authors. Reference lists of included studies and a search of the grey literature were not checked for relevant studies. No restrictions were placed on full-text or language of publication. No mention of personal contact with experts. Q4: *Did the review's authors do enough to assess quality of the included studies?* No quality appraisal was reported.

Study details	Participants	Methods	Themes and findings	Limitations
Source of funding Not reported	Ethnicity of participants in included studies: Six studies reported demographic information on race, with several samples lacking demographic diversity, specifically in regard to race, gender, and access to private insurance. - European-American: 72.6% - African American: 12.3% - Mixed or unreported race: 15.1% **Inclusion criteria** - Study published in English - Study focuses on adolescents aged 10-19 years with diagnosis of any chronic illness - Study addressed ongoing illness management regimens and discussed parent-child relationships **Exclusion criteria** - Primary diagnosis of study participants was a mental health condition	- Outcomes - Study design, - Sample including sexes and ages of participants - Illness diagnosis - Key findings and clinical significance **Quality assessment of included studies** Not performed **Analysis** Narrative synthesis conducted	semi-structured interview (Dashiff et al., 2013), one study conducted separate adolescent and caregiver focus groups (Kayle et al., 2016), while another utilized a series of questionnaires and also downloaded data from medical charts and glucometers (Hilliard et al., 2013) **Participants** Condition of participants in included studies (k): - Diabetes mellitus Type I (DM1), k = 5 - Cystic Fibrosis, k = 1 - Cystic Fibrosis-related diabetes (CRFD), k = 1 - Sickle cell disease (SCD), k = 1 - Decision making for adolescents with CF, rheumatoid arthritis, SCD, or irritable bowel syndrome, k = 1 **Themes:** - Medical decision-making **Findings** Utilizing the cross-sectional method, Knopf et al. 2008 evaluated comparisons between passive, shared or active preferences, reported parent and adolescent preference in decision making. Parents and adolescents favoured a passive decision-making style, with adolescent input	Q5: *If the results of the review have been combined, was it reasonable to do so?* Can't tell. Thematic analysis applied to the data, with a good description of the process of combining quantitative and qualitative data, but thin evidence base. Q6: *What are the overall results of the review?* The table presented key characteristics of included studies, details on participant characteristics, study design, and summary of findings - 7 general themes identified. However, descriptions of design, context and qualitative findings were not detailed enough. Q7: *How precise are the results?* Not applicable. Q8: *Can the results be applied to the local population?* Can't tell. The review incorporates data from a wide range of settings and homogenous participants - chronic diseases. However, only 1 study was conducted in the UK. Seven were conducted in the USA, which has a very different healthcare system, where cost plays a large part to access and this might influence one's ability to express needs.

Study details	Participants	Methods	Themes and findings	Limitations
	• Article not narrowly focused on the target population by including children younger than adolescents • Non-peer reviewed articles		considered, but the final word from the practitioner.	Q9: *Were all important outcomes considered?* Not applicable. Themes are driven by data. Q10: *Are the benefits worth the harms and costs?* Not applicable. Literature review. *Overall judgement of quality:* Serious concerns **Other information** None
Full citation Lowes, L., Eddy, D., Channon, S., McNamara, R., Robling, M., Gregory, J. W., The experience of living with type 1 diabetes and attending clinic from the perception of children, adolescents and carers: analysis of qualitative data from the DEPICTED study, Journal of Pediatric Nursing, 30, 54-62, 2015 **Country/ies where the study was carried out** Cardiff, UK **Study type** Mixed-methods	**Sample size** N=518 children and young people at baseline • Intervention group, n=259 • Control group, n=259 N=390 children and young people at 12-mo follow up • Intervention group, n=185 • Control group, n=205 **Characteristics** Age (range): 7-15 years Gender (M/F): not reported	**Setting** 26 UK secondary and tertiary care paediatric diabetes services within the context of participating in the DEPICTED study **Sample selection** 693 children aged 4–15 years with T1D of at least 1-year duration and one of their carers were recruited from 26 UK secondary and tertiary care paediatric diabetes services into the DEPICTED trial. No further details reported. **Data collection** DEPICTED is a pragmatic cluster randomised controlled trial investigating the effectiveness of a training programme in consultation skills for UK paediatric diabetes teams. DEPICTED study participants	**Author's themes:** • Communication skills **Findings** Good communication using direct, accurate advice with empathy by health care professionals, especially when accompanied by options, flexible approaches were described as empowering by parent and [child] when attending the clinic. This created a positive experience. Children, young people and parents were able to make their own decisions in their own time and felt heard and seek additional support.	**Limitations (assessed using the CASP checklist for qualitative studies).** Q1: *Was there a clear statement of the aims of the research?* Yes Q2: *Was a qualitative methodology appropriate?* Yes *Q3: Was the research design appropriate to address the aims of the research?* Yes. Qualitative methodology used to identify the aspect of healthcare young people find helpful or unhelpful. Q4: *Was the recruitment strategy appropriate to the aims of the research?* Can't tell. Sample was taken from the DEPICTED study, which recruited 693 children aged 4-

Study details	Participants	Methods	Themes and findings	Limitations
Aim of the study To explore experiences of living with and managing Type 1 diabetes in children and adolescents, as well as attending specialist paediatric diabetic services. **Study dates** Not reported **Source of funding** This study received support from the UK National Institute for Health Research Health Technology Assessment Programme and Novo Nordisk UK.	**Inclusion criteria** Participants in DEPICTED trial had to be: • Aged 7-15 years old • Diagnosed with type 1 diabetes for at least 12 months **Exclusion criteria** Not reported	completed a questionnaire on quality of life and other self-reported psychosocial outcomes at baseline, first clinic visit (to assess enablement after enrolment) and 1 year. Questionnaires were age-appropriate (1 for 7-10-year-olds, 1 for 11-15-year-olds) and contained 5 free-text boxes on attendance at diabetes clinics, living with diabetes and managing diabetes. **Analysis** Qualitative descriptive analysis. Responses in the 5 free-text boxes were transcribed verbatim from the returned questionnaires and entered into a database by an independent researcher. Data were labelled as child/adolescent/carer, intervention group/control group, baseline/follow-up and which box it corresponded to. Two researchers individually analysed these responses before identifying patterns to inform initial codes. These codes were then collated into themes and sub-themes.		15 years old with type 1 diabetes from 26 UK specialist paediatric diabetic clinics. This is a wide population, but there were no further details reported, including any demographic information. Q5: *Were the data collected in a way that addressed the research issue?* Can't tell. Use of questionnaires was justified as part of the DEPICTED study. Free-text questions published in the article and are accompanied by a detailed description of response rates for individual questions. However, no mention of alternative forms of the questionnaire (for example, large font). It is mentioned that that free-text boxes were not mandatory and so individuals with particularly strong views on certain questions were more likely to use these boxes to elaborate. Q6: *Has the relationship between researcher and participants been adequately considered?* Yes. No discussion presented regarding potential bias/influence between researcher and participants but unlikely to be an issue with postal questionnaires. Q7: *Have ethical issues been taken into consideration?* Yes. The study was approved by South East Wales NHS Research Ethics Committee (DEPICTED intervention

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

Study details	Participants	Methods	Themes and findings	Limitations
				current literature and the UK population, and how they can be used to inform best practice.2. Can't tell. The initial RCT had a wide sample population but demographic information is not presented. May be generalizable to other chronic diseases. *Overall judgement of quality:* Moderate concerns **Other information** Part of the larger DEPICTED study. Another questionnaire on enablement was administered at the 1st clinic visit since the start of the trial, but no qualitative data were reported.
Full citation Mitchell W. Parents' accounts: Factors considered when deciding how far to involve their son/daughter with learning disabilities in choice-making. Children and Youth Services Review, 34, 1560-1569, 2012 **Country/ies where the study was carried out** York, UK **Study type** Semi-structured interview	**Sample size** N=14 parental proxies (11 mothers and 3 fathers) representing 11 families ○ Parental proxies were included because children had learning disabilities and life-limiting conditions **Characteristics** Age: not reported Gender (M/F): 3/11 **Inclusion criteria** Participants had to:	**Setting** Children's hospices **Sample selection** A convenience sample of young people (with a wide range of degenerative conditions) and their parents were recruited from two children's hospices in England. Thirty-three families were recruited to the study. **Data collection** Repeat semi-structured interviews (lasting between 60-180 minutes) with parents of children with learning disabilities. The deteriorating health of	**Author's themes:** • Experience opportunities **Findings** The possibility of being able to experience the different options constituting a choice facilitated increased levels of involvement for young people. Educational and leisure choices were examples of areas where experiencing opportunities appeared to support young people's involvement in choice-making.	**Limitations (assessed using the <u>CASP checklist for qualitative studies</u>).** Q1: *Was there a clear statement of the aims of the research?* Yes. Q2: *Was a qualitative methodology appropriate?* Yes. *Q3: Was the research design appropriate to address the aims of the research?* Yes. Qualitative design; semi-structured interviews allowed for the discussion of sensitive topics with parents of children with life-limiting conditions.

Study details	Participants	Methods	Themes and findings	Limitations
Aim of the study To explore parental perspectives on their and their child's role in choice-making when there were important choices to be made regarding their son/daughter's life. **Study dates** Thirty-month period from 2007 to 2010 **Source of funding** This project was funded by the UK Department of Health Policy Research Programme.	• Parents of children with learning disabilities and life-limiting conditions • Have participated in all three-interview rounds. o Important as it provided data on different choices and opportunities for reflection. **Exclusion criteria** Not reported	the young people affected how the interviews were conducted. Interviews were fully transcribed. **Analysis** Thematic (Framework) analysis using MAXqda software.		Q4: *Was the recruitment strategy appropriate to the aims of the research?* Yes. Due to the sensitive nature of the topic area, participants were recruited from hospices, and flexible approaches were used. Q5: *Were the data collected in a way that addressed the research issue?* Yes. Repeated interviews were used to ensure data triangulation and richness. Q6: *Has the relationship between the researcher and participants been adequately considered?* Yes. Data were double coded by a colleague; two researchers discussed their coding and amended the coding frame accordingly, as well as the project research team meeting regularly to discuss their analysis and data summary, sharing ideas and experiences. Q7: *Have ethical issues been taken into consideration?* Yes. Ethical approval was received from an English National Health Service medical research ethics committee. Q8: *Was the data analysis sufficiently rigorous?* Yes. Probably, although themes were not presented to participants for triangulation, data collection was conducted in stages to

Study details	Participants	Methods	Themes and findings	Limitations
				allow the data to evolve naturally, and the study team met regularly to review the themes critically. Q9: *Is there a clear statement of findings?* Yes. The authors discuss results on SDM among children, young people and parents as well as practitioners using broader UK evidence to support their conclusions. Q10: *Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* Yes. 1. The study findings were well placed within the current literature on improving access within UK clinical settings and implications for practice. Ideas and directions for future research were presented. 2. Probably. Adequate population size for qualitative study and well-represented samples of the parent population. *Overall judgement of quality:* No/very minor concerns **Other information** None.
Full citation Nightingale, R., Hall, A., Gelder, C., Friedl, S., Brennan, E., Swallow, V., Desirable Components for	**Sample size** N=36 children, young people, parents and healthcare professionals	**Setting** Paediatric kidney unit **Sample selection**	**Author's themes:** • Suggestions for a Digital Care-Management App **Findings**	**Limitations (assessed using the CASP checklist for qualitative studies).**

Study details	Participants	Methods	Themes and findings	Limitations
a Customized, Home-Based, Digital Care-Management App for Children and Young People With Long-Term, Chronic Conditions: A Qualitative Exploration, Journal of medical Internet research, 19, e235, 2017 **Country/ies where the study was carried out** Leeds and London, UK **Study type** Qualitative **Aim of the study** To explore the views of children with CKD, their parents, and key professionals to inform the future development of a digital care-management app. **Study dates** Not reported **Study funding** Research award from the British Renal Society and the British Kidney Patient Association	• n=17 children and young people • n=10 parents • n=9 healthcare professionals ○ Only the views of children and young people are included in this review. **Characteristics** Age (range): 5-18 years • 5-10 years-old, n=6 • 11-14 years-old, n=6 • 15-18 years-old, n=5 Gender (M/F): 9/8 **Inclusion criteria** Not reported. **Exclusion criteria** Not reported.	Two UK paediatric kidney units, participants were purposively sampled and included children with CKD and their parents. Using a purposive sampling strategy to achieve maximum variation regarding the children's age, developmental stage, ethnicity, and sex. 6-8 participants from each of the following groups: 5-10-year-olds, 11-14-year-olds, 15-18-year-olds, and parents or carers of children with CKD. Potential participants were identified by our two local principal investigators, who work clinically with children with CKD and their families. Verbal consent was gained for the researcher (RN). 6-8 professionals (eg, clinical psychologists, dieticians, doctors, nurses, social workers, and play specialists) with experience in supporting families with CKD. Participants were interviewed until reaching theoretical saturation. **Data collection** A combination of semi-structured individual or focus group interviews, depending on the individuals' preferences, using child-friendly settings, such as children's hospital-based venues or patients' homes. Where children were interviewed jointly with their parents, the emphasizes was initially focused on the child's views; therefore, all questions were directed at the child first, using developmentally	Participants from all groups recommended an interactive, age and developmentally appropriate care-management app, to help a child understand about their current treatment via questions, signposting to trustworthy links and shared experiences, for record-keeping, monitoring adherence, facilitate integration with clinical records while instilling independence in children and young people, and could potentially help with learning about what the future may involve.	Q1: *Was there a clear statement of the aims of the research?* Yes Q2: *Is a qualitative methodology appropriate?* Yes Q3: *Was the research design appropriate to address the aims of the research?* Yes. Qualitative design using interviews and focus groups, authors gained consent from children, young people and parents Q4: *Was the recruitment strategy appropriate to the aims of the research?* Yes. Convenience sampling was used to recruit case load managers, although the inclusion criteria may have limited the sample, but this was necessary to ensure a sample that was fit for purpose. Q5: *Was the data collected in a way that addressed the research issue?* Yes. An innovative strategy but applicable to the patient group and age ranges. Data familiarisation was guided by stratification and iterative integration. Q6: *Has the relationship between researcher and participants been adequately considered?* No. Descriptions of potential bias/influence between researcher and

Study details	Participants	Methods	Themes and findings	Limitations
		appropriate language. Of the 27 interviews conducted, lasted between 8 and 55 minutes, were digitally recorded, and later transcribed verbatim.25 of 27 interviews = face-to-face; 2 out of 27 = telephone interviews. Individual = 19; Joint—8; 5 out of 8 =joint interviews for a child or young person and their parent; 1 out of 8 = child and both parents; 2 out of 8 = 2 professionals. **Analysis** Framework analysis in context of behaviour change theories. Independent reviews of data samples were discussed by the authors until a consensus was achieved.		participants was not described, neither was reflexivity considered. Q7: *Have ethical issues been taken into consideration?* Yes. Parental consent was received and ethical approval obtained from Health Research Authority, a National Health Service (NHS) Research Ethics Committee (reference No. 16/NW/0227), and the NHS Trust Research and Development Departments. Q8: *Was the data analysis sufficiently rigorous?* Yes. Although themes were not presented to participants for triangulation, this was probably due to the age range of participants. Q9: *Is there a clear statement of findings?* Yes. The authors discuss findings on the development of a digital app that meets the identified information and support needs and preferences of children with CKD. Q10: *Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* 1. Yes. Details how the study findings fit in with current literature and the UK population were provided, and how they can be used to inform best practice. Ideas and directions for future research presented. 2. Probably. Good population size for qualitative study

Study details	Participants	Methods	Themes and findings	Limitations
				and wide age of participants were enrolled. *Overall judgment of quality:* Moderate concerns **Other information** Study also includes views of healthcare professionals and parents but these are outside scope of protocol so data not extracted.
Full citation Robards, F., Kang, M., Usherwood, T., Sanci, L., How Marginalized Young People Access, Engage With and Navigate Health-Care Systems in the Digital Age: Systematic Review, Journal of Adolescent Health, 365-381, 2018 **Country/ies where the study was carried out** Multiple countries **Study type** Systematic review **Aim of the study** To explore the current literature and determine the factors affecting access to, engagement with, and	**Sample size** K=68 studies Range of sample size in included studies: N=3 to 1388 **Characteristics** Type of study (k): - Qualitative, k=44 - Quantitative, k=16 - Mixed-methods, k=8 - This study incorporated all their results (qualitative and quantitative) into a narrative summary, which was then used in the findings of this review. Participants (k): - Young people=61	**Search strategy** A systematic literature search of 5 online databases (Medline, CINAHL, PyscInfo, The University of Sydney Library database and Google Scholar) for qualitative, quantitative and mixed-methods studies (published between Jan 2006 and Feb 2017) identified 1758 articles. Hand searching of reference lists and a grey literature search identified 38 more articles. The search was conducted in 2 phases. First phase involved a generalised search of the literature for terms relating to access, barriers or navigation of healthcare. The second phase specifically searched for 5 marginalised groups of young people (those who are homeless, living in remote areas, refugees and migrants, LGBTQ and part of the indigenous population). While reviewing the literature, 3 more populations were identified (young offenders, low income and living with a disability).	**Features of included studies** **Themes:** - Youth participation empowers young people in the design of relevant and engaging health services **Findings** Youth participation was a minor but distinct theme identified in three studies as a way to improve access and engagement. Youth participation was variously proposed as a way to ensure that gender and sexuality diverse young people are treated equally, to design technology-supported care that is useful and useable, and to give homeless young people a sense of agency by identifying solutions for themselves and the community.	**Limitations (assessed using the CASP checklist for systematic reviews).** Q1: *Did the review address a clearly focused question?* Yes. Q2: *Did the authors look for the right type of papers?* Yes. Q3: *Do you think all the important, relevant studies were included?* Yes. A wide variety of online databases was used, and the search strategy was devised in collaboration with a librarian from University of Sydney. Reference lists of included studies were checked for relevant studies and a search of the grey literature was conducted. No restrictions were placed on full-text or language of publication. No mention of personal contact with experts. However, only 5 of the 8 marginalised groups of young people

Study details	Participants	Methods	Themes and findings	Limitations
navigation through healthcare systems for marginalised young people in the digital age. **Study dates** Search conducted from January 2006 to February 2017 **Source of funding** None.	• Professionals=11 • Parents=7 o Although the study notes that their themes were identified by all the participants in their population (marginalised young people up to age 24 years old, parents and healthcare professionals), views of people > 18 years old, parents and health professionals will also have been included in their results. Our findings have been downgraded for relevance where applicable Marginalised group: • Homeless, k=20 • Living in remote areas, k=14 • Refugees and migrants, k=11 • LGBTQ, k=11 • Indigenous populations, k=4 • Low income, k=4 • Young offenders, k=2 • Living with a disability, k=2	These terms were subsequently included but were not included in the original systematic search terms. Abstracts were screened, with 2 researchers performing an initial 200-paper pilot and achieving more than 95% inter-rater agreement. Any disagreements were discussed, and an agreement reached. Out of 1241 abstracts screen, 235 full texts were read and 68 were included for the final review. **Data extraction** Key findings for access to, engagement with and/or navigation through healthcare systems were recorded through each study. Following details were extracted from included studies: • Year • Language of publication • Country • Marginalised group • Sample size • Age definition • Gender distribution • Healthcare setting focus of the study • Key limitations in study protocol. **Analysis** Qualitative thematic synthesis was conducted with all included studies, beginning with free-coding of the		were pre-defined before searching and included in the systematic search terms. Young offenders, low income and young people living with a disability were only included after reviewing the identified studies. Authors decided to include studies encompassing these populations but did not re-do the systematic search to with these terms included. This means that all available papers for these 3 populations may not have been identified and they may be under-represented in the findings. Q4: *Did the review's authors do enough to assess quality of the included studies?* Yes. Quality appraisal of studies was done using both quantitative and qualitative appraisal tools. Qualitative studies received an average CASP checklist score of 7.96/10 (range 3-10). Each criterion was met by 67% of studies, excepting considering the relationship between interviewer and participants (only 25% of studies addressed this). Quantitative studies received an average Glasziou criteria score of 2.88/5 (range 1-5). Participant demographics and ethical review was well scoring among the studies. However, drop-out rates, sampling, use of validate questionnaires and description of outcome measurements were each addressed by 50% of studies or less.

Study details	Participants	Methods	Themes and findings	Limitations
	Study country: • USA, k=24 • Australia, k=24 • Canada, k=11 • UK, k=7 • New Zealand, k=1 • Portugal, k=1 Area of healthcare: • General, k=37 • Mental health services, k=13 • Sexual health services, k=7 • Substance use services, k=2 • Emergency departments, k=2 • Pregnancy-related services, k=2 • Primary care, k=2 • Youth services, k=1 • School health services, k=1 • Social services, k=1 **Inclusion criteria** Studies had to: • Studies focused on marginalised groups (defined as refugees and migrants, homeless,	extracted themes. These were input into an Excel spreadsheet alongside the other extracted data, forming a matrix. This matrix was then transferred through to NVivo, allowing grouping of codes and the organisation of higher-level thematic analysis. The method of synthesis involved integrating multiple data components (i.e. qualitative and quantitative) into the analysis, to allow comparisons within and across categories. **Quality assessment of included studies** Glasziou criteria used to assess quantitative studies; CASP checklist for qualitative studies used for qualitative studies; both used for mixed-methods studies as appropriate.		Q5: *If the results of the review have been combined, was it reasonable to do so?* Yes. Thematic analysis applied to the data, with a good description of the process of combining quantitative and qualitative data. Q6: *What are the overall results of the review?* A table presenting the characteristics of included studies is very informative, including details on the country, health issue focus, study design, participant characteristics and summary of findings. However, it would have been helpful to see the marginalised group listed in there as well. Very good qualitative description of the 8 general themes identified across the literature, presented in chronological order, i.e. help-seeking, access to healthcare services, engagement with healthcare services, navigation through healthcare services, and future directions for increasing access to healthcare (technology). Further discussion surrounding the variation in the themes between marginalised groups of young people, as well as parental and professional views. Q7: *How precise are the results?* Not applicable. Q8: *Can the results be applied to the local population?* Can't tell. The

Study details	Participants	Methods	Themes and findings	Limitations
	LGBTQ, living in remote areas, part of the indigenous population; young offenders, low income, living with a disability) • At least 75% of study participants aged 12-24, their parents or healthcare professionals • Study question involved access and barriers to access to, engagement with, and/or navigation through healthcare services • Study conducted in a high-income country • Study reports original research • Be published from Jan 2006 onwards **Exclusion criteria** Not reported			review incorporates data from a wide range of setting and participants. However, only 7 studies were conducted in the UK. 24 were conducted in the USA, which has a very different healthcare system here, in which cost plays a huge part to access. Convenience sampling used by single services were prevalent within the studies, which also affects generalisability. Q9: *Were all-important outcomes considered?* Not applicable. Themes are driven by data. Q10: *Are the benefits worth the harms and costs?* Not applicable. Literature review. *Overall judgement of quality:* Minor concerns **Other information** None

BYCP: Babies, children and young people; CAMHS: Child and Adolescent Mental Health Service; CF: Cystic fibrosis; CKD: Chronic kidney disease; CICC: Children in Care Council; HCP:; healthcare professional; IPA: interpretive phenomenological analysis; K: number of studies; LAC: Looked After Children; LGBTQ: Lesbian, Gay, Bisexual, Transgender and Queer; MHS: mental health service; NHS: National Health Service; NRES: National Research Ethics Service; N: number; PPI: public and patient involvement; PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses; RCT: randomised controlled trial

Appendix E – Forest plots

Forest plots for review question: How can children and young people be empowered to advocate for themselves?

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

Appendix F – GRADE-CERQual tables

GRADE-CERQual tables for review question: How can children and young people be empowered to advocate for themselves?

Table 6: Evidence summary (GRADE-CERQual) for theme 1: External factors

Study information		Description of review finding	CERQUAL Quality assessment				
No of studies	**Design**		**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
Sub-theme 1.1: Flexible and interactive environment							
4 (Alderson 2019, Grealish 2013, Holley 2018, Nightingale 2017)	Semi-structured interview; semi-structured interview and focus group	Data from 4 studies showed that being mindful of creating a relaxed and interactive environment kept participants engaged with healthcare discussions. Children, young people and their parents placed a high value on having a sense of choice and control during discussions with healthcare professionals, which was empowering. Using developmentally appropriate care-management approaches and talking to healthcare professionals who understand their circumstances and an awareness of the care system and the complexities were described as facilitators. *'Do like, activities basically, because sitting round a desk and talking isn't very engaging.' (Alderson 2019, page 2)*	Moderate concerns[1]	No/very minor concerns	Minor concerns[2]	No/very minor concerns	MODERATE
Sub-theme 1.2: Power dynamics							
1 (Alderson 2019)	Semi-structured interview	Data from 1 study suggested that vulnerable children and young people feel that healthcare professionals have a preconceived idea of their ability and motivation to engage with healthcare decisions. Additionally, healthcare professionals might try to 'protect' these	Minor concerns[3]	No/very minor concerns	No/very minor concerns	Serious concerns[4]	VERY LOW

Study information		Description of review finding	CERQUAL Quality assessment				
No of studies	**Design**		**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
		children and young people from certain aspects and details of their healthcare. This means that healthcare staff miss opportunities to encourage vulnerable children and young people to engage in their care and advocate for their choices. *'Some people will treat us differently, but you have come to us to ask us whether we want to do it. Rather than just going to a group of young people, "Right, do you want to do this?" you've come to children that are in care and given us the opportunity to get our voices heard'. (Alderson 2019, page 4)*					

1 Evidence downgraded for methodological limitations as per CASP qualitative checklist
2 Evidence downgraded for coherence because some minor concerns regarding triangulating the views of parents/guardians and healthcare professionals into themes
3 Evidence downgraded for methodological limitations as per CASP qualitative checklist
4 Evidence downgraded for adequacy because studies together did not offer rich data

Table 7: Evidence summary (GRADE-CERQual) for theme 2: Internal factors

Study information		Description of review finding	CERQUAL Quality assessment				
No of studies	**Design**		**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
Sub-theme 2.1: Independence							
2 (Grealish 2013, Harper 2014)	Semi-structured interview	Data from 2 studies showed that children and young people viewed rule-based approaches as restrictive rather than empowering. Young children valued opportunities to develop their coping mechanisms for symptoms and valued validation of such strategies by health professionals. They also wanted private appointments, which enabled them to	Moderate concerns[1]	No/very minor concerns	No/very minor concerns	No/very minor concerns	MODERATE

Study information		**Description of review finding**	**CERQUAL Quality assessment**				
No of studies	**Design**		**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
		disclose more information without the fear of parental involvement or nagging. *'…your parents have to be there don't they so if they make appointments it's with your parents, so the child is just there to talk about what the parents say is the problem (…) it's always like the child is an afterthought kind of thing. When I got to about 13 or 15 that was getting very frustrating that you know they're here to see you and they're just talking to everyone else…'. (Harper 2014, page 93)*					
Sub-theme 2.2: Respecting their choice							
1 (Alderson 2019)	Semi-structured interview	Data from 1 study showed that ensuring group dynamics using an 'open access' PPI group rather than a closed group, enabled children to attend without feeling excluded or pressured. They voiced their frustration that people without lived experience parachute in and conduct tokenistic consultations with children, without providing feedback as to how their input had influenced anything. *'I don't want to be on camera, so you gave me the opportunity of videoing it instead….so you gave all of us a choice of whether we want to be on camera or not'. (Alderson 2019, page 5)*	Minor concerns[2]	No/very minor concerns	No/very minor concerns	Serious concerns[3]	LOW
Sub-theme 2.3: Offering sessions of therapy							

Study information		**Description of review finding**	**CERQUAL Quality assessment**				
No of studies	**Design**		**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
1 (Harper 2014)	Semi-structured interview	Evidence from 1 study showed that, as participants matured from childhood to adolescence, they felt better able to describe their feelings and express themselves during therapy sessions. This was a gradual learning curve, and offering therapy sessions early prepared young people to discuss more mature or sensitive issues as they arise. *'It's quite hard to talk about, when you're little, you know something's up but don't know how to get it across, I mean now I've learnt to say this is what I'm like, I just feel more able to talk about it cause I've done it all before'. (Harper 2014, page 93)*	No/very minor concerns	No/very minor concerns	No/very minor concerns	Serious concerns[3]	MODERATE
Sub-theme 2.4: Participation							
1 (Robards 2018)	Systematic review	Data from 1 systematic review showed that youth participation was a minor but distinct theme as a way to improve engagement. Youth participation was proposed as a way to ensure that gender and sexually diverse young people are treated equally, and to design healthcare that is useful and inclusive. It also gives young people a sense of agency by identifying solutions for themselves and the community. *No quotes to support this finding.*	No/very minor concerns	No/very minor concerns	Minor concerns[4]	Minor concerns[5]	HIGH
Sub-theme 2.5: Experience opportunities							

Study information		Description of review finding	CERQUAL Quality assessment				
No of studies	Design		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
1 (Mitchell 2012)	Semi-structured interview	Facilitating increased levels of involvement for children and young people may be facilitated by allowing them to experience the different options offered. *'When he visited [local college] his face lit up … once he'd seen [local college] that was it, his mind was made up'. (Mitchell 2012, page 19)*	No/very minor concerns	No/very minor concerns	No/very minor concerns	Serious concerns[3]	MODERATE

1 Evidence downgraded for methodological limitations as per CASP qualitative checklist
2 Evidence downgraded for methodological limitations as per CASP qualitative checklist
3 Evidence downgraded for adequacy because studies together did not offer rich data
4 Evidence downgraded for relevance because it contains a systematic review which includes views of children and young people, parents and health professionals from countries with different models of healthcare
5 Evidence downgraded for adequacy because studies together offered some rich data

Table 8: Evidence summary (GRADE-CERQual) for theme 3: Strategies

Study information		Description of review finding	CERQUAL Quality assessment				
No of studies	Design		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
Sub-theme 3.1: Collaborative sessions							
4 (Edbrooke-Childs 2019, Grealish 2013, Harper 2014, Lerch 2019)	Semi-structured interview; systematic review	Data from 3 studies and 1 systematic review showed that poor collaboration between children and young people and their healthcare professionals, where no explanation or justification of decision outcomes was provided, proved disempowering. Children and young people expressed the desire for deeper collaboration as they matured and a consideration of their desire for increased independence. These reduced feelings of being controlled by services and service dynamics. However, some parents and	Moderate concerns[1]	No/very minor concerns	Minor concerns[2]	No/very minor concerns	MODERATE

Study information		Description of review finding	CERQUAL Quality assessment				
No of studies	Design		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
		adolescents favoured a passive decision-making style. Here adolescent input is considered, but with the final decision is made by the healthcare professional. *'I had 9 doctors telling me erm they diagnosed me with 9 different things in a day and I was absolutely fuming because they wouldn't listen to me, it was like it didn't matter cause I was a child'. (Harper 2014, page 93)*					
Sub-theme 3.2: Having direct conversations							
3 (Grealish 2013, Holley 2018, Lowes 2015)	Focus group, free-text questionnaire; semi-structured interview	Data from 3 studies showed that young people and their parents found direct communication with clinicians empowering, both through direct conversations between clinicians and young people and indirectly through their parents. Regular education and visual information are useful in creating a positive experience and ensuring children and young people understand their healthcare decisions. Children and young people (and the parents of babies) were able to make their own decisions in their own time and felt heard and able to seek additional support. *'I feel more confident about talking in clinic because the doctors and nurses ask me more questions than before. I also like to think of my questions before I come to clinic, which I write down in my book'. (Lowes 2015, page 57)*	Moderate concerns[3]	No/very minor concerns	Minor concerns[2]	Moderate concerns[4]	LOW
Sub-theme 3.3: Validation by healthcare professionals							

Study information		**Description of review finding**	**CERQUAL Quality assessment**				
No of studies	**Design**		**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
1 (Grealish 2013)	Semi-structured interview	Data from 1 study showed that effective communication (being listened to) was empowering to children and young people because it made them feel as though they were being understood. When clinicians communicate in a jargon-free, non-patronizing and reassuring manner, they help to validate children's personal distress and empower them. *'F—they had a laugh with me. . . and that helped me to relax and I felt I could open up to them they were so caring friendly and always listened to me talk me and stuff and they tried to understand me as well and I had fun with them as well..'. (Grealish 2013, page 144)*	Moderate concerns[1]	No/very minor concerns	No/very minor concerns	Serious concerns[6]	LOW

1 Evidence downgraded for methodological limitations as per CASP qualitative checklist
2 Evidence downgraded for relevance because it contains a systematic review which includes views of children and young people, parents and health professionals from countries with different models of healthcare
3 Evidence downgraded for methodological limitations as per CASP qualitative checklist
4 Evidence downgraded for adequacy because studies together offered some rich data
6 Evidence downgraded for adequacy because studies together did not offer rich data

Appendix G – Economic evidence study selection

Economic evidence study selection for review question: How can children and young people be empowered to advocate for themselves?

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

Appendix H – Economic evidence tables

Economic evidence tables for review question: How can children and young people be empowered to advocate for themselves?

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

Appendix I – Economic evidence profiles

Economic evidence profiles for review question: How can children and young people be empowered to advocate for themselves?

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

Appendix J – Economic analysis

Economic evidence analysis for review question: How can children and young people be empowered to advocate for themselves?

No economic analysis was conducted for this review question.

Appendix K – Excluded studies

Excluded studies for review question: How can children and young people be empowered to advocate for themselves?

Clinical studies:

Table 9: Excluded studies and reasons for their exclusion

Study	Reason for Exclusion
Aarthun, A., Akerjordet, K., Parent participation in decision-making in health-care services for children: an integrative review, Journal of nursing management, 22, 177-191, 2014	Population of included studies not in protocol. Included studies checked for inclusion.
Abbott, M., Bernard, P., Forge, J., Communicating a diagnosis of Autism Spectrum Disorder - a qualitative study of parents' experiences, Clinical Child Psychology and Psychiatry, 18, 370-382, 2013	Phenomenon of interest not in protocol - No themes relating to advocacy and support in healthcare, and views are very parent-centric
Abrines Jaume, N., Hoffman, J., Wolpert, M., Law, D., Wright, E., Shared decision making in child and adolescent mental health services, Neuropsychiatrie de l'Enfance et de l'Adolescence, 1), S294, 2012	Conference abstract
Actrn,, Improving outcomes in mental health for children and families: a study of Enhanced Stepping Stones Triple P, Http://www.who.int/trialsearch/trial2.aspx?Trialid=actrn12618000981224, 2018	Protocol for ongoing clinical trial
Ahuja, Alka S., Williams, Richard, Telling stories: Learning from patients' and families' experiences of specialist child and adolescent mental health services, International Journal of Consumer Studies, 34, 603-609, 2010	Population not in protocol - 15 parents/carers of patients aged 5-15. Patients only (jointly) participated in 2 of the interviews.
Alderdice, F., Gargan, P., McCall, E., Franck, L., Online information for parents caring for their premature baby at home: A focus group study and systematic web search, Health Expectations, 30, 30, 2018	Phenomenon of interest not in protocol - No themes relating to advocacy and support in healthcare
Alexander, S., Bath, L., McDonald, M., Adolescent diabetic outpatient clinics-more than just an HbA1c, Archives of disease in childhood, 101 (Supplement 1), A275-A277, 2016	Conference abstract
Allcock, D., Smith, K., Exploring parent views of community matrons, Nursing Times, 110, 21-23, 2014	Study design not in protocol - No qualitative data analysis performed
Allen, D., Scarinci, N., Hickson, L., The Nature of Patient- and Family-Centred Care for Young Adults Living with Chronic Disease and their Family Members: A Systematic Review, International Journal of Integrated Care [Electronic Resource]Int J Integr Care, 18, 14, 2018	Population of included studies not in protocol. Included studies checked for inclusion.
Allen, N., McFarlane, L., Shanahan, R., Bassett, E. Z. A., Wellcome home: The work of shelter, a charitable organisation in facilitating the discharge of children with medical complexities (CMIC) at birmingham children's hospital, Developmental medicine and child neurology, 59 (Supplement 4), 76, 2017	Conference abstract
Anderson, L., Wilson, J., Williams, G., Cognitive Orientation to daily Occupational Performance (CO-OP) as group therapy for children living with motor coordination difficulties: An integrated literature review, Australian occupational therapy journal, 64, 170-184, 2017	Study design of included studies not in protocol. Included studies checked for inclusion.
Antao, V., Evaluation of post-diagnostic support to families and children with autism spectrum disorder, Developmental medicine and child neurology, 4), 69, 2010	Conference abstract

Study	Reason for Exclusion
Aranda, K., Coleman, L., Sherriff, N. S., Cocking, C., Zeeman, L., Cunningham, L., Listening for commissioning: A participatory study exploring young people's experiences, views and preferences of school-based sexual health and school nursing, Journal of Clinical Nursing, 27, 375-385, 2018	Phenomenon of interest not in protocol - No themes related to advocacy and support
Arenson, M., Hudson, P. J., Lee, N., Lai, B., The Evidence on School-Based Health Centers: A Review, Lobal Pediatric HealthGlob, 6, 2333794X19828745, 2019	Narrative review. Included studies checked for inclusion.
Armitage, S., Swallow, V., Kolehmainen, N., Ingredients and change processes in occupational therapy for children: a grounded theory study, Scandinavian journal of occupational therapy, 24, 208-213, 2017	Population and phenomenon of interest not in protocol - Any themes relating to advocacy and support were from parents of children aged 7-11.
Armstrong, V. G., Howatson, R., Parent-infant art psychotherapy: A creative dyadic approach to early intervention, Infant mental health journal, 36, 213-222, 2015	Study design not in protocol - No qualitative data analysis presented.
Ashcraft, L. E., Asato, M., Houtrow, A. J., Kavalieratos, D., Miller, E., Ray, K. N., Parent Empowerment in Pediatric Healthcare Settings: A Systematic Review of Observational Studies, Patient, 12, 199-212, 2019	Population of included studies not in protocol. Included studies checked for inclusion.
Ashfield-Watt, P., Philips, A., Dale, P., Hale, M., McDowell, I., Exploring digital arts-based approaches that empower children and young people with Familial Hypercholesterolaemia (FH), Atherosclerosis Supplements, 28, e6, 2017	Conference abstract
Aston, Hermione Jane, An ecological model of mental health promotion for school communities: Adolescent views about mental health promotion in secondary schools in the UK, International Journal of Mental Health Promotion, 16, 289-307, 2014	Phenomenon of interest not in protocol - Mental health promotion within a secondary school curriculum.
Audrey, S., Batista Ferrer, H., Ferrie, J., Evans, K., Bell, M., Yates, J., Roderick, M., Macleod, J., Hickman, M., Impact and acceptability of self-consent procedures for the school-based human papillomavirus vaccine: A mixed-methods study protocol, BMJ open, 8 (3) (no pagination), 2018	Published protocol for ongoing trial
Babbage, C., Jackson, G. M., Nixon, E., Desired Features of a Digital Technology Tool for Self-Management of Well-Being in a Nonclinical Sample of Young People: Qualitative Study, JMIR Mental Health, 5, e10067, 2018	Phenomenon of interest not in protocol - No themes relating to advocacy and support in healthcare
Cavaleri, Mary A., Olin, S., Kim, Annie, Hoagwood, Kimberly E., Burns, Barbara J., Family support in prevention programs for children at risk for emotional/behavioral problems, Clinical Child and Family Psychology Review, 14, 399-412, 2011	Study design of included studies not in protocol. Included studies checked for inclusion.
Dale, H., Watson, L., Adair, P., Moy, M., Humphris, G., The perceived sexual health needs of looked after young people: findings from a qualitative study led through a partnership between public health and health psychology, Journal of Public Health, 33, 86-92, 2011	Phenomenon of interest not in protocol - Sexual health and contraception with no generalizable themes.
Daniels, Karen, Cultural agents creating texts: A collaborative space adventure, Literacy, 48, 103-111, 2014	Setting not in protocol - Early years compulsory education setting
Datt, C., Travers, M., Odell, C., Improving the hospital experience for young people (YP) with autism, Archives of disease in childhood, 102 (Supplement 1), A20, 2017	Conference abstract
Dawson, A., Jackson, D., The primary health care service experiences and needs of homeless youth: a narrative synthesis of current evidence, Contemporary nurse, 44, 62-75, 2013	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Dublon, V. E., Green, S., Benitez-Castillo, M., Edwards, T., Leiva, A., The production of a diabetes information film, by young people	Conference abstract

Study	Reason for Exclusion
who have diabetes, as a means of educating others, Archives of disease in childhood, 103 (Supplement 1), A166, 2018	
Dunn, V., O'Keeffe, S., Stapley, E., Midgley, N., Facing Shadows: working with young people to coproduce a short film about depression, Research Involvement & Engagement, 4, 46, 2018	Study design not in protocol - No qualitative data analysis presented
Dunne, A., Carolan, R., Swords, L., Fortune, G., Patient and family perspectives of paediatric psychogenic non-epileptic seizures: A systematic review, Seizure, 71, 279-285, 2019	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Eaton, Kim, Ohan, Jeneva L., Stritzke, Werner G., Courtauld, Hannah M., Corrigan, Patrick W., Mothers' decisions to disclose or conceal their child's mental health disorder, Qualitative health research, 27, 1628-1639, 2017	Country: Australia
Edbrooke-Childs, J., Edridge, C., Averill, P., Delane, L., Hollis, C., Craven, M. P., Martin, K., Feltham, A., Jeremy, G., Deighton, J., Wolpert, M., A Feasibility Trial of Power Up: Smartphone App to Support Patient Activation and Shared Decision Making for Mental Health in Young People, JMIR MHealth and UHealth, 7, e11677, 2019	Phenomenon of interest not in protocol - No themes relating to how children want their healthcare staff to support them
Edwards, D., Noyes, J., Lowes, L., Haf Spencer, L., Gregory, J. W., An ongoing struggle: A mixed-method systematic review of interventions, barriers and facilitators to achieving optimal self-care by children and young people with Type 1 Diabetes in educational settings, BMC pediatrics, 14 (1) (no pagination), 2014	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Ellis, J., Boger, E., Latter, S., Kennedy, A., Jones, F., Foster, C., Demain, S., Conceptualisation of the 'good' self-manager: A qualitative investigation of stakeholder views on the self-management of long-term health conditions, Social Science and Medicine, 176, 25-33, 2017	Population not in protocol - >18 years old
Fargas-Malet, Montserrat, McSherry, Dominic, Pinkerton, John, Kelly, Greg, Home on a care order: Who the children are and what the care order is for, Child & Family Social Work, 22, 813-821, 2017	Phenomenon of interest not in protocol - No themes relating to advocacy and support in healthcare
Fasciano, K., Souza, P., Bielaczyc, A., Englander, S., Building connection and creating community through the development of a young adult cancer conference, Psycho-Oncology, 3), 191-192, 2014	Conference abstract
Fawcett, R., Porritt, K., Stern, C., Carson-Chahhoud, K., Experiences of parents and carers in managing asthma in children: A qualitative systematic review, JBI Database of Systematic Reviews and Implementation Reports, 17, 793-984, 2019	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Foster, M. J., Whitehead, L., Maybee, P., Cullens, V., The parents', hospitalized child's, and health care providers' perceptions and experiences of family centered care within a pediatric critical care setting: a metasynthesis of qualitative research, Journal of Family Nursing, 19, 431-468, 2013	Population and phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Franck, L. S., Oulton, K., Bruce, E., Parental involvement in neonatal pain management: an empirical and conceptual update, J Nurs Scholarsh, 44, 45-54, 2012	Parental views of under 5's but poor proxy. Themes are developed around how parents want to be included in their children's care, rather than how they think their child would want them to be involved.
Giambra, B. K., Stiffler, D., Broome, M. E., An integrative review of communication between parents and nurses of hospitalized technology-dependent children, Worldviews on evidence-based nursing / Sigma Theta Tau International, Honor Society of Nursing, 11, 369-375, 2014	Population of included studies not in protocol. Included studies checked for inclusion.

Study	Reason for Exclusion
Jacob, J., Edbrooke-Childs, J., Holley, S., Law, D., Wolpert, M., Horses for courses? A qualitative exploration of goals formulated in mental health settings by young people, parents, and clinicians, Clinical child psychology and psychiatry, 21, 208-223, 2016	Phenomenon of interest not in protocol - Qualitative analysis of goals set by patients rather than their views on/experiences with goal setting
Jacob, J., Edbrooke-Childs, J., Law, D., Wolpert, M., Measuring what matters to patients: Using goal content to inform measure choice and development, Clinical Child Psychology and Psychiatry, 22, 170-186, 2017	Outcomes not in protocol - No qualitative data presented. Secondary analysis of goal themes devised by children to build framework for outcomes measurements.
Kohut, Sara Ahola, Stinson, Jennifer, van Wyk, Margaret, Giosa, Lidia, Luca, Stephanie, Systematic review of peer support interventions for adolescents with chronic illness, International Journal of Child and Adolescent Health, 7, 183-197, 2014	Study design of included studies not in protocol. Included studies checked for inclusion.
Larkin, M., Boden, Z. V., Newton, E., On the Brink of Genuinely Collaborative Care: Experience-Based Co-Design in Mental Health, Qualitative health research, 25, 1463-1476, 2015	Study design not in protocol - Narrative description and reflection on study with no data presented.
Lea, S., Martins, A., Morgan, S., Cargill, J., Taylor, R. M., Fern, L. A., Online information and support needs of young people with cancer: A participatory action research study, Adolescent Health, Medicine and Therapeutics, 9, 121-135, 2018	Population not in protocol - Aged 13 - 24 years old (50% under 18 years) with no way of attaching themes to ages
Lerch, Matthew F., Thrane, Susan E., Adolescents with chronic illness and the transition to self-management: A systematic review, Journal of Adolescence, 72, 152-161, 2019	Phenomenon of interest
Lester, H., Marshall, M., Jones, P., Fowler, D., Amos, T., Khan, N., Birchwood, M., Views of young people in early intervention services for first-episode psychosis in England, Psychiatric Services, 62, 882-887, 2011	Population not in protocol - Age 14-35 years (mean male age 21 years, mean female age 23) with no way of assigning age to themes.
Lowes, L., Eddy, D., Channon, S., McNamara, R., Robling, M., Gregory, J. W., The experience of living with type 1 diabetes and attending clinic from the perception of children, adolescents and carers: analysis of qualitative data from the DEPICTED study, Journal of pediatric nursing, 30, 54- 62, 2015	Phenomenon of interest not in protocol - No themes relating to how children want their healthcare staff to support them
Macdonald, K., Greggans, A., 'Cool friends': an evaluation of a community befriending programme for young people with cystic fibrosis, Journal of Clinical Nursing, 19, 2406-14, 2010	Phenomenon of interest not in protocol - No themes relating to advocacy or support
Mattacola, E., "They Think It's Helpful, but It's Not": a Qualitative Analysis of the Experience of Social Support Provided by Peers in Adolescents with Type 1 Diabetes, International journal of behavioral medicine, 27, 444-454, 2020	Phenomenon of interest not in protocol - No relevant type of support for young people
McMillan, S. S., Wilson, B., Stapleton, H., Wheeler, A. J., Young people's experiences with mental health medication: A narrative review of the qualitative literature, Journal of Mental Health, 2020	Narrative review. Included studies checked for inclusion.
McTavish, J. R., Kimber, M., Devries, K., Colombini, M., MacGregor, J. C. D., Wathen, N., MacMillan, H. L., Children's and caregivers' perspectives about mandatory reporting of child maltreatment: A meta-synthesis of qualitative studies, BMJ open, 9 (4) (no pagination), 2019	Population of included studies not in protocol. Included studies checked for inclusion.
Mehmood, A., Cammidge, S., Guy, E., Peckham, D., Duff, A., Evaluation of youth work support for teenagers and young adults with cystic fibrosis, Journal of Cystic Fibrosis, 17 (Supplement 3), S128, 2018	Conference abstract
Mitchell, Wendy, Parents' accounts: Factors considered when deciding how far to involve their son/daughter with learning disabilities in choice-making, Children and Youth Services Review, 34, 1560-1569, 2012	Phenomenon of interest not in protocol - No themes relating to how children want their healthcare staff to support them

Study	**Reason for Exclusion**
Neill, S. J., Jones, C. H., Lakhanpaul, M., Roland, D. T., Thompson, M. J., Parents' help-seeking behaviours during acute childhood illness at home: A contribution to explanatory theory, Journal of child health care : for professionals working with children in the hospital and community, 20, 77-86, 2016	Parental views of under 5's but poor proxy. Themes are developed around how parents want to be included in their children's care, rather than how they think their child would want them to be involved.
Nightingale, R., Hall, A., Gelder, C., Friedl, S., Brennan, E., Swallow, V., Desirable Components for a Customized, Home-Based, Digital Care-Management App for Children and Young People With Long-Term, Chronic Conditions: A Qualitative Exploration, Journal of medical Internet research, 19, e235, 2017	Phenomenon of interest not in protocol - No themes relating to how children want their healthcare staff to support them
O'Neill, T., Wakefield, J., Fifteen-minute consultation in the normal child: Challenges relating to sexuality and gender identity in children and young people, Archives of Disease in Childhood: Education and Practice Edition, 102, 298-303, 2017	Study design not in protocol - Narrative review with 2 case studies included.
Oulton, K., Sell, D., Kerry, S., Gibson, F., What do children and young people with learning disabilities want from hospital services?, Archives of disease in childhood, 3), A84-A85, 2015	Conference abstract
Petrie, K., McArdle, A., Cookson, J., Powell, E., Poblete, X., 'Let us speak'-children's opinions of doctors, Archives of Disease in Childhood, 102 (Supplement 1), A200-A201, 2017	Conference abstract
Pini, S., Education mentoring for teenagers and young adults with cancer, British journal of nursing (Mark Allen Publishing), 18, 1316-1319, 2009	Study design not in protocol - Description of the development/implementation of a unique learning mentor with illustrative quotes
Richardson, C., Paslakis, G., Men's experiences of eating disorder treatment: A qualitative systematic review of men-only studies, Journal of psychiatric and mental health nursing, 2020	Population of included studies not in protocol. Included studies checked for inclusion.
Robards, F., Kang, M., Usherwood, T., Sanci, L., How Marginalized Young People Access, Engage With, and Navigate Health-Care Systems in the Digital Age: Systematic Review, Journal of Adolescent Health, 365-381, 2018	Phenomenon of interest not in protocol - No themes relating to how children want their healthcare staff to support them
Robert, Marie, Leblanc, Line, Boyer, Thierry, When satisfaction is not directly related to the support services received: Understanding parents' varied experiences with specialised services for children with developmental disabilities, British Journal of Learning Disabilities, 43, 168-177, 2015	Country: Canada
Rodrigues, S., Melchionda, V., Rodney, K., Coppens, K., Comparing children's and parents' perspectives on hospital care, Archives of disease in childhood, 1), A101, 2014	Conference abstract
Rossiter, C., Levett-Jones, T., Pich, J., The impact of person-centred care on patient safety: An umbrella review of systematic reviews, International journal of nursing studies, 109, 103658, 2020	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Scholefield, B., Gosney, J., Callens, C., Duncan, H., Morris, K., Draper, H., Consultation with children regarding deferred consent in emergency care research, Pediatric critical care medicine, 1), A44, 2011	Conference abstract
Scott, E., Dale, J., Russell, R., Wolke, D., Young people who are being bullied - do they want general practice support?, BMC family practice, 17, 116, 2016	Phenomenon of interest not in protocol - No themes relating to advocacy and support for healthcare
Stafford, V., Hutchby, I., Karim, K., O'Reilly, M., "Why are you here?" Seeking children's accounts of their presentation to Child and Adolescent Mental Health Service (CAMHS), Clinical child psychology and psychiatry, 21, 3-18, 2016	Phenomenon of interest not in protocol - No themes relating to advocacy or support for healthcare

Study	Reason for Exclusion
Stenberg, U., Haaland-Overby, M., Koricho, A. T., Trollvik, A., Kristoffersen, L. G. R., Dybvig, S., Vagan, A., How can we support children, adolescents and young adults in managing chronic health challenges? A scoping review on the effects of patient education interventions, Health expectations : an international journal of public participation in health care and health policy, 2019	Scoping review. Included studies checked for inclusion.
Sutcliffe, P., Martin, S., Sturt, J., Powell, J., Griffiths, F., Adams, A., Dale, J., Systematic review of communication technologies to promote access and engagement of young people with diabetes into healthcare, BMC endocrine disorders, 11 (no pagination), 2011	Study design of included studies not in protocol. Included studies checked for inclusion.
Troy, E., Doltani, D., Harmon, D., The role of a companion attending consultations with the patient. A systematic review, Irish Journal of Medical Science, 188, 743-750, 2019	Population not in protocol - Companions to adult patients only
Ulph, F., Cullinan, T., Qureshi, N., Kai, J., Informing children of their newborn screening carrier result for sickle cell or cystic fibrosis: qualitative study of parents' intentions, views and support needs, Journal of Genetic Counseling, 23, 409-20, 2014	Parental views of under 5's but poor proxy. Themes are developed around how parents want to tell their child about medical information relating to genetic risks, rather than how and when children want to be informed of these.
Valentine, J. C., Leach, S. M., Fowler, A. P., Stojda, D. K., Macdonald, G., Families and schools together (FAST) for improving outcomes for children and their families, Cochrane Database of Systematic Reviews, 2019, 2019	Population of included studies not in protocol. Included studies checked for inclusion.
Vasey, J., Smith, J., Kirschbaum, M., Chirema, K., Tokenism or true partnership: Parental involvement in the child's acute pain care, Archives of disease in childhood, 101 (Supplement 1), A189, 2016	Conference abstract
Watts, R., Zhou, H., Shields, L., Taylor, M., Munns, A., Ngune, I., Family-centered care for hospitalized children aged 0-12 years: A systematic review of qualitative studies, JBI Database of Systematic Reviews and Implementation Reports, 12, 204-283, 2014	Population of included studies not in protocol. Included studies checked for inclusion.
Yamaji, Noyuri, Suto, Maiko, Takemoto, Yo, Suzuki, Daichi, Lopes, Katharina da Silva, Ota, Erika, Supporting the Decision Making of Children With Cancer: A Meta-synthesis, Journal of pediatric oncology nursing : official journal of the Association of Pediatric Oncology Nurses, 1043454220919711, 2020	Population of included studies not in protocol. Included studies checked for inclusion.

Economic studies

No economic evidence was identified for this review.

Appendix L – Research recommendations

Research recommendations for review question: How can children and young people be empowered to advocate for themselves?

No research recommendations were made for this review question.

Appendix M – Evidence from reference groups and focus groups

Reference group and focus group evidence for review question: How can children and young people be empowered to advocate for themselves?

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

Table 10: Evidence from the focus and reference groups

Age < 7 years	Age 7-11 Years	Age 11-14 years	Overall quality of the evidence
• "I help myself sometimes and I use my brain" • 'I like to talk to the doctor because it is my body.'	• I feel comfortable speaking to the dentist or doctor by myself o 4 disagreed - 'I like it when my parents are with me' (all agreed with this statement) • What can the doctor do to make you want to speak to them by yourself? - 'I don't know, they look scary'	• What would help you be involved in decisions about your own health and speak up for yourself? o Willingness of young person to talk and the doctor to let you talk (mentioned by multiple young people) o Doctor being willing for a young person to have a say – saying it at the beginning of the session. - 'Giving us permission'. x2 - 'When starting to make your own decisions you need lots of support, Doctors need to explain and provide lots of information to help you do this' o Pre-meetings with healthcare staff. Video or phone telephone call before the main session or drop in session at school. Chance to talk in a more informal way to build trust e.g. doctor could find out what you enjoy doing etc. x 2 o 'I don't know, I'm not a confident speaker' o 'Communicate in other ways e.g. write it down, text it, draw it' o 'Confidence' o 'Communication skills' o 'Giving it a go and if it doesn't work out it doesn't matter' o 'I don't know, I'm not a confident speaker' (several young people felt they just weren't confident and there wasn't much that would change that) o 'Socialise with more people that you don't know, get used to it' o 'Keep trying'	• Low

Age < 7 years	Age 7-11 Years	Age 11-14 years	Overall quality of the evidence
		○ 'Bank of resources e.g. pamphlets and videos to help young people understand the situation and feel able to speak up • How could confidence be developed? ○ Only one young person had specific ideas for how confidence could be developed (the others thought you were either confident or not) • What could a doctor do or say to make you feel more confident advocating for yourself? ○ 'Give me permission to speak – tell me' ○ 'Having someone there' ○ 'Said things in a way you could understand it' ○ 'Just ask you' ○ 'Ask me 'are you ok' or 'what do you think'' ○ 'Explaining what's going on ○ 'Tell you what's happening' ○ 'At the beginning, explain you can have a choice and ask questions' ○ Meet you and get to know what you like first' • What qualities do you need so you could advocate for yourself? ○ 'I try to put myself in other people's shoes' ○ 'Patience' ○ 'Strong in what they say and mean what they say' ○ 'Trustworthy – still keep secrets from my friends even if they're not my friends anymore' ○ 'Wanting to help' ○ 'Good listener' • What qualities would you like to learn so you could advocate for yourself? ○ 'Practice' ○ 'Go on a course' ○ 'Doing drama' ○ 'Just going through it'	

Age < 7 years	Age 7-11 Years	Age 11-14 years	Overall quality of the evidence
		○ 'Joining groups like this one' ○ 'Trying it'	

Appendix N – Evidence from national surveys

Evidence from national surveys for review question: How can children and young people be empowered to advocate for themselves?

No evidence from the national surveys was identified for this review question.