

## Babies, children and young people's experience of healthcare

[I] Independent advocacy in healthcare for children and young people

*NICE guideline NG204*

*Evidence reviews underpinning recommendations 1.5.18 to 1.5.24 and research recommendations in the NICE guideline*

*August 2021*

*Final*

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



## **Disclaimer**

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or service users. The recommendations in this guideline are not mandatory and the guideline does not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian.

Local commissioners and/or providers have a responsibility to enable the guideline to be applied when individual health professionals and their patients or service users wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with compliance with those duties.

NICE guidelines cover health and care in England. Decisions on how they apply in other UK countries are made by ministers in the [Welsh Government](#), [Scottish Government](#), and [Northern Ireland Executive](#). All NICE guidance is subject to regular review and may be updated or withdrawn.

## **Copyright**

© NICE 2021 All rights reserved. Subject to [Notice of Rights](#).

ISBN: 978-1-4731-4231-2

# Contents

<b>Independent advocacy in healthcare for children and young people .....</b>	<b>6</b>
Review question .....	6
Introduction .....	6
Summary of the protocol .....	6
Methods and process .....	7
Clinical evidence .....	7
Summary of studies included in the evidence review.....	8
Quality assessment of studies included in the evidence review.....	8
Evidence from reference groups and focus groups.....	8
Evidence from national surveys.....	8
Evidence from an expert witness.....	8
Economic evidence .....	9
Summary of studies included in the economic evidence review.....	9
Economic model.....	9
The committee’s discussion of the evidence.....	9
Recommendations supported by this evidence review .....	11
<b>Appendices.....</b>	<b>12</b>
Appendix A – Review protocol.....	12
Review protocol for review question: How can the views of babies, children and young people be best represented by independent advocates?.....	12
Appendix B – Literature search strategies .....	21
Literature search strategies for review question: How can the views of babies, children and young people be best represented by independent advocates? .....	21
Appendix C – Clinical evidence study selection .....	28
Study selection for: How can the views of babies, children and young people be best represented by independent advocates? .....	28
Appendix D – Clinical evidence tables .....	29
Evidence tables for review question: How can the views of babies, children and young people be best represented by independent advocates?.....	29
Appendix E – Forest plots.....	30
Forest plots for review question: How can the views of babies, children and young people be best represented by independent advocates?.....	30
Appendix F – GRADE-CERQual tables .....	31
GRADE-CERQual tables for review question: How can the views of babies, children and young people be best represented by independent advocates? .....	31
Appendix G – Economic evidence study selection.....	32
Economic evidence study selection for review question: How can the views of babies, children and young people be best represented by independent advocates? .....	32

Appendix H – Economic evidence tables.....	33
Economic evidence tables for review question: How can the views of babies, children and young people be best represented by independent advocates? .....	33
Appendix I – Economic evidence profiles .....	34
Economic evidence profiles for review question: How can the views of babies, children and young people be best represented by independent advocates? .....	34
Appendix J – Economic analysis .....	35
Economic evidence analysis for review question: How can the views of babies, children and young people be best represented by independent advocates? .....	35
Appendix K – Excluded studies .....	36
Excluded studies for review question: How can the views of babies, children and young people be best represented by independent advocates? .....	36
Appendix L – Research recommendations .....	44
Research recommendations for review question: How can the views of babies, children and young people be best represented by independent advocates? .....	44
Appendix M – Evidence from reference groups and focus groups .....	46
Reference group and focus group evidence for review question: How can the views of babies, children and young people be best represented by independent advocates? .....	46
Appendix N – Evidence from national surveys.....	48
Evidence from national surveys for review question: How can the views of babies, children and young people be best represented by independent advocates? .....	48
Appendix O – Evidence from an expert witness.....	50
Evidence from an expert witness for review question: How can the views of babies, children and young people be best represented by independent advocates? .....	50

# Independent advocacy in healthcare for children and young people

## Review question

How can the views of babies, children and young people be best represented by independent advocates?

## Introduction

The Care Act 2014 and Mental Health Act 1983/2007 place a duty on UK councils to provide an independent advocate for a baby, child or young person who has substantial difficulties being involved in their own healthcare or who may not have an appropriate person to represent them. In addition to this, independent advocates may be used in healthcare situations where babies, children and young people cannot agree with their parents or healthcare professionals over a healthcare decision, or where it is not appropriate for their parents or carers to represent them.

Independent advocates provide information and an opportunity for children and young people to express their wishes and concerns about healthcare, with the reassurance that the advocates are independent from their healthcare providers and that these discussions will not impact the care they receive. Furthermore, the independent advocate develops a trusting relationship with the child or young person, empowering them to make decisions, and acts as an objective supporter. However, independent advocates can be obtained from a range of providers, with individual advocates having different competencies and experience, and there may be variation in practice and quality of support.

The aim of this review is to determine how children and young people can be best represented by independent advocates.

## 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**

<b>Population</b>	<ul style="list-style-type: none"> <li>• People &lt;18 years-old who have experience of healthcare</li> <li>• 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 <ul style="list-style-type: none"> <li>○ The baby or child of the parent or carer is under 5 years, or</li> <li>○ There is a clear rationale provided as to why the study is using parents' or carers' view</li> </ul> </li> </ul>
<b>Phenomenon of interest</b>	Experience of healthcare, in particular how babies, children and young people feel they can be represented by independent advocates
<b>Primary outcome</b>	<p>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):</p> <ul style="list-style-type: none"> <li>• Access to records of healthcare staff discussions</li> <li>• Adequate training for independent advocates including knowledge about developmentally-appropriate approaches</li> <li>• Appeal to, or use of, advocacy groups</li> <li>• Availability and accessibility of appropriate advocacy services</li> <li>• Awareness of independent advocate services</li> <li>• Encouraging and supporting self-advocacy when possible</li> <li>• Sensitivity and responsiveness of independent advocate to feedback from child or young person</li> <li>• Views on timing of support provided from the independent advocate, establishing views regarding where and when advocacy is beneficial, including continuity of support</li> </ul>

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 babies, children and young people prefer to be supported by independent advocates in healthcare.

A systematic review of the literature was conducted using a combined search but no studies were identified which were applicable to this review question.

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

No studies were identified which were applicable to this review question (and so there are no evidence tables in appendix D). No meta-analysis was undertaken for this review (and so there are no forest plots in appendix E).

## Quality assessment of studies included in the evidence review

No studies were identified which were applicable to this review question (and so there are no evidence profiles in appendix F).

## Evidence from reference groups and focus groups

The children and young people's reference groups and focus groups provided additional evidence for this review. A summary of the evidence is presented in Table 2.

**Table 2: Summary of the evidence from reference groups and focus groups**

<b>Age groups</b>	<ul style="list-style-type: none"> <li>• 11-14 years</li> </ul>
<b>Areas covered</b>	<ul style="list-style-type: none"> <li>• What is an advocate</li> <li>• What skills and qualities should an advocate have</li> </ul>
<b>Illustrative quotes</b>	<ul style="list-style-type: none"> <li>• What is an advocate? <ul style="list-style-type: none"> <li>○ 'My mum is one... for vulnerable people'</li> <li>○ 'Makes sure their voice gets heard'</li> <li>○ 'Helps them have their voices heard'</li> </ul> </li> <li>• What skills/qualities should an advocate have? <ul style="list-style-type: none"> <li>○ 'Not sugar coating anything'</li> <li>○ 'Never over reacting'</li> <li>○ 'Understanding – 'they understand what the child is thinking and why they are feeling that way'</li> <li>○ 'Empathetic/sympathetic'</li> <li>○ 'Wants to help'</li> </ul> </li> </ul>

See the full evidence summary in appendix M.

## Evidence from national surveys

The grey literature review of national surveys provided additional evidence for this review. A summary of the evidence is presented in Table 3.

**Table 3: Summary of the evidence from national surveys**

<b>National surveys</b>	<ul style="list-style-type: none"> <li>• Opinion Matters. Declare your care survey 2018</li> </ul>
<b>Areas covered</b>	<ul style="list-style-type: none"> <li>• Encouragement to raise concerns</li> </ul>
<b>Key findings</b>	<ul style="list-style-type: none"> <li>• 19% of young people aged 12-15 reported that having an advocate or third party who could raise concerns, would encourage them to express concerns about healthcare</li> </ul>

See the evidence summary in appendix N.

## Evidence from an expert witness

An expert witness (an independent advocate) provided additional evidence for this review.

See the evidence summary in appendix O.

There was no evidence available from a child or young person with experience of using advocacy services.

## **Economic evidence**

### **Included studies**

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

### **Excluded studies**

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

## **Summary of studies included in the economic evidence review**

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

## **Economic model**

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

## **The committee's discussion of the evidence**

### **Interpreting the evidence**

#### ***The outcomes that matter most***

This review focused on how babies, children and young people feel that their views and needs can be best represented by independent advocates. To adequately cover this issue, the review was designed to include qualitative data. Due to this, the committee could not specify in advance what data might be located in the literature but they did identify the following main themes in advance to guide the review:

- Access to records of healthcare staff discussions
- Adequate training for independent advocates including knowledge about developmentally-appropriate approaches
- Appeal to, or use of, advocacy groups
- Availability and accessibility of appropriate advocacy services
- Awareness of independent advocate services
- Encouraging and supporting self-advocacy when possible
- Sensitivity and responsiveness of independent advocate to feedback from child or young person
- Views on timing of support provided from the independent advocate, establishing views regarding where and when advocacy is beneficial, including continuity of support

No studies were identified in the literature for this review. However, the expert witness addressed most of the themes identified by the committee, except the use of developmentally-appropriate training and the use of advocacy groups.

### ***The quality of the evidence***

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

### ***Benefits and harms***

The committee were aware of the legal requirement for UK Councils to provide an independent advocate for any person under 18 who has been detained under the Mental Health Act 183, or for a looked after child or young person under the terms of the Care Act 2014 and the Mental Capacity Act 2005. Therefore, the committee made a recommendation to inform eligible children and young people that they could have an independent advocate to support them. However, access to independent advocates for children and young people who do not meet the criteria specified in these pieces of legislation depends on the local commissioning arrangements and, despite it not being a legal requirement, the committee were aware that independent advocates could provide invaluable support to babies, children or young people who did not have parents or carers or another professional who could adequately advocate for them. The committee also made a recommendation for commissioners to consider independent advocacy for a wider population of children and young people who would not be eligible under statutory provision, to protect their interests and wishes and to contribute towards a positive healthcare experience.

The testimony of the expert witness included information on the role of an independent advocate in the mental health setting, how children and young people are able to access them, and the independent nature of the role. The committee discussed that children and young people often are not aware of this service and do not know how an advocate could support them.. Therefore, the committee made a recommendation to ensure that children and young people are provided with this information. The committee agreed this information should also include the fact that an independent advocate is separate from their healthcare team, and any concerns they may raise will not affect their healthcare. If a child or young person decide that they would like to meet with an independent advocate, the committee made a recommendation that healthcare staff should support them.

The committee discussed that the period when an independent advocate might be needed can be a stressful time for children and young people. The expert witness described the importance of building a trusting relationship with children and young people, allowing a rapport to developed. Confidentiality is an important aspect of this trust, but the expert witness reported that the limits of this confidentiality (and when it will be broken) must also be explained. In order to best explain healthcare processes and translate medical language, independent advocates need to be familiar with medical terminology and with relevant healthcare systems. All these attributes are core to an independent advocate being able to support children and young people in their healthcare. Therefore, the committee made a recommendation describing the essential competencies of an independent advocate. Additionally, the expert witness and the committee discussed the importance of understanding the role of an independent advocate in empowering children and young people to make decisions, rather than making decisions on their behalf. This aspect of the role can sometimes be misconstrued by both healthcare staff and the public. Therefore, the committee made a recommendation clarifying this supportive role of the independent advocate.

The expert witness reported the use of feedback within the advocacy service. The committee discussed the importance of gaining views on service provision directly from children and young people, as there are aspects to paediatric independent advocacy that will not apply to adult advocacy and vice versa. Therefore, the committee made a recommendation to include a review process to make sure the advocacy service is good quality and is working well for children and young people.

In addition to the evidence from the expert witness, there was a limited amount of evidence presented from the grey literature review of national surveys and reference groups (age 11 to

14 years) on the meaning of and use of advocates. The committee agreed that the evidence from the reference group reinforced the testimony from the expert witness about the need to build trusting relationships with children and young people, and to empower them to make their healthcare decisions rather than having decisions made for them. The evidence from the national surveys showed that some young people may have found an advocate useful to help them to raise concerns about their healthcare.

The committee also discussed the potential harms of independent advocacy, most of which relate to the competency and experience of the independent advocate. One of these was the chance of information being presented to children and young people in either a misleading or misrepresentative manner, including what options are available to them. Both the expert witness and committee members with experience of independent advocates agreed that advocacy on behalf of children and young people required a different set of skills than advocating for adults. If a child was allocated an advocate experienced only in advocating for adults, this could be detrimental to the child or young person. Lack of time was also a potential area of harm, as independent advocates needed time to work with children and young people, and insufficient time may lead to sub-optimal advocacy.

All of these concerns might lead to poor representation of a child or young person's views or insensitivity when talking about past experiences. This will affect both the immediate consultation and perhaps affect the child or young person's views of independent advocates in the future.

As there was no evidence from the systematic review of the literature for this review the committee agreed that research was needed in this area and they made a research recommendation.

### **Cost effectiveness and resource use**

No economic studies were identified which were applicable to this review question. The committee discussed that there may be some resource implications associated with a wider cohort of children and young people having access to an independent advocate, but that the extension of the service suggested in their recommendations would only apply to children or young people who had no one else to support them (neither parent nor carer nor another professional such as a social worker) and so was not likely to include a very large number of children. The committee agreed that for the majority of children and young people who would require such service, it is already a legal requirement under the Mental Health Act 1983, the Care Act 2014 and the Mental Capacity Act 2005. The recommendations in this area may make more children and young people aware of such services and there may be a greater uptake of independent advocate services which may have a financial impact for the NHS. The committee also discussed that there may be some resource implications in terms of healthcare professionals' time in facilitating access to an independent advocate such as providing support in the initial contact and subsequent meetings. All the other 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 1.5.18 to 1.5.24 and the research recommendation on independent advocates.

### **References**

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

# Appendices

## Appendix A – Review protocol

**Review protocol for review question: How can the views of babies, children and young people be best represented by independent advocates?**

**Table 4: Review protocol**

Field	Content
PROSPERO registration number	CRD42019159564
Review title	Independent advocacy in healthcare for children and young people
Review question	How can the views of babies, children and young people be best represented by independent advocates?
Objective	The Care Act 2014 and Mental Health Act 1983/2007 place a duty on UK Councils to provide an independent advocate to a child or young person who has substantial difficulties being involved in their own healthcare and who may not have an appropriate person to represent them. The aim of this review is to establish what babies, children and young people find beneficial from having an independent advocate to support them. To help determine good practice for the advocate, in the view of babies, children and young people.
Searches	<p>The following databases will be searched:</p> <ul style="list-style-type: none"> <li>• CCTR</li> <li>• CDSR</li> <li>• Embase</li> <li>• MEDLINE</li> <li>• MEDLINE IN-Process</li> <li>• PsycINFO</li> </ul> <p>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.</p>

Field	Content
	<p>Searches will be restricted by:</p> <ul style="list-style-type: none"> <li>• Date: 2009</li> <li>• Language of publication: English language only</li> <li>• Publication status: Conference abstracts will be excluded because these do not typically provide sufficient information to fully assess risk of bias</li> <li>• Standard exclusions filter (animal studies/low level publication types) will be applied</li> </ul> <p>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</p>
Condition or domain being studied	<ul style="list-style-type: none"> <li>• Babies, children's and young people's experience of healthcare</li> </ul>
Population	<ul style="list-style-type: none"> <li>• People &lt;18 years-old who have experience of healthcare</li> <li>• 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               <ul style="list-style-type: none"> <li>○ The baby or child of the parent or carer is under-5 years-old, or</li> <li>○ 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.</li> </ul> </li> </ul> <p>Note: Studies where part of the population is &lt;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.</p>
Phenomenon of interest	<ul style="list-style-type: none"> <li>• Children's experience of independent advocates who have represented their views and interests in decisions about healthcare. For example, when a child or young person has been supported by an independent advocate did they feel more confident/involved in decisions about their healthcare? When was it helpful to the child or young person to have support from the advocate?</li> <li>• Children's views on what elements of advocacy they found beneficial, for example how did the child feel that the advocate represented their views? What did the advocate do which they found useful and supportive to their care?</li> </ul> <p>Note: An 'independent advocate' in this context is a person who helps the child or young person to find information relevant to a healthcare decision and to support them in making and communicating healthcare decisions, or who is empowered to speak on the child or young person's behalf when they cannot do so themselves.</p>
Comparator/Reference standard/Confounding factors	Not applicable

Field	Content
Types of study to be included	<ul style="list-style-type: none"> <li>• Systematic reviews of qualitative studies</li> <li>• Studies using qualitative methods: focus groups, semi-structured and structured interviews, observations</li> <li>• Surveys conducted using open ended questions and a qualitative analysis of responses</li> </ul> <p>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.</p>
Other exclusion criteria	<p><b>STUDY DESIGN</b></p> <ul style="list-style-type: none"> <li>• Studies using quantitative methods only (including surveys that report only quantitative data)</li> <li>• Surveys using mainly closed questions or which quantify open ended answers for analysis</li> </ul> <p><b>TOPIC OF STUDY</b></p> <p>Studies on the following topics will also be excluded:</p> <ul style="list-style-type: none"> <li>• Experience of independent advocates whilst child or young person is receiving non-NHS commissioned health promotion interventions</li> <li>• Non-NHS commissioned health promotion interventions</li> <li>• UK Law and legal protections relating to independent advocacy for babies, children and young people. This will include (but will not be limited to) Care Act 2014, Mental Capacity Act 2005, and Child Abuse and Prevention Act 1974</li> <li>• Views and experiences of healthcare professionals and service managers</li> <li>• Views and experiences of people reporting on shared decision making in the context of social care planning. Where a study covers both health and social care advocacy, the study will be excluded unless there are clear and relevant responses relating to support received within the healthcare system independent from the views on social care advocacy.</li> </ul> <p>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:</p> <ul style="list-style-type: none"> <li>• Child abuse and maltreatment: <ul style="list-style-type: none"> <li>○ Child abuse and neglect (NG76)</li> <li>○ Child maltreatment: when to suspect maltreatment in under 18s (CG89)</li> </ul> </li> <li>• Community engagement <ul style="list-style-type: none"> <li>○ Community engagement (NG44)</li> </ul> </li> </ul>

Field	Content
	<ul style="list-style-type: none"> <li>• Drug misuse in children and young people: <ul style="list-style-type: none"> <li>○ Alcohol: school-based interventions (PH7)</li> <li>○ Alcohol-use disorders: diagnosis, assessment and management of harmful drinking and alcohol dependence (CG115)</li> <li>○ Alcohol-use disorders: prevention (PH24)</li> <li>○ Drug misuse prevention: targeted interventions (NG64)</li> </ul> </li> <li>• End of life care for infants, children and young people with life-limiting conditions: planning and management (NG61)</li> <li>• Immunisations: reducing differences in uptake in under 19s (PH21)</li> <li>• Oral health promotion: general dental practice (NG30)</li> <li>• Physical activity and weight management: <ul style="list-style-type: none"> <li>○ Maternal and child nutrition (PH11)</li> <li>○ Obesity prevention (CG43)</li> <li>○ Physical activity for children and young people (PH17)</li> <li>○ Weight management: lifestyle services for overweight or obese children and young people (PH47)</li> </ul> </li> <li>• Pregnancy, including routine antenatal, intrapartum or postnatal care: <ul style="list-style-type: none"> <li>○ Antenatal and postnatal mental health: clinical management and service guidance (CG192)</li> <li>○ Antenatal care for uncomplicated pregnancies (CG62)</li> <li>○ Intrapartum care for healthy women and babies (CG190)</li> <li>○ Intrapartum care for women with existing medical conditions or obstetric complications and their babies (NG121)</li> <li>○ Multiple pregnancy: antenatal care for twin and triplet pregnancies (CG129)</li> <li>○ Postnatal care up to 8 weeks after birth (CG37)</li> <li>○ Pregnancy and complex social factors: a model for service provision for pregnant women with complex social factors (CG110)</li> </ul> </li> <li>• Self-harm: <ul style="list-style-type: none"> <li>○ Self-harm in over 8s: long-term management (CG133)</li> <li>○ Self-harm in over 8s: short-term management and prevention of recurrence (CG16)</li> </ul> </li> <li>• Sexual health and contraception <ul style="list-style-type: none"> <li>○ Contraceptive services for under 25s (PH51)</li> <li>○ Sexually transmitted infections and under-18 conceptions: prevention (PH3)</li> <li>○ Harmful sexual behaviour among children and young people (NG55)</li> </ul> </li> <li>• Smoking prevention: <ul style="list-style-type: none"> <li>○ Smoking: preventing uptake in children and young people (PH14)</li> </ul> </li> </ul>

Field	Content
	<ul style="list-style-type: none"> <li>○ Smoking prevention in schools (PH23)</li> <li>○ Stop smoking interventions and services (NG92)</li> <li>● Transition from children's to adults services for young people using health or social care services (NG43)</li> </ul>
Context	<p>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.</p>
Primary outcomes (critical outcomes)	<p>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):</p> <ul style="list-style-type: none"> <li>● Access to records of healthcare staff discussions</li> <li>● Adequate training for independent advocates including knowledge about developmentally-appropriate approaches</li> <li>● Appeal to, or use of, advocacy groups</li> <li>● Availability and accessibility of appropriate advocacy services (e.g. drop-in centres, ease of referral to advocacy services, mental health advocacy)</li> <li>● Awareness of independent advocate services</li> <li>● Encouraging and supporting self-advocacy when possible</li> <li>● Sensitivity and responsiveness of independent advocate to feedback from child or young person</li> <li>● Views on timing of support provided from the independent advocate, establishing views regarding where and when advocacy is beneficial, including continuity of support</li> </ul>
Secondary outcomes (important outcomes)	Not applicable

Field	Content
Data extraction (selection and coding)	<ul style="list-style-type: none"> <li>• 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.</li> <li>• 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.</li> </ul>
Risk of bias (quality) assessment	<p>Risk of bias of individual qualitative studies will be assessed using the CASP Qualitative checklist. Risk of bias of systematic reviews of Qualitative studies will be assessed using the CASP (Critical Skills Appraisal Programme) Systematic Review checklist. See Appendix H in <a href="#">Developing NICE guidelines: the manual</a> for further details. The quality assessment will be performed by one reviewer and this will be quality assessed by a senior reviewer.</p>
Strategy for data synthesis	<ul style="list-style-type: none"> <li>• Extracted second-order study themes and related first-order quotes will be synthesised by the reviewer into third-order themes and related sub-themes.</li> <li>• The GRADE-CERQual (Confidence in the Evidence from Reviews of Qualitative research; Lewin 2015) approach will be used to summarise the confidence in the third-order themes or sub-themes synthesized from the qualitative evidence. The overall confidence in evidence about each theme or sub-theme will be rated on four dimensions: methodological limitations, coherence, adequacy, and relevance.</li> <li>• Methodological limitations refer to the extent to which there were problems in the design or conduct of the studies and will be assessed with the CASP checklist for qualitative studies or systematic reviews as appropriate. Coherence of findings will be assessed by examining the clarity of the data. Adequacy of data will be assessed by looking at the degree of richness and quantity of findings. Relevance of evidence will be assessed by determining the extent to which the body of evidence from the primary studies are applicable to the context of the review question with respect to the characteristics of the study population, setting, place and time, healthcare system, intervention, and broader social, policy, or political issues.</li> </ul>
Analysis of sub-groups	<p>If there is sufficient data, views and experiences will be analysed separately by the following age ranges:</p> <ul style="list-style-type: none"> <li>• &lt;1 year-old (i.e. 364 days-old or less)</li> <li>• ≥1 to &lt;12 years-old (i.e. 365 days-old to 11 years and 364 days-old)</li> <li>• ≥12 to &lt;18 years-old (i.e. 12 years and 0 days-old to 17 years and 364 days-old)</li> </ul> <p>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</p>

Field	Content		
	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. Of particular relevance to this question will be the differing views of those living in care		
Type and method of review	<input type="checkbox"/>	Intervention	
	<input type="checkbox"/>	Diagnostic	
	<input type="checkbox"/>	Prognostic	
	<input checked="" type="checkbox"/>	Qualitative	
	<input type="checkbox"/>	Epidemiologic	
	<input type="checkbox"/>	Service Delivery	
	<input type="checkbox"/>	Other (please specify)	
Language	English		
Country	England		
Anticipated or actual start date			
Anticipated completion date	07/04/2021		
Stage of review at time of this submission	Review stage	Started	Completed
	Preliminary searches		<input checked="" type="checkbox"/>
	Piloting of the study selection process		<input checked="" type="checkbox"/>
	Formal screening of search results against eligibility criteria		<input checked="" type="checkbox"/>
	Data extraction		<input checked="" type="checkbox"/>
	Risk of bias (quality) assessment		<input checked="" type="checkbox"/>
	Data analysis		<input checked="" type="checkbox"/>
Named contact	<b>5a. Named contact</b> National Guideline Alliance <b>5b. Named contact e-mail</b> infant&younghealth@nice.org.uk <b>5c. Organisational affiliation of the review</b>		

Field	Content	
	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 <a href="#">Developing NICE guidelines: the manual</a> . Members of the guideline committee are available on the NICE website: <a href="https://www.nice.org.uk/guidance/indevelopment/gid-ng10119/documents">https://www.nice.org.uk/guidance/indevelopment/gid-ng10119/documents</a>	
Other registration details	-	
Reference/URL for published protocol	<a href="https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42019159564">https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42019159564</a>	
Dissemination plans	<p>NICE may use a range of different methods to raise awareness of the guideline. These include standard approaches such as:</p> <ul style="list-style-type: none"> <li>• notifying registered stakeholders of publication</li> <li>• publicising the guideline through NICE's newsletter and alerts</li> <li>• 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.</li> </ul>	
Keywords	Advocacy; advocacy groups; babies; children; experience; healthcare; independent advocacy; independent advocate; young people.	
Details of existing review of same topic by same authors	Not applicable	
Current review status	<input checked="" type="checkbox"/>	Ongoing
	<input type="checkbox"/>	Completed but not published
	<input type="checkbox"/>	Completed and published
	<input type="checkbox"/>	Completed, published and being updated

Field	Content	
	<input type="checkbox"/>	Discontinued
Additional information		
Details of final publication	<a href="http://www.nice.org.uk">www.nice.org.uk</a>	

*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 the views of babies, children and young people be best represented by independent advocates?

Databases: Embase/Medline/PsycINFO

Date searched: 29/07/2020

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

#	Searches
27	general practice*.tw.
28	(health* and (nursery or nurseries or school*)).tw.
29	(respite adj2 care).tw.
30	(foster care or "looked after children" or "children in care").tw.
31	or/11-30
32	(Experience/ or personal experience/ or attitude to health/ or patient attitude/ or patient preference/ or patient satisfaction/) use emez
33	(attitude to death/ or patient advocacy/ or consumer advocacy/ or professional-patient relationship/) use emez
34	(adverse childhood experience/ or exp attitude to health/ or exp Patient satisfaction/) use ppez
35	(exp Consumer Participation/ or "Patient Acceptance of Health Care"/ or *exp consumer satisfaction/ or patient preference/ or Attitude to Death/ or health knowledge, attitudes, practice/ or Patient Advocacy/ or consumer advocacy/ or narration/ or focus groups/ or Patient-Centered Care/ or exp Professional-Patient Relations/) use ppez
36	(exp Client Attitudes/ or exp Client Satisfaction/ or exp Attitudes/ or exp Health Attitudes/ or exp Preferences/ or exp Client Satisfaction/ or exp Death Attitudes/ or exp Advocacy/ or exp Preferences/ or client centered therapy/) use psych
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 psych
50	interview*.tw.
51	thematic analysis/ use emez
52	(theme\$ or thematic).mp.
53	qualitative.af.
54	questionnaire\$.mp.
55	ethnological research.mp.
56	ethnograph\$.mp.
57	ethnonursing.af.
58	phenomenol\$.af.
59	(life stor\$ or women* stor\$.mp.
60	(grounded adj (theor\$ or study or studies or research or analys?s)).af.
61	((data adj1 saturat\$) or participant observ\$).tw.
62	(field adj (study or studies or research)).tw.
63	biographical method.tw.
64	theoretical samp\$.af.
65	((purpos\$ adj4 samp\$) or (focus adj group\$)).af.
66	open ended questionnaire/ use emez
67	(account or accounts or unstructured or openended or open ended or text\$ or narrative\$.mp.
68	(life world or life-world or conversation analys?s or personal experience\$ or theoretical saturation).mp.
69	((lived or life) adj experience\$.mp.
70	narrative analys?s.af.
71	or/46-70
72	45 and 71
73	limit 72 to (yr="2009 - current" and english language)
74	exp United Kingdom/
75	(national health service* or nhs*).ti,ab,in,ad,cq.

#	Searches
76	(english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab.
77	(gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*).ti,ab,jx,in,ad,cq.
78	(bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worchester not (massachusetts* or boston* or harvard*)) or ("worchester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york**" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york**" or ny or ontario* or ont or toronto*))))).ti,ab,in,ad,cq.
79	(bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's").ti,ab,in,ad,cq.
80	(aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's").ti,ab,in,ad,cq.
81	(armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's").ti,ab,in,ad,cq.
82	or/74-81
83	((exp africa/ or exp americas/ or exp antarctic regions/ or exp arctic regions/ or exp asia/ or exp oceania/) not (exp united kingdom/ or europe/)) use ppez
84	((exp "arctic and antarctic"/ or exp oceanic regions/ or exp western hemisphere/ or exp africa/ or exp asia/ or exp "australia and new zealand"/) not (exp united kingdom/ or europe/)) use emez
85	83 or 84
86	82 not 85
87	73 and 86
88	Letter/ use ppez
89	letter.pt. or letter/ use emez
90	note.pt.
91	editorial.pt.
92	Editorial/ use ppez
93	News/ use ppez
94	news media/ use psyh
95	exp Historical Article/ use ppez
96	Anecdotes as Topic/ use ppez
97	Comment/ use ppez
98	Case Report/ use ppez
99	case report/ or case study/ use emez
100	Case report/ use psyh
101	(letter or comment*).ti.
102	or/88-101
103	randomized controlled trial/ use ppez
104	randomized controlled trial/ use emez
105	random*.ti,ab.
106	cohort studies/ use ppez
107	cohort analysis/ use emez
108	cohort analysis/ use psyh
109	case-control studies/ use ppez
110	case control study/ use emez
111	or/103-110
112	102 not 111

#	Searches
113	animals/ not humans/ use ppez
114	animal/ not human/ use emez
115	nonhuman/ use emez
116	"primates (nonhuman)"/
117	exp Animals, Laboratory/ use ppez
118	exp Animal Experimentation/ use ppez
119	exp Animal Experiment/ use emez
120	exp Experimental Animal/ use emez
121	animal research/ use psych
122	exp Models, Animal/ use ppez
123	animal model/ use emez
124	animal models/ use psych
125	exp Rodentia/ use ppez
126	exp Rodent/ use emez
127	rodents/ use psych
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 psychlit 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 psychlit 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 psych
153	150 or 151 or 152
154	73 and 153
155	154 not 130
156	155 not 129

### Database: Cochrane Library

Date searched: 29/07/2020

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

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

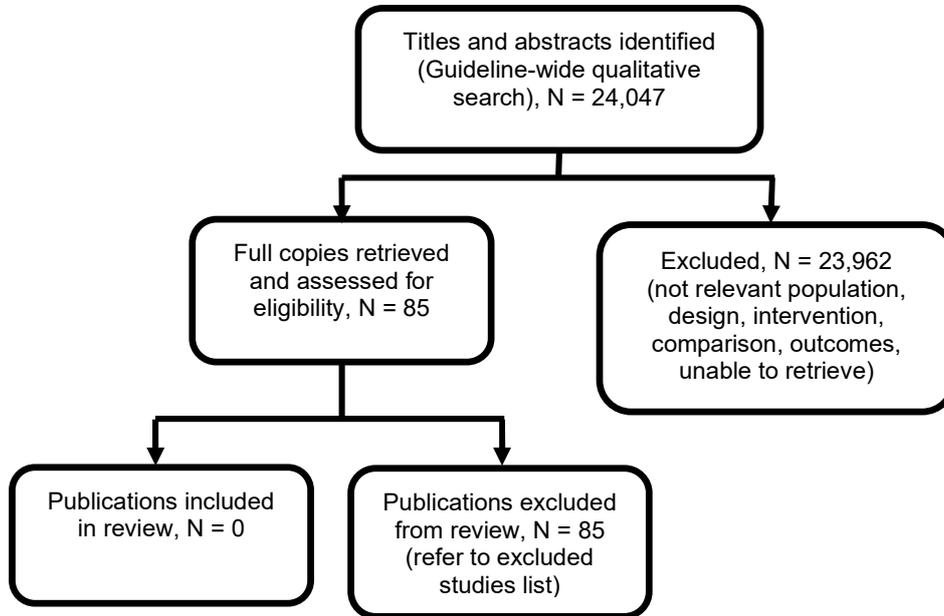
#	Search
58	(health* near/3 (care or center* or centre* or clinic* or facility or facilities or service* or setting* or specialist*)):ti,ab,kw
59	((dental or communit* or emergency or hospital* or home or intensive or high-dependen* or mental* or primary or secondary or tertiary) near/3 (care or health*)):ti,ab,kw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

#	Search
105	((data near/1 saturat*) or participant observ*):ti,ab,kw
106	(field near (study or studies or research)):ti,ab,kw
107	(biographical method):ti,ab,kw
108	(theoretical sampl*):ti,ab,kw
109	((purpos* near/4 samp** or (focus near group*)):ti,ab,kw
110	(account or accounts or unstructured or openended or open ended or text* or narrative*):ti,ab,kw
111	(life world or life-world or conversation analys*s or personal experience* or theoretical saturation):ti,ab,kw
112	((lived or life) near experience*):ti,ab,kw
113	(narrative analys*s):ti,ab,kw
114	#93 OR #94 OR #95 OR #96 OR #97 OR #98 OR #99 OR #100 OR #101 OR #102 OR #103 OR #104 OR #105 OR #106 OR #107 OR #108 OR #109 OR #110 OR #111 OR #112 OR #113
115	#11 AND #71 AND #92 AND #114 with Cochrane Library publication date Between Jan 2009 and Aug 2020
116	MeSH descriptor: [United Kingdom] explode all trees
117	(national health service* or nhs*):ti,ab,kw
118	(english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) near/5 english)):ti,ab,kw
119	(gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*):ti,ab,kw
120	(gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*):so
121	(bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worchester not (massachusetts* or boston* or harvard*)) or ("worchester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))):ti,ab,kw
122	(bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's"):ti,ab,kw
123	(aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's"):ti,ab,kw
124	armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's":ti,ab,kw
125	#116 OR #117 OR #118 OR #119 OR #120 OR #121 OR #122 OR #123 OR #124
126	MeSH descriptor: [Africa] explode all trees
127	MeSH descriptor: [Americas] explode all trees
128	MeSH descriptor: [Antarctic Regions] explode all trees
129	MeSH descriptor: [Arctic Regions] explode all trees
130	MeSH descriptor: [Asia] explode all trees
131	MeSH descriptor: [Oceania] explode all trees
132	#126 OR #127 OR #128 OR #129 OR #130 OR #131
133	MeSH descriptor: [United Kingdom] explode all trees
134	MeSH descriptor: [Europe] this term only
135	#133 OR #134
136	#132 not #135
137	#125 not #136
138	#115 AND #137 with Cochrane Library publication date Between Jan 2009 and Aug 2020

## Appendix C – Clinical evidence study selection

**Study selection for: How can the views of babies, children and young people be best represented by independent advocates?**

**Figure 1: Study selection flow chart**



## **Appendix D – Clinical evidence tables**

### **Evidence tables for review question: How can the views of babies, children and young people be best represented by independent advocates?**

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

## **Appendix E – Forest plots**

### **Forest plots for review question: How can the views of babies, children and young people be best represented by independent advocates?**

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 the views of babies, children and young people be best represented by independent advocates?**

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

## **Appendix G – Economic evidence study selection**

**Economic evidence study selection for review question: How can the views of babies, children and young people be best represented by independent advocates?**

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 the views of babies, children and young people be best represented by independent advocates?**

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

## **Appendix I – Economic evidence profiles**

**Economic evidence profiles for review question: How can the views of babies, children and young people be best represented by independent advocates?**

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

## **Appendix J – Economic analysis**

### **Economic evidence analysis for review question: How can the views of babies, children and young people be best represented by independent advocates?**

No economic analysis was conducted for this review question.

## Appendix K – Excluded studies

### Excluded studies for review question: How can the views of babies, children and young people be best represented by independent advocates?

#### Clinical studies:

**Table 5: 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, <i>Journal of nursing management</i> , 22, 177-191, 2014	Population of included studies not in protocol. Included studies checked for possible inclusion
Abbott, M., Bernard, P., Forge, J., Communicating a diagnosis of Autism Spectrum Disorder - a qualitative study of parents' experiences, <i>Clinical Child Psychology and Psychiatry</i> , 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, <i>Neuropsychiatrie de l'Enfance et de l'Adolescence</i> , 1), S294, 2012	Conference abstract
Actrn,, Improving outcomes in mental health for children and families: a study of Enhanced Stepping Stones Triple P, <a href="http://www.who.int/trialssearch/trial2.aspx?Trialid=actrn12618000981224">Http://www.who.int/trialssearch/trial2.aspx?Trialid=actrn12618000981224</a> , 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, <i>International Journal of Consumer Studies</i> , 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, <i>Health Expectations</i> , 30, 30, 2018	Phenomenon of interest not in protocol - No themes relating to advocacy and support in healthcare
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, <i>Health expectations : an international journal of public participation in health care and health policy.</i> , 21, 2019	Phenomenon of interest not in protocol - No themes relating to independent advocacy
Alexander, S., Bath, L., McDonald, M., Adolescent diabetic outpatient clinics-more than just an HbA1c, <i>Archives of disease in childhood</i> , 101 (Supplement 1), A275-A277, 2016	Conference abstract
Allcock, D., Smith, K., Exploring parent views of community matrons, <i>Nursing Times</i> , 110, 21-23, 2014	Outcomes not in protocol - No qualitative data analysis performed
Allen, D., Scarinci, N., Hickson, L., The Nature of Patient- and Family-Centred Care for Young Adults Living with Chronic Disease and their Family Members: A Systematic Review, <i>International Journal of Integrated Care [Electronic Resource]</i> <i>Int J Integr Care</i> , 18, 14, 2018	Population of included studies not in protocol. Included studies checked for possible included studies.
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, <i>Developmental medicine and child neurology</i> , 59 (Supplement 4), 76, 2017	Conference abstract

Study	Reason for exclusion
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 possible included studies.
Antao, V., Evaluation of post-diagnostic support to families and children with autism spectrum disorder, Developmental medicine and child neurology, 4), 69, 2010	Conference abstract
Aranda, K., Coleman, L., Sherriff, N. S., Cocking, C., Zeeman, L., Cunningham, L., Listening for commissioning: A participatory study exploring young people's experiences, views and preferences of school-based sexual health and school nursing, Journal of Clinical Nursing, 27, 375-385, 2018	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, Loyal Pediatric HealthGlob, 6, 2333794X19828745, 2019	Study design not in protocol - Narrative review.
Armitage, S., Swallow, V., Kolehmainen, N., Ingredients and change processes in occupational therapy for children: a grounded theory study, Scandinavian journal of occupational therapy, 24, 208-213, 2017	Population and outcomes not in protocol - Any themes relating to advocacy and support were from parents of children aged 7-11.
Armstrong, V. G., Howatson, R., Parent-infant art psychotherapy: A creative dyadic approach to early intervention, Infant mental health journal, 36, 213-222, 2015	Study design not in protocol - No qualitative data analysis presented
Ashcraft, L. E., Asato, M., Houtrow, A. J., Kavalieratos, D., Miller, E., Ray, K. N., Parent Empowerment in Pediatric Healthcare Settings: A Systematic Review of Observational Studies, Patient, 12, 199-212, 2019	Phenomenon of interest of included studies not in protocol. Included studies checked for possible included studies
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
Astbury, R., Shepherd, A., Cheyne, H., Working in partnership: the application of shared decision-making to health visitor practice, Journal of Clinical Nursing, 26, 215-224, 2017	Phenomenon of interest not in protocol - No themes relating to independent advocacy
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 possible included studies

Study	Reason for exclusion
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, <i>Journal of Public Health</i> , 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, <i>Literacy</i> , 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, <i>Archives of disease in childhood</i> , 102 (Supplement 1), A20, 2017	Conference abstract
Davies, Karen E., Marshall, Julie, Brown, Laura J., Goldbart, Juliet, Co-working: Parents' conception of roles in supporting their children's speech and language development, <i>Child Language Teaching and Therapy</i> , 33, 171-185, 2017	Phenomenon of interest not in protocol - No themes relating to independent advocacy
Davison, Jo, Zamperoni, Victoria, Stain, Helen J., Vulnerable young people's experiences of child and adolescent mental health services, <i>Mental Health Review Journal</i> , 22, 95-110, 2017	Phenomenon of interest not in protocol - No themes relating to independent advocacy
Dawson, A., Jackson, D., The primary health care service experiences and needs of homeless youth: a narrative synthesis of current evidence, <i>Contemporary nurse</i> , 44, 62-75, 2013	Phenomenon of interest of included studies not in protocol. Included studies checked for possible included studies
Dublon, V. E., Green, S., Benitez-Castillo, M., Edwards, T., Leiva, A., The production of a diabetes information film, by young people who have diabetes, as a means of educating others, <i>Archives of disease in childhood</i> , 103 (Supplement 1), A166, 2018	Conference abstract
Dunn, V., O'Keeffe, S., Stapley, E., Midgley, N., Facing Shadows: working with young people to coproduce a short film about depression, <i>Research Involvement &amp; Engagement</i> , 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, <i>Seizure</i> , 71, 279-285, 2019	Population of included studies not in protocol. Included studies checked for possible included studies
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, <i>Qualitative health research</i> , 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, <i>JMIR MHealth and UHealth</i> , 7, e11677, 2019	Phenomenon of interest not in protocol - No themes relating to independent advocacy
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, <i>BMC pediatrics</i> , 14 (1) (no pagination), 2014	Phenomenon of interest of included studies not in protocol. Included studies checked for possible included studies
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	Population not in protocol – Adults > 18 years old

Study	Reason for exclusion
the self-management of long-term health conditions, <i>Social Science and Medicine</i> , 176, 25-33, 2017	
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, <i>Child &amp; Family Social Work</i> , 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, <i>Psycho-Oncology</i> , 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, <i>JBIC Database of Systematic Reviews and Implementation Reports</i> , 17, 793-984, 2019	Phenomenon of interest of included studies not in protocol. Included studies checked for possible included studies
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, <i>Journal of Family Nursing</i> , 19, 431-468, 2013	Population of included studies not in protocol. Included studies checked for possible included studies
Franck, L. S., Oulton, K., Bruce, E., Parental involvement in neonatal pain management: an empirical and conceptual update, <i>J Nurs Scholarsh</i> , 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, <i>Worldviews on evidence-based nursing / Sigma Theta Tau International, Honor Society of Nursing</i> , 11, 369-375, 2014	Population of included studies not in protocol. Included studies checked for possible included studies
Grealish, A., Tai, S., Hunter, A., Morrison, A. P., Qualitative exploration of empowerment from the perspective of young people with psychosis, <i>Clinical Psychology &amp; Psychotherapy</i> , 20, 136-148, 2013	Phenomenon of interest not in protocol - No themes relating to independent advocacy
Harper, B., Dickson, J. M., Bramwell, R., Experiences of young people in a 16-18 Mental Health Service, <i>Child and Adolescent Mental Health</i> , 19, 90-96, 2014	Phenomenon of interest not in protocol - No themes relating to independent advocacy
Holley, S., Walker, D., Knibb, R., Latter, S., Lioffi, 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, <i>Clinical and experimental allergy</i> , 48, 944-956, 2018	Phenomenon of interest not in protocol - No themes relating to independent advocacy
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, <i>Clinical child psychology and psychiatry</i> , 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, <i>Clinical Child Psychology and Psychiatry</i> , 22, 170-186, 2017	Study design not in protocol - No qualitative data presented. Secondary analysis of goal themes devised by children to build framework for outcomes measurements

Study	Reason for exclusion
Kohut, Sara Ahola, Stinson, Jennifer, van Wyk, Margaret, Giosa, Lidia, Luca, Stephanie, Systematic review of peer support interventions for adolescents with chronic illness, <i>International Journal of Child and Adolescent Health</i> , 7, 183-197, 2014	Study design of included studies not in protocol. Included studies checked for possible included studies
Larkin, M., Boden, Z. V., Newton, E., On the Brink of Genuinely Collaborative Care: Experience-Based Co-Design in Mental Health, <i>Qualitative health research</i> , 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, <i>Adolescent Health, Medicine and Therapeutics</i> , 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, <i>Journal of Adolescence</i> , 72, 152-161, 2019	Phenomenon of interest not in protocol - No themes relating to independent advocacy
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, <i>Psychiatric Services</i> , 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, <i>Journal of pediatric nursing</i> , 30, 54- 62, 2015	Phenomenon of interest not in protocol - No themes relating to independent advocacy
Macdonald, K., Greggans, A., 'Cool friends': an evaluation of a community befriending programme for young people with cystic fibrosis, <i>Journal of Clinical Nursing</i> , 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, <i>International journal of behavioral medicine</i> , 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, <i>Journal of Mental Health</i> , 2020	Narrative review. Included studies checked for possible included studies
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, <i>BMJ open</i> , 9 (4) (no pagination), 2019	Population of included studies not in protocol. Included studies checked for possible included studies
Mehmood, A., Cammidge, S., Guy, E., Peckham, D., Duff, A., Evaluation of youth work support for teenagers and young adults with cystic fibrosis, <i>Journal of Cystic Fibrosis</i> , 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, <i>Children and Youth Services Review</i> , 34, 1560-1569, 2012	Phenomenon of interest not in protocol - No themes relating to independent advocacy
Neill, S. J., Jones, C. H., Lakhanpaul, M., Roland, D. T., Thompson, M. J., Parents' help-seeking behaviours during	Parental views of under 5's but poor proxy. Themes are developed around

Study	Reason for exclusion
acute childhood illness at home: A contribution to explanatory theory, <i>Journal of child health care : for professionals working with children in the hospital and community</i> , 20, 77-86, 2016	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, <i>Journal of medical Internet research</i> , 19, e235, 2017	Phenomenon of interest not in protocol - No themes relating to independent advocacy
O'Neill, T., Wakefield, J., Fifteen-minute consultation in the normal child: Challenges relating to sexuality and gender identity in children and young people, <i>Archives of Disease in Childhood: Education and Practice Edition</i> , 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?, <i>Archives of disease in childhood</i> , 3), A84-A85, 2015	Conference abstract
Petrie, K., McArdle, A., Cookson, J., Powell, E., Poblete, X., 'Let us speak'-children's opinions of doctors, <i>Archives of Disease in Childhood</i> , 102 (Supplement 1), A200-A201, 2017	Conference abstract
Pini, S., Education mentoring for teenagers and young adults with cancer, <i>British journal of nursing (Mark Allen Publishing)</i> , 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, <i>Journal of psychiatric and mental health nursing</i> , 2020	Population of included studies not in protocol. Included studies checked for possible included studies
Robards, F., Kang, M., Usherwood, T., Sancu, L., How Marginalized Young People Access, Engage With, and Navigate Health-Care Systems in the Digital Age: Systematic Review, <i>Journal of Adolescent Health</i> , 365-381, 2018	Phenomenon of interest not in protocol - No themes relating to independent advocacy
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, <i>British Journal of Learning Disabilities</i> , 43, 168-177, 2015	Country: Canada
Robinson, S., Children and young people's views of health professionals in England, <i>Journal of child health care : for professionals working with children in the hospital and community</i> , 14, 310-326, 2010	Phenomenon of interest not in protocol - No themes relating to independent advocacy
Rodrigues, S., Melchionda, V., Rodney, K., Coppens, K., Comparing children's and parents' perspectives on hospital care, <i>Archives of disease in childhood</i> , 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, <i>International journal of nursing studies</i> , 109, 103658, 2020	Phenomenon of interest of included studies not in protocol. Included studies checked for possible included studies
Scholefield, B., Gosney, J., Callens, C., Duncan, H., Morris, K., Draper, H., Consultation with children regarding	Conference abstract

Study	Reason for exclusion
deferred consent in emergency care research, <i>Pediatric critical care medicine</i> , 1), A44, 2011	
Scott, E., Dale, J., Russell, R., Wolke, D., Young people who are being bullied - do they want general practice support?, <i>BMC family practice</i> , 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), <i>Clinical child psychology and psychiatry</i> , 21, 3-18, 2016	Phenomenon of interest not in protocol - No themes relating to advocacy or support for healthcare
Stenberg, U., Haaland-Overby, M., Koricho, A. T., Trollvik, A., Kristoffersen, L. G. R., Dybvig, S., Vagan, A., How can we support children, adolescents and young adults in managing chronic health challenges? A scoping review on the effects of patient education interventions, <i>Health expectations : an international journal of public participation in health care and health policy</i> , 2019	Scoping review. Included studies checked for possible included studies
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, <i>BMC endocrine disorders</i> , 11 (no pagination), 2011	No qualitative data presented. Included studies checked for possible included studies
Taylor, S., Haase-Casanovas, S., Weaver, T., Kidd, J., Garralda, E. M., Child involvement in the paediatric consultation: a qualitative study of children and carers' views, <i>Child: care, health and development</i> , 36, 678-685, 2010	Phenomenon of interest not in protocol - No themes relating to independent advocacy
Troy, E., Doltani, D., Harmon, D., The role of a companion attending consultations with the patient. A systematic review, <i>Irish Journal of Medical Science</i> , 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, <i>Journal of Genetic Counseling</i> , 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, <i>Cochrane Database of Systematic Reviews</i> , 2019, 2019	Population of included studies not in protocol. Included studies checked for possible included studies
Vasey, J., Smith, J., Kirschbaum, M., Chirema, K., Tokenism or true partnership: Parental involvement in the child's acute pain care, <i>Archives of disease in childhood</i> , 101 (Supplement 1), A189, 2016	Conference abstract
Walsh, J., Scaife, V., Notley, C., Dodsworth, J., Schofield, G., Perception of need and barriers to access: The mental health needs of young people attending a Youth Offending Team in the UK, <i>Health and Social Care in the Community</i> , 19, 420-428, 2011	Phenomenon of interest not in protocol - No themes relating to independent advocacy
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, <i>JBI Database of Systematic Reviews and Implementation Reports</i> , 12, 204-283, 2014	Population of included studies not in protocol. Included studies checked for possible included studies

<b>Study</b>	<b>Reason for exclusion</b>
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 possible included studies

### **Economic studies**

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

## Appendix L – Research recommendations

### Research recommendations for review question: How can the views of babies, children and young people be best represented by independent advocates?

#### Research question

How can the views of babies, children and young people be best represented by independent advocates?

#### Why this is important

The involvement of children and young people in decisions about their healthcare can help to optimise their experience of healthcare, but there may be children who are unable to advocate for themselves or do not have parents or carers to support them. For these children and young people, support can be provided by independent advocates. However, the literature review to determine how children and young people can be best represented by independent advocates did not yield any evidence. Understanding how children and young people can be best represented by independent advocates is important to enable them to have an opportunity to express themselves and empowerment to make decisions.

**Table 6: Research recommendation rationale**

<b>Research question</b>	
<b>Why is this needed</b>	
<b>Importance to ‘patients’ or the population</b>	Children and young people who have difficulty advocating for themselves may find the support of an independent advocate very helpful to improve their experience of healthcare.
<b>Relevance to NICE guidance</b>	High. The use of independent advocates in healthcare was a topic identified as important by stakeholders during scoping for this guideline.
<b>Relevance to the NHS</b>	The relevance to the NHS is high, because improving support to children and young people has the potential to improve their experience of healthcare, quality of life, engagement with services, and thus potentially outcomes
<b>National priorities</b>	The National Service Framework for children, young people and maternity services aims for long-term and sustained improvement in children’s health, and sets standards for health and social care services for children, young people and pregnant women.
<b>Current evidence base</b>	No evidence was identified for this review question.
<b>Equality</b>	Children and young people who do not have parents or carers to support them, such as unaccompanied asylum seekers or care-leavers, and those with communication difficulties or learning disabilities may have particular need for independent advocacy services and so this topic is of particular concern to ensure equality in healthcare provision.
<b>Feasibility</b>	This study would need to encompass the use of independent advocacy in a range of healthcare settings, and would need to access children and young people in all these settings.

**Table 7: Research recommendation modified PICO table**

<b>Criterion</b>	<b>Explanation</b>
<b>Population</b>	<ul style="list-style-type: none"> <li>• People &lt;18 years-old who have experience of healthcare</li> <li>• 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               <ul style="list-style-type: none"> <li>○ The baby or child of the parent or carer is under 5 years, or</li> <li>○ There is a clear rationale provided as to why the study is using parents' or carers' view</li> </ul> </li> </ul>
<b>Phenomena of interest</b>	Experience of healthcare, in particular how babies, children and young people feel they can be represented by independent advocates
<b>Context</b>	<p>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):</p> <ul style="list-style-type: none"> <li>• Access to records of healthcare staff discussions</li> <li>• Adequate training for independent advocates including knowledge about developmentally-appropriate approaches</li> <li>• Appeal to, or use of, advocacy groups</li> <li>• Availability and accessibility of appropriate advocacy services</li> <li>• Awareness of independent advocate services</li> <li>• Encouraging and supporting self-advocacy when possible</li> <li>• Sensitivity and responsiveness of independent advocate to feedback from child or young person</li> <li>• Views on timing of support provided from the independent advocate, establishing views regarding where and when advocacy is beneficial, including continuity of support</li> </ul>
<b>Study design</b>	Qualitative – using semi-structured interviews or focus groups
<b>Timeframe</b>	1 year
<b>Additional information</b>	Consider preferences in a variety of healthcare settings, and for mental health and physical health

*Insert abbreviations*

## Appendix M – Evidence from reference groups and focus groups

### Reference group and focus group evidence for review question: How can the views of babies, children and young people be best represented by independent advocates?

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

**Table 8: Evidence from focus groups and reference groups**

Age <7 years	Age 7-11 years	Age 11-14 years	Overall quality of the evidence
<ul style="list-style-type: none"> <li>• There was no evidence from this group for this question</li> </ul>	<ul style="list-style-type: none"> <li>• There was no evidence from this group for this question</li> </ul>	<ul style="list-style-type: none"> <li>• What is an advocate?               <ul style="list-style-type: none"> <li>○ ‘My mum is one... for vulnerable people’</li> <li>○ ‘Makes sure their voice gets heard’</li> <li>○ ‘Helps them have their voices heard’</li> </ul> </li> <li>• What skills/qualities should an advocate have?               <ul style="list-style-type: none"> <li>○ ‘Confidence’ x 2</li> <li>○ ‘Keeping it confidential’ x2</li> <li>○ ‘Always there to help, not just when they want’</li> <li>○ ‘Not shy’</li> <li>○ ‘Can explain things clearly’</li> <li>○ ‘Public speaking’</li> <li>○ ‘Understanding if they have learning difficulties’</li> <li>○ ‘They have to care’</li> <li>○ ‘Not sugar coating anything’</li> <li>○ ‘Never over reacting’</li> <li>○ ‘Understanding – ‘they understand what the child is thinking and why they are feeling that way’</li> <li>○ ‘Empathetic/sympathetic’</li> <li>○ ‘Wants to help’</li> <li>○ ‘Nice’</li> <li>○ ‘Trustworthy’</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Low</li> </ul>

Age <7 years	Age 7-11 years	Age 11-14 years	Overall quality of the evidence
		<ul style="list-style-type: none"> <li>○ 'Patient'</li> <li>○ 'Caring'</li> <li>○ 'Not over reacting and acting calm'</li> <li>○ 'Understanding they have learning disabilities – speaking slowly, putting yourself in their shoes, understanding what they might need to help'</li> <li>○ 'Good listener'</li> <li>○ 'Always there to help, not just when they want'</li> <li>○ 'Act professionally'</li> <li>○ 'Professionally and well dressed' because this will help you to trust them, wouldn't trust them if they are just in jeans'</li> <li>○ 'Be protective of the young person'</li> <li>○ 'Addressing a child how they want to be addressed – by their first name or by a nickname or something like that'</li> <li>○ 'Use terminology that isn't confusing'</li> <li>○ 'Get down to the level of the young person'</li> <li>○ 'Speak to them and comfort them'</li> <li>○ 'Prepared for any scenario'</li> <li>○ 'Training to support others'</li> </ul>	

## Appendix N – Evidence from national surveys

### Evidence from national surveys for review question: How can the views of babies, children and young people be best represented by independent advocates?

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

**Table 9: Evidence from national surveys**

Survey	Findings	Overall quality of the evidence
Association for Young People's Health. Young people's views on involvement and feedback in healthcare 2014	<ul style="list-style-type: none"> <li>No relevant findings were identified for this question</li> </ul>	<ul style="list-style-type: none"> <li>N/A</li> </ul>
Care Quality Commission. Children and young people's inpatient and day case survey 2018	<ul style="list-style-type: none"> <li>No relevant findings were identified for this question</li> </ul>	<ul style="list-style-type: none"> <li>N/A</li> </ul>
Child Outcomes Research Consortium. Child- and Parent-reported Outcomes and Experience from Child and Young People's Mental Health Services 2011-2015	<ul style="list-style-type: none"> <li>No relevant findings were identified for this question</li> </ul>	<ul style="list-style-type: none"> <li>N/A</li> </ul>
Health and Social Care Information Centre. Children's Dental Health Survey 2013. (Country specific report for England, published 2015)	<ul style="list-style-type: none"> <li>No relevant findings were identified for this question</li> </ul>	<ul style="list-style-type: none"> <li>N/A</li> </ul>
HM Inspectorate of Prisons. Children in Custody 2016-2017	<ul style="list-style-type: none"> <li>No relevant findings were identified for this question</li> </ul>	<ul style="list-style-type: none"> <li>N/A</li> </ul>
Opinion Matters. Declare your care survey 2018	<p><b>ENCOURAGEMENT TO RAISE CONCERNS:</b></p> <ul style="list-style-type: none"> <li>19% of young people aged 12-15 reported that having an advocate or third party who could raise concerns, would encourage them to express concerns about healthcare.</li> </ul>	<ul style="list-style-type: none"> <li>Low</li> </ul>

Survey	Findings	Overall quality of the evidence
National Children's Bureau. Listening to children's views on health provision 2012	<ul style="list-style-type: none"> <li>No relevant findings were identified for this question</li> </ul>	<ul style="list-style-type: none"> <li>N/A</li> </ul>
Picker Institute. Children and Young People's Patient Experience Survey 2018.	<ul style="list-style-type: none"> <li>No relevant findings were identified for this question</li> </ul>	<ul style="list-style-type: none"> <li>N/A</li> </ul>
Picker Institute. Paediatric Emergency Department Survey 2015 and Children and Young People's Outpatient Survey 2015	<ul style="list-style-type: none"> <li>No relevant findings were identified for this question</li> </ul>	<ul style="list-style-type: none"> <li>N/A</li> </ul>
Picker Institute/NHS England/Bliss. Neonatal Survey 2014  <i>Results for individual questions were converted into scores on a scale of 1 to 100, with 100 representing the best possible outcome (the scores are not percentages).</i>	<ul style="list-style-type: none"> <li>No relevant findings were identified for this question</li> </ul>	<ul style="list-style-type: none"> <li>N/A</li> </ul>
Word of Mouth Research and Point of Care Foundation. An options appraisal for obtaining feedback on the experiences of children and young people with cancer 2018	<ul style="list-style-type: none"> <li>No relevant findings were identified for this question</li> </ul>	<ul style="list-style-type: none"> <li>N/A</li> </ul>

N/A: not applicable

## Appendix O – Evidence from an expert witness

**Evidence from an expert witness for review question: How can the views of babies, children and young people be best represented by independent advocates?**

<b>Name:</b>	Zoe Carter
<b>Role:</b>	Independent advocate / Supervising advocate
<b>Institution/Organisation (where applicable):</b>	Rethink All Age Advocacy Service Saxon House 27 Duke Street Chelmsford Essex CM1 1HT Office: 0300 7900 559
<b>Contact information:</b>	
<b>Guideline title:</b>	Babies, children and young people's experience of healthcare
<b>Guideline Committee:</b>	Topic specific committee for above guideline
<b>Subject of expert testimony:</b>	Independent advocacy
<b>Evidence gaps or uncertainties:</b>	How can the views of babies, children and young people be best represented by independent advocates?
<p><b>Aim of review:</b> The Care Act 2014 and Mental Health Act 1983/2007 place a duty on UK councils to provide an independent advocate for a baby, child or young person who has substantial difficulties being involved in their own healthcare or who may not have an appropriate person to represent them. In addition to this, independent advocates may be used in healthcare situations where babies, children and young people cannot agree with their parents or healthcare professionals over a healthcare decision, or where it is not appropriate for their parents or carers to represent them.</p> <p>Independent advocates may be obtained from a range of providers, with a range of experiences and remits, and there may be variation in practice.</p> <p>The aim of this review is to determine how children and young people can be best represented by independent advocates. This may include ease of accessing independent advocacy services, and how the services can be helpful, supportive and useful.</p>	

**Evidence gap:** We conducted a systematic review of qualitative literature and found no evidence relating to babies, children or young people's experience of independent advocates.

We also conducted a grey literature review of national healthcare surveys for babies, children and young people and found no evidence relating to babies, children or young people's experience of independent advocates.

The committee are interested in the views of an independent advocate and reported testimony from children and young people who have used an independent advocate. The committee are particularly, but not exclusively, interested in the following themes:

- Access to records of healthcare staff discussions
- Adequate training for independent advocates including knowledge about developmentally-appropriate approaches
- Appeal to, or use of, advocacy groups
- Availability and accessibility of appropriate advocacy services
- Awareness of independent advocate services
- Encouraging and supporting self-advocacy when possible
- Sensitivity and responsiveness of independent advocate to feedback from child or young person
- Views on timing of support provided from the independent advocate, establishing views regarding where and when advocacy is beneficial, including continuity of support

### **Summary of testimony**

A true advocate will be independent of the organisation/health care setting they may be working in. Coming from an independent place allows a trusting relationship. When a child knows you are not part of the health care system, they are freer to share their thoughts, feelings and wishes.

My experience as an advocate spans 25 years. Advocacy organisations introduced a qualification by City and Guilds around 2011, prior to this advocacy did not have any formal training mechanisms. I became a qualified Independent Mental Health Advocate then. I worked with children for four years in a mental health unit in Colchester for 13 – 18-year olds, and used the Mental Health Act in my practice.

When a child is detained under the Mental Health Act it is the responsibility of the hospital to let them know they are entitled to an advocate if they wish. The advocacy provider must respond to a request for advocacy within a specific time frame agreed by the commissioning body for that contract. It is the responsibility of the advocacy provider to make this as accessible to the children as possible. Posters are placed on the wards and time for drop-ins to make the service available are also used.

Access to advocacy for children not detained under the Mental Health Act depends on the commissioning bodies of the counties, and the contracts that deliver advocacy to children.

In my relationships and meetings with each child I would explain who I was and what my role was, this would include an explanation about how I was independent from the staff and all other professionals. I would reassure them that they could share anything with me, and it would stay with me. I would include in this an explanation of the only situation where this confidence would be broken and who I would have to speak to. This laid the foundations of trust. It was important to ensure that they were aware of our independence of the hospital to enable them to feel they could talk freely knowing that we would not share anything unless they agreed, which also helped them.

The skills I used was knowledge of the Mental Health act and hospital processes. I would observe body language and actively listen to answers and paraphrase to gain knowledge of them and build an understanding. This would always be at their pace remaining calm.

The rights of patients detained under the act was also something I had to explain to them to ensure they were met. It is the responsibility of the advocacy provider to ensure an Independent Mental Health Advocate is available for all requests. Cover for advocacy absences is arranged by the advocacy provider. There is a requirement of the hospital to ensure all advocacy requests and referrals are made. The use of the Human Rights act was also something I held in mind if necessary. Often these rights are written down which can be harder to understand, it was important that they were explained in a way that the young person could relate to so I developed a method of explaining them in a way that was less frightening and easier to understand. I had resources I had researched that had been written for children that are detained. They explained the section appeal process and tribunals. Advocates use information they find to help clients understand their situation in a more accessible way.

A lot of the work I did was to support clients at Care and Support meetings (CPA's). These were meetings held with everyone to do with the care of the child in hospital. Often there were eight or more adults in the room and the child. An advocate can help a child feel they have someone on their side in the meeting, as they can be intimidated by the number of people and feel overwhelmed. My role was to help the child prepare for their meeting so they could have their say and ask questions about their treatment. I would meet with the child ahead of the meeting to go through the reports that had been written about them from the Dr, Therapist and school. I provided an independent view and an opportunity to understand the system and their rights. Parents would attend and support the child also; I would explain my role and independence. What viewing the reports ahead does is empower the child to know some of what will be discussed and to have their say. We would read them together and I would help them understand and prepare questions. I would empower them to do this themselves but if they were unsure, I would agree with them what I would say. They were always in control. This helped them connect with the process they were in and feel they had a say. I also made sure the professionals gave the child information in a way they could understand.

Another part of the work I did was around support at Dr reviews. I would spend time with the child before the meeting to help them work out what they wanted to say.

Talk about questions they might like to ask about their treatment. In the meetings I made sure the child understood what was being said and that they had an opportunity to have their say. Independent Mental Health Advocates have the right to view medical records. Patients and parents also have the right too. The data protection act sets the age of thirteen for children to have access to their records. There is an administrative process that is used to request these. Dr can have view if they feel it would be detrimental to the patient for them to see them.

Advocates are not decision makers, we are people that empower people including children to have their say over their situation, whatever that is. We help children to understand their rights and feel they have some control. We measure this through outcomes we add to the case before and after. In addition, we use feedback questionnaires for both children and stakeholders. The information is collated by the provider and shared anonymously.

When the child leaves the unit generally the Independent Mental Health Advocate role ends. It ends when the child comes off section and the entitlement is no longer there. If a child goes into adult services, and is detained and local, then the same service can continue if there is an advocacy contract in place to do this. If appropriate, signposting is provided to other advocacy providers. Children receiving support from Social Care could be eligible for other statutory advocacy.