National Institute for Health and Care Excellence

FINAL

Babies, children and young people's experience of healthcare

[D] Providing information

NICE guideline NG204

Evidence reviews underpinning recommendations 1.1.4 to 1.1.9 and 1.2.17 to 1.2.28 in the NICE guideline

August 2021

Final

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

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Review question

How do children and young people, and the parents or carers of babies and young children, prefer to access healthcare information?

Introduction

Having accurate and developmentally appropriate information is an integral part of informed shared decision making. It can help facilitate self-management for children and young people, and contribute to a good experience of healthcare. In contrast, difficulties in accessing information can have consequences on the ability to make informed decisions, which can lead to non-participation in health management, poor health outcomes and ineffective use of health resources. Children, young people and parents of babies and young children have different and varied needs and may prefer to access healthcare information in different ways, to enable them to receive content that is useful to them.

The aim of this review is to determine how children and young people, and the parents or carers of babies and young children, prefer to access healthcare information.

Summary of the protocol

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

Table 1: Summary of the protocol

Population	• People <18 years-old who have experience of healthcare • Studies that use the responses of parents or carers as proxies for their child will be included only if they are responding on behalf of their child or charge, and: ○ the baby or child of the parent or carer is under-5 years-old, or ○ there is a clear rationale provided as to why the study is using parents' or carers' views on healthcare as proxies for their child.
Phenomenon of interest	Experience of healthcare, in particular of accessing healthcare information.
Primary outcomes	Themes will be identified from the literature. The committee identified the following potential themes (however, not all of these themes may be found in the literature, and additional themes may be identified): • Acceptability of means of, and barriers to, accessing information (e.g. product, portal, literature) • Avoidance of use of medical jargon • Co-production of healthcare information with children and families • Developmentally-relevant, culturally-appropriate information • Lack of accessibility (e.g. for people whose first language is not English; for people who have a sensory impairment) • Quality, quantity, type and pace of information provided (including too much information) • Role of charities, support groups, social media and social networks in finding and accessing information • Source and mode of information (e.g. website, charity, social media page; digital apps, online videos, pamphlets, podcasts, websites)

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:

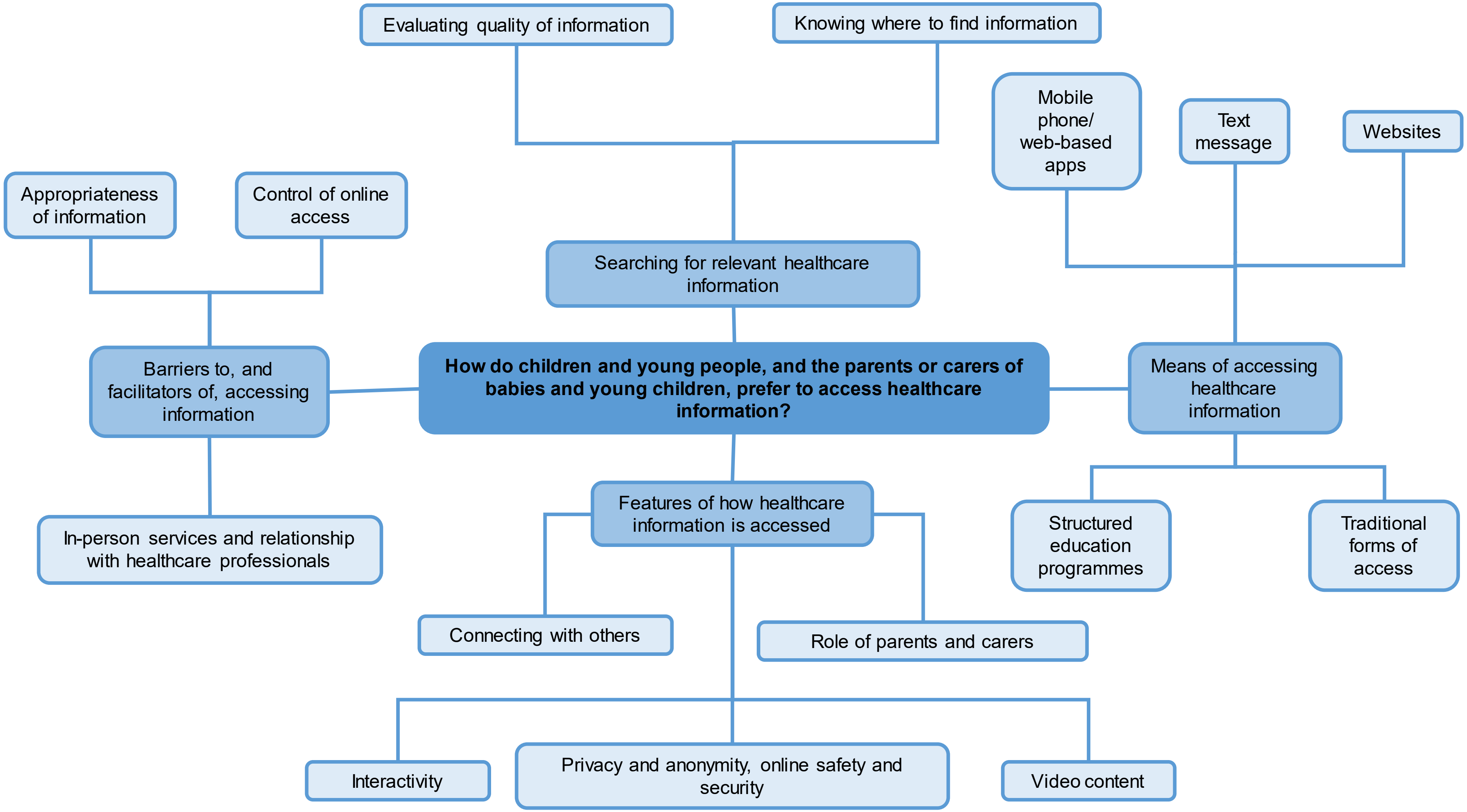
- Determining how children and young people and the parents or carers of babies and young children prefer to access healthcare information.

A systematic review of the literature was conducted using a combined search. Thirteen articles were included in this review: 11 primary studies reported in 12 articles (Alderice 2018, Aranda 2018, Arnott 2012, Best 2016, Chaney 2012, Harvey 2013, Huby 2017, Ingram 2013, Neill 2015/2016, Nightingale 2017, Waite-Jones 2018), and 1 systematic review (Reen 2019). The 11 primary studies used primarily qualitative methods and were all conducted in the UK. Two articles reported data from the same study (Neill 2015, Neill 2016). Methods of data collection in the included studies were focus groups (Alderdice 2018, Aranda 2018, Best 2016, Chaney 2012), semi-structured interviews (Arnott 2012, Harvey 2013, Waite-Jones 2018), a mixture of both (Ingram 2013, Neill 2015/Neill 2016, Nightingale 2017), and other age-/developmentally-appropriate participatory-based activities (e.g. ‘Write, draw and tell’) (Huby 2017).

The included studies are summarised in Table 2.

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

Figure 1: Theme map



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

Excluded studies

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

Summary of studies included in the evidence review

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

Table 2: Summary of included studies

Study	Population	Methods	Themes
Alderdice 2018 **Study design** Focus group **Aim of the study** To explore what parents deem important after returning home from hospital with their premature baby Northern Ireland, UK	N=23 parents (21 mothers, 2 fathers) of premature babies **Characteristics:** Age of babies: Born at <37 weeks' gestation Gender of babies: not reported	**Recruitment** Eligible participants were identified by a premature and sick baby charity, through parents on their mailing list and through social media **Data collection** Three focus groups **Analysis** Content analysis	• Searching for relevant healthcare information: Evaluating quality of information • Searching for relevant healthcare information: Knowing where to find information • Means of accessing healthcare information: Websites • Features of how healthcare information is delivered: Appropriateness of information • Features of how healthcare information is delivered: Connecting with others • Features of how healthcare information is delivered: Video content
Aranda 2018 **Study design** Focus group **Aim of the study** To explore experiences, views and preferences of young people aged 11–19 years	N=74 children and young people **Characteristics:** Age (range): 11-19 years • 11-13 years, n=16 • 14-15 years, n=40 • 16-17 years, n=17 • 18-19 years, n=1 Gender (M/F): 43/31	**Recruitment** Recruitment across 5 districts/boroughs of one local authority from a range of educational settings **Data collection** Participatory focus groups **Analysis** Thematic analysis and content analysis	• Searching for relevant healthcare information: Knowing where to find information • Means of accessing information: Text message • Means of accessing healthcare information: Websites • Features of how healthcare information is delivered: Privacy, anonymity, safety and security • Barriers to, and facilitators of, accessing information:

Study	Population	Methods	Themes
regarding school-based sexual health and school nursing UK (exact location not specified)			Knowing where to find information • Barriers to, and facilitators of, accessing information: Control of online access • Barriers to, and facilitators of, accessing information: In-person services and relationship with healthcare professional
Arnott 2012 **Study design** Semi-structured interview **Aim of the study** To identify unmet information and communication needs of parents whose child has had a suspected adverse drug reaction. Liverpool, UK	N=45 parents of 44 children (41 mothers, 4 fathers) • Some data from parents of children over 5 years were extracted and included in this review. These views of parents of children over 5 years were consistent with the views of parents of children under 5 years **Characteristics**: Age of child (range): 0-17 years Gender of child (M/F): 24/20	**Recruitment** Sampling conducted via either Adverse Drug Reaction programme at UK paediatric centre or Yellow Card scheme (UK drug surveillance system) **Data collection** Semi-structured interviews **Analysis** Modified grounded theory	• Searching for relevant healthcare information: Evaluating quality of information • Searching for relevant healthcare information: Knowing where to find information • Means of accessing healthcare information: Traditional forms of access • Barriers to, and facilitators of, accessing information: In-person services and relationship with healthcare professional
Best 2016 **Study design** Focus group **Aim of the study** To conceptualize the process of online help-seeking by	N=56 young people **Characteristics**: Age (range): 14-15 years Gender (M/F): 56/0	**Recruitment** Seven schools selected by cluster-based sampling according to education level and gender composition. Quasi-random selection of pupils from each class **Data collection** Eight focus groups, 6-8 participants, with topic guides and photo-elicitation technique or vignette **Analysis**	• Searching for relevant healthcare information: Evaluating quality of information • Searching for relevant healthcare information: Knowing where to find information • Means of accessing healthcare information: Websites • Features of how healthcare information is delivered: Privacy, anonymity, safety and security

Study	Population	Methods	Themes
exploring how adolescent males locate and access support online Northern Ireland, UK		Inductive thematic analysis by 3 researchers	
Chaney 2012 **Study design** Focus group **Aim of the study** To establish adolescents' beliefs about the need for a structured diabetes education programme and their views on how it should be organised and what topics need to be addressed. Northern Ireland, UK	N=21 young people **Characteristics**: Age (range): 13-19 years Gender (M/F): not reported	**Recruitment** Participants recruited from diabetes clinic lists of three Northern Irish acute Hospital Trusts. Purposive sampling used according to age, gender and duration of diabetes to ensure diversity of participants **Data collection** Five semi-structured focus groups lasting 4-90 min preceded by short presentation of Berger structured diabetes education programme (for adults). Topic guide and list of questions used. **Analysis** Thematic content analysis including of notes taken during focus groups	• Means of accessing information: Structured education programmes • Means of accessing information: Text message • Features of how healthcare information is delivered: Interactivity • Features of how healthcare information is delivered: Privacy, anonymity, safety and security • Barriers to, and facilitators of, accessing information: In-person services and relationship with healthcare professional
Harvey 2013 **Study design** Semi-structured interview **Aim of the study**	N=18 parents (13 mothers and 5 fathers) of 15 neonates **Characteristics:** Age of neonate: Born at <33 weeks' gestation Gender of neonate (M/F): 8/7	**Recruitment** Purposeful sample of eligible parents in one tertiary neonatal unit **Data collection** Semi-structured interviews **Analysis** Grounded theory	• Searching for relevant healthcare information: Evaluating quality of information • Searching for relevant healthcare information: Knowing where to find information • Means of accessing healthcare information: Websites

Study	Population	Methods	Themes
To explore information and communication needs of parents during their baby's care in the neonatal unit, focusing on brain imaging and neuro-logical prognosis London, UK			• Features of how healthcare information is delivered: Connecting with others • Barriers to, and facilitators of, accessing information: In-person services and relationship with healthcare professional
Huby 2017 **Study design** Age-appropriate participa-tory-based activities **Aim of the study** To explore children's and young people's views on the content of a proposed application to support personal manage-ment of their condition. North England, UK	N=26 children and young people **Characteristics:** Age (range): 5-17 years • 5-10 years, n=7 • 11-15 years, n=10 • 16+, n=9 Gender (M/F): 14/12	**Recruitment** Patients with CKD stages 3–5 were identified from hospital records of a children's kidney unit by using a purposive sampling approach based on age, sex, ethnicity and CKD stage **Data collection** Children aged 5-10 years were encouraged to 'draw and tell'; those aged 11-15 years were engaged in face-to-face discussion; young people aged over-16 years were interviewed in a semi-structured way. Specific topic guides were developed and used for all age groups **Analysis** Thematic (Framework) analysis assuming self-efficacy theory	• Searching for relevant healthcare information: Evaluating quality of information • Means of accessing information: Mobile phone/web-based apps • Means of accessing healthcare information: Websites • Features of how healthcare information is delivered: Appropriateness of information • Features of how healthcare information is delivered: Connecting with others • Features of how healthcare information is delivered: Video content • Barriers to, and facilitators of, accessing information: Control of online access • Barriers to, and facilitators of, accessing information: In-person services and relationship with healthcare professional

Study	Population	Methods	Themes
Ingram 2013 **Study design** Focus group, semi-structured interview, focus group and semi-structured interview **Aim of the study** To explore what parents' think about their support and information needs prior to consulting when their children have respiratory tract infections with cough, and to identify the facilitators and barriers to consulting primary care. Bristol, UK	N=60 parents (58 mothers, 2 fathers) Focus group only, n=30 mothers Semi-structured interview only, n=23 parents (21 mothers, 2 fathers) Focus group and semi-structured interview, n=7 mothers • Data from parents of children over 5 years were not extracted nor included in this review **Characteristics:** Age of child (range): 5-mo-17 years Gender of child (M/F): not reported	**Recruitment** Eligible parents for the interviews were identified through a search of patient records, in six GP practices, for those who had consulted in the previous 3 months for a child with a respiratory infection **Data collection** Seven focus groups, comprising 4-6 mothers, and 30 semi-structured interviews **Analysis** Thematic analysis using constant comparison	• Searching for relevant healthcare information: Evaluating quality of information • Searching for relevant healthcare information: Knowing where to find information • Means of accessing healthcare information: Traditional forms of access
Neill 2015/2016 **Study design** Focus group and semi-structured interview	N=27 parents (24 mothers, 3 fathers) **Characteristics:** Age of child: under 5 years Gender of child (M/F): not reported	**Recruitment** Eligible parents were recruited at Sure Start Children's Centre and a private day nursery **Data collection** Five focus groups comprising 2-8 parents and 3 semi-structured interviews **Analysis**	• Searching for relevant healthcare information: Evaluating quality of information • Searching for relevant healthcare information: Knowing where to find information • Means of accessing information: Mobile phone/web-based apps

Study	Population	Methods	Themes
Aim of the study To explore how parents use information resources at home to make decisions about their child's acute illness East Midlands, UK		Modified grounded theory using constant comparative analysis	• Means of accessing healthcare information: Traditional forms of access • Means of accessing healthcare information: Websites • Features of how healthcare information is delivered: Connecting with others • Barriers to, and facilitators of, accessing information: In-person services and relationship with healthcare professional
Nightingale 2017 **Study design** Focus group and semi-structured interview **Aim of the study** To explore the views of children with chronic kidney disease, their parents, and health care profession-als to inform future develop-ment of a child-focused, care-management mobile app UK	N=36 • n=17 children and young people • n=12 parents (10 mothers, 2 fathers) • n=7 healthcare professionals Data from parents and healthcare professionals was not extracted nor included in this review **Characteristics:** Age of child (range): • 5-10 years, n=6 • 11-14 years, n=6 • 15-18 year, n=5 Gender of child (M/F): 9/8	**Recruitment** Participants were purposively sampled and included from 2 paediatric kidney units ensuring variation regarding the children's age, developmental stage, ethnicity, and sex **Data collection** Semi-structured interviews and focus groups as preferred by participants conducted in child-friendly setting (e.g. home) **Analysis** Thematic (Framework) analysis	• Searching for relevant healthcare information: Evaluating quality of information • Searching for relevant healthcare information: Knowing where to find information • Means of accessing information: Mobile phone/web-based apps • Means of accessing healthcare information: Websites • Features of how healthcare information is delivered: Appropriateness of information • Features of how healthcare information is delivered: Interactivity • Features of how healthcare information is delivered: Privacy, anonymity, safety and security

Study	Population	Methods	Themes
Reen 2019 **Study design** Systematic review **Aim of the study** To determine the preferences of adolescent regarding the usability of specific health information websites and to identify the difficulties they face when attempting to access their content. Various countries	K=25 qualitative studies including a total of 2621 participants **Characteristics of participants in included studies:** Age (range; mean): 11-25 years; 15.2 Participants from non-clinical population: 2074/2621 (79.1%) Participants from clinical population: • Adolescents diagnosed with diabetes: 322/2621 (12.3%) • Juvenile idiopathic arthritis: 54/2621 (2.1%) • Haemophilia: 47/2621 (1.8%) • Depression: 42/2621 (1.6%) • Participants with other conditions (all <1%): Cancer; Cystic Fibrosis, Migraines, recent kidney transplant	PRISMA guidelines followed to present review, which was not previously published or registered. **Search strategy** Uniform search terms developed and used in systematic search of PubMed, PsychInfo, and Education Resources Information Center (ERIC) databases. **Data extraction** Following details were extracted from included studies: • Participant demographics (age, gender, clinical or nonclinical population) • Specific health information website including topic of website and characteristics • Currently availability of website on the internet • Method used to evaluate usability of website • Any data on children's and young people's feedback on usability **Quality assessment of included studies** CASP checklist used to evaluate each study by 2 reviewers independently but not to exclude studies. Discrepancies between reviewers were slight and resolved after discussion.	• Features of how healthcare information is delivered: Appropriateness of information • Features of how healthcare information is delivered: Connecting with others • Features of how healthcare information is delivered: Interactivity • Features of how healthcare information is delivered: Video content
Waite-Jones 2018 **Study design** Focus group and semi-structured interview **Aim of the study**	N=25 • n=9 children and young people • n=8 parents or carers • n=8 healthcare professionals ○ Data from parents, carers and healthcare professionals were not extracted nor included in this review	**Recruitment** Purposeful (criterion) sampling from paediatric rheumatology clinic database of large teaching hospital in England conducted by rheumatology nurse specialist, who also invited associated parents, carers and professionals to participate in study **Data collection**	• Means of accessing information: Mobile phone/web-based apps • Features of how healthcare information is delivered: Appropriateness of information • Features of how healthcare information is delivered: Connecting with others

Study	Population	Methods	Themes
To explore views of young people with juvenile arthritis, their parents or carers, and related healthcare professionals regarding what should be included in a self-management app for chronic juvenile arthritis Northern England, UK	**Characteristics**: Age of child (range): 10-17 years Gender of child (M/F): 2/7	Semi-structured interviews, using participatory approach and developmentally-appropriate topic guides, conducted with young people and their parents or carers; two focus groups with professionals conducted. **Analysis** Thematic (Framework) analysis by 5 researchers with all stages of research including consultation with a user ambassador	• Features of how healthcare information is delivered: Interactivity • Features of how healthcare information is delivered: Privacy, anonymity, safety and security • Features of how healthcare information is delivered: Role of parents and carers

CKD: chronic kidney disease; F: Female; M: Male; N/n: Number

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

Quality assessment of studies included in the evidence review

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

Main theme 1: Searching for relevant healthcare information

- Sub-theme 1.1: Evaluating quality of information. The overall confidence in this sub-theme was judged to be moderate.
- Sub-theme 1.2: Knowing where to find information. The overall confidence in this sub-theme was judged to be moderate.

Main theme 2: Means of accessing healthcare information

- Sub-theme 2.1: Mobile phone/web-based phone apps. The overall confidence in this sub-theme was judged to be moderate.
- Sub-theme 2.2: Structured education programme. The overall confidence in this sub-theme was judged to be very low.
- Sub-theme 2.3: Text message. The overall confidence in this sub-theme was judged to be very low.
- Sub-theme 2.4: Traditional forms of access. The overall confidence in this sub-theme was judged to be moderate

- Sub-theme 2.5: Websites. The overall confidence in this sub-theme was judged to be moderate.

Main theme 3: Features of how healthcare information is delivered

- Sub-theme 3.1: Connecting with others. The overall confidence in this sub-theme was judged to be low.
- Sub-theme 3.2: Interactivity. The overall confidence in this sub-theme was judged to be low.
- Sub-theme 3.3: Privacy, anonymity, online safety and security. The overall confidence in this sub-theme was judged to be low.
- Sub-theme 3.4: Role of parents/carers. The overall confidence in this sub-theme was judged to be very low.
- Sub-theme 3.5: Video content. The overall confidence in this sub-theme was judged to be low.

Main theme 4: Barriers to, and facilitators of, accessing healthcare information

- Sub-theme 4.1: Appropriateness of information. The overall confidence in this sub-theme was judged to be low.
- Sub-theme 4.2: Control of online access. The overall confidence in this sub-theme was judged to be low.
- Sub-theme 4.3: In-person services and relationship with healthcare professional. The overall confidence in this sub-theme was judged to be moderate.

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

Evidence from reference groups and focus groups

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

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

Age groups	• 11-14 years
Areas covered	• Preferred way to access healthcare information • Sources of information
Illustrative quotes	• How do you prefer to access healthcare information? ○ 'Have helplines' ○ 'Don't make it overwhelming' • Sources of information ○ 'Tiktok - video of young person explaining' ○ 'Video of adult explaining' ○ 'Leaflet from hospital/school etc.'

See the full evidence summary in appendix M.

Evidence from national surveys

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

Table 4: Summary of the evidence from national surveys

National surveys	• Care Quality Commission. Children and young people's inpatient and day case survey 2018 • Child Outcomes Research Consortium. Child- and Parent-reported Outcomes and Experience from Child and Young People's Mental Health Services 2011-2015 • Opinion Matters. Declare your care survey 2018 • Picker Institute. Paediatric Emergency Department Survey 2015 and Children and Young People's Outpatient Survey 2015 • Picker Institute/NHS England/Bliss. Neonatal Survey 2014
Areas covered	• Specific information about different topics, such as surgery, mental health support available, outpatient visits, pre-natal and post-natal, neonatal unit • Lack of information
Key findings	• Most children and young people agreed that they were adequately informed about their health condition, although some mentioned that they did not know what was going to happen to them before visiting the hospital • Parents of babies in the neonatal unit felt that they were given enough information, although some mentioned that they were not told what to expect after the birth, or to help understand their baby's condition

See the full evidence summary in appendix N.

Economic evidence

Included studies

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

Excluded studies

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

Summary of studies included in the economic evidence review

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

Economic model

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

The committee's discussion of the evidence

Interpreting the evidence

The outcomes that matter most

This review focused on how children and young people, and the parents or carers of babies or young children, prefer to access healthcare information. To address this issue, the review was designed to include qualitative data, and as a result, the committee could not specify in advance the data that would be located. Instead, they identified the following main themes to guide the review:

- Acceptability of means of, and barriers to, accessing information (e.g. product, portal, literature)
- Avoidance of use of medical jargon
- Co-production of healthcare information with children and families
- Developmentally-relevant, culturally-appropriate information
- Lack of accessibility (e.g. for people whose first language is not English; for people who have a sensory impairment)
- Quality, quantity, type and pace of information provided (including too much information)
- Role of charities, support groups, social media and social networks in finding and accessing information
- Source and mode of information (e.g. website, charity, social media page; digital apps, online videos, pamphlets, podcasts, websites)

With the exception of sources of healthcare information, the evidence did not map neatly onto these above themes. Additional themes identified were: ‘Searching for relevant healthcare information’; ‘Means of accessing healthcare information’; ‘Features of how healthcare information is delivered’; and ‘Barriers to, and facilitators of, accessing healthcare information’. The committee did not prioritise any of these themes above other ones, and considered all the evidence as valuable in making their recommendations.

The quality of the evidence

The quality of the evidence for this review was assessed using GRADE-CERQual. The quality of the methodology of the individual studies was assessed using either the Critical Appraisal Skills Programme (CASP) qualitative checklist or CASP systematic review checklist as appropriate.

The quality of evidence for the sub-themes ranged from very low to moderate. The studies contributing to each theme were generally free of substantive methodological limitations, with only two studies (Alderdice 2018, Chaney 2012) rated as being of moderate concern and the remaining studies rated as either ‘minor concerns’ or ‘no or very minor concerns’. Sub-themes were downgraded for coherence of findings as some sub-themes only had one study contributing to the findings, thus not providing sufficient variety of data to determine whether the finding is compelling. When more than one study contributed to a finding, some sub-themes were downgraded for coherence because the evidence supporting them came from a variety of populations/sources and some inductive leaps (i.e. interpretations) were required. Sub-themes were downgraded for relevance of evidence due to a variety of clinical and non-clinical populations, and settings in the included studies. In addition, the study sample of one study included a large proportion (>66% of the sample) of parents of children over the age of 5 years (Arnott 2012) whilst one systematic review on the views of 11-19 year-olds on the usability of websites included studies whose study populations included people over 18. Finally, sub-themes were also downgraded for adequacy of data as not all of the included studies reported rich data sets and some provided relatively few quotes to support their putative findings.

Benefits and harms

The committee noted that the systematic review provided evidence from a number of different settings, including home, school, primary care, secondary care and a children’s centre. The evidence therefore represented the provision of information across a spectrum of healthcare. The committee also noted there was evidence from all ages – from parents of babies, to children and young people themselves.

The committee discussed that there could be such a wide variety in the ways information was provided, when it could be provided, and the quantity of information, that it was important to ask children and young people and the parents or carers of babies and young children for their individual preferences. The committee noted that a recommendation to this effect was already included in the adult experience of healthcare guideline and so they adapted this recommendation, including the suggestions from this guideline on what routine information provided to all users of healthcare services should include. The committee also agreed however, that these needs and preferences may change, particularly as children grow older, and so should be reconfirmed regularly, and so they recommended this.

The committee then reviewed the themes identified in the systematic literature review to develop additional specific recommendations based on the evidence.

The committee discussed how information should be provided and noted that there was evidence from the sub-theme on in-person services and relationship with healthcare professional, that face-to-face provision of information was valued, particularly if there was an ongoing and trusting relationship with a healthcare professional. The committee agreed that this reflected their experience and that face-to-face communication allowed a discussion and promotion of this trusting relationship. However, there was also evidence from the theme on means of accessing healthcare information, that other methods were preferred in some circumstances. Text messages were preferred by young people accessing a sexual health service as they avoided face-to-face contact. The committee discussed that no evidence relating specifically to video calls had been identified, but from their experience this was becoming a more common method of conducting consultations. Evidence from the sub-theme on traditional forms of access showed that verbal information was welcomed, but as it was only said once, follow-up written information was also appreciated as that could be used to refer to later. The committee therefore made recommendations on using the preferred method of communication and included in person face-to-face, as well as alternative methods of communication and providing additional information to back-up verbal information.

There was evidence from several sub-themes about information being provided privately to children and young people. The committee discussed the evidence from the sub-theme of privacy that children liked accessing information anonymously online, and also the evidence from the sub-theme on the role of parents and carers that showed that children and young people sometimes felt that having their parents or carers involved in information-sharing inhibited their privacy or independence. The committee agreed achieving information-sharing without involving parents or carers would involve seeing children and young people without their parents or carers present, or by telephoning or texting them directly, or by sending written information directly to them, and so the committee made this recommendation. There was additional evidence from this sub-theme that showed that children and young people do recognise that in some circumstances their parents or carers should be given information, such as in an emergency situation. The committee discussed this, and from their own knowledge and experience, identified that there were also situations where parents would need to be supplied with information directly in order that they could care for their children appropriately. For example, if children or young people had to have special diets or post-operative care, this information should be given to the parents or carers, and so the committee included a recommendation that reflected this.

There was evidence from the sub-theme on the appropriateness of information that any information supplied should be age-appropriate, easy to understand relative to the user's age, and concise. The evidence also showed that children and young people preferred information that was targeted or appropriate for them, for example it related to their diagnosis. The committee therefore included these factors in a recommendation, and based on their own knowledge and experience also added that the information should be culturally sensitive, provided consistently, and be in an accessible format that took into account the needs of the user.

There was evidence from several themes that children and young people, and the parents or carers of babies and young children liked to receive information that was engaging and interactive, and although websites and apps were preferred by children and young people, parents or carers also like leaflets and books. The evidence from the sub-themes on structured education programmes and interactivity showed that information needed to be engaging, fun and interactive and so the committee recommended this. There was evidence that children and young people liked peer accounts and stories, but no evidence for the co-production of information sources. However, based on their experience the committee agreed that the best way to develop engaging information resources was to develop them in partnership with children and young people themselves.

Evidence from the sub-theme of in person services and relationship with healthcare professional provided evidence that information that was provided at the appropriate time was preferred. The amount of information provided at any one time was also an important consideration, and there was evidence that time for questions should be allowed. The committee therefore combined all these factors into their recommendations, and also included that it was important to check understanding, and to make sure children or young people knew what to do if they didn't understand or thought of questions at a later date.

Based on their knowledge and experience the committee discussed there were some potential harms when providing information: providing too much information in one go could overload children, young people, or their parents or carers, so the committee recommended this should be staged. The committee noted that some information, particularly if it was bad news or potentially frightening could have an emotional impact, , and that support may be required to help children deal with information that they had been given. The committee also recognised that with the healthcare professional providing all the information, there could be a power imbalance which may lead to the child or young person feeling intimidated. The committee therefore made a recommendation for this to be taken into consideration by healthcare professionals and to consider if extra support would be required.

There was evidence from the sub-themes on knowing where to find information, websites, and evaluating the quality of information that children and young people may use multiple sources to find information for themselves, and often used websites or social media, but may find it difficult to evaluate the quality of online information, or know what to look for. Evidence from the theme on traditional forms of access showed that parents or carers may use television as a source of information. The committee also identified a potential harm in the use of peers, family or social media, digital media or social networks as sources for information, as using information from these sources could lead to incorrect or inappropriate information being used. There was also evidence from the sub-theme on evaluating quality that NHS sources were trusted. The committee therefore recommended that healthcare professionals could support children and young people to identify reliable sources of information and signpost children, young people and their parents or carers to other credible sources of information such as NHS websites, and warn them that other online sources may be inaccurate.

There was some evidence from the sub-theme on online access that Wi-Fi access was important to children and young people so they could access online information and use apps, but the committee did not make a recommendation on this but the committee did not think it was in the remit of the guideline to recommend that children and young people should always have internet access so they could access medical information. However, the committee recognised that there may be difference in access to the internet and to digital resources in general depending if children lived in rural or urban areas, and on their socioeconomic background. For example, not all children and young people, or the parents or carers of babies and young children would have access to smartphones or computers, which could make accessing information online, taking part in virtual consultations or using healthcare apps impossible, The committee therefore made an over-arching recommendation at the beginning of the guideline to suggest that non-digital methods of communicating and providing information should be available for those who could not access digital methods.

In addition to the systematic review evidence the committee reviewed some evidence from the reference groups and focus groups, and from the national surveys of children's experience. The evidence from the groups reinforced the message that information should be provided in a way that is not overwhelming. The young people aged 11 to 14 had also suggested that they liked helplines but the committee did not make a specific recommendation relating to this, as the recommendation on signposting to other sources of credible information could include signposting to existing helplines, such as those run by the voluntary sector or charities. The young people had also identified that other potential sources of information included explanatory videos (featuring either other children or adults), books, leaflets from the hospital, asking their parents, or internet search engines such as Alexa and Google. The committee agreed that their recommendations included the use of leaflets and websites, and discussed the fact that websites highlighted by Alexa and Google may not be evidence-based or factually correct. This therefore confirmed that it was important to include in the recommendations that people should be directed to credible and evidence-based sources of information.

The national surveys had identified children and young people had mixed views about information provision. Children and young people reported that information about surgery and the mental health help available to them was well explained, but other surveys found that about half of children and people were not given enough information what would happen on a hospital visit, about a health condition, or the treatment options. Feedback from parents of babies on neonatal units found that parents were mainly happy about the information provided to them about the neonatal unit and their baby's condition, but scores were lower for the provision of written information, and for information about practical matters (expenses, financial support) and additional support that was available such as support groups. The committee agreed that these findings supported their conclusions from the systematic review.

Cost effectiveness and resource use

There was no existing economic evidence for this review. The committee agreed that there may be resource implications relating to the time taken to develop a range of appropriate materials and to co-produce these materials with children and young people and parents/carers of babies. There may also be extra time needed by staff to deliver information on an ongoing basis. However, the impact of this could be reduced if there was greater coordination across the health service for the development of resources. Also, once produced such materials could be used on many children and young people and parents/carers of babies and costs per individual user are likely to be negligible, if any. Overall, the view was that recommendations in this area reflect current practice for most services and would have only modest resource implications, if any.

Recommendations supported by this evidence review

This evidence review supports recommendations 1.1.4 to 1.1.9 and 1.2.17 to 1.2.28 in the NICE guideline.

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Appendices

Appendix A – Review protocol

Review protocol for review question: How do children and young people, and the parents or carers of babies and young children, prefer to access healthcare information?

Table 5: Review protocol

Field	Content
PROSPERO registration number	CRD42019145425
Review title	Accessing healthcare information
Review question	How can health services support babies, children, and young people to participate in usual activities (for example family relationships, schooling, peer friendships, social activities)?
Objective	To establish how children and young people, and the parents or carers of babies and young children, prefer to access healthcare information
Searches	The following databases will be searched: • CCTR • CDSR • Embase • MEDLINE • MEDLINE IN-Process • PsycINFO Searches will be restricted by: • Date: 2009 • Language of publication: English language only • Publication status: Conference abstracts will be excluded because these do not typically provide sufficient information to fully assess risk of bias • Standard exclusions filter (animal studies/low level publication types) will be applied • For each search (including economic searches), the principal database search strategy is quality assured by a second information specialist using an adaption of the PRESS 2015 Guideline Evidence-Based Checklist
Condition or domain being studied	Babies, children and young people’s experience of healthcare

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

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

Field	Content
	• Self-harm: ○ Self-harm in over 8s: long-term management (CG133) ○ Self-harm in over 8s: short-term management and prevention of recurrence (CG16) • Sexual health and contraception ○ Contraceptive services for under 25s (PH51) ○ Sexually transmitted infections and under-18 conceptions: prevention (PH3) ○ Harmful sexual behaviour among children and young people (NG55) • Smoking prevention: ○ Smoking: preventing uptake in children and young people (PH14) ○ Smoking prevention in schools (PH23) ○ Stop smoking interventions and services (NG92) • Transition from children's to adults services for young people using health or social care services (NG43)
Context	UK studies from 2009 onwards will be prioritised for decision making by the committee as those conducted in other countries may not be representative of current expectations about either services or current attitudes and behaviours of healthcare professionals. The committee presumes that due to their development, particular circumstances and/or condition, there are some topics that babies, children and young people may not be in a position to pronounce on, and that in these circumstances, it may be necessary to treat the 'indirect' responses of their parents or carers as proxies for their own views on and experiences of healthcare in order to make recommendations. The guideline committee will be consulted on whether a study should be included if it is unclear why parents' or carer's responses are being used instead of their child or charge, and reasons for exclusion if appropriate will be documented. Recommendations will apply to those receiving care in all settings where NHS- or local authority- commissioned healthcare is provided (including home, school, community, hospital, specialist and transport settings). Specific recommendations for groups listed in the Equality Considerations section of the scope may be also be made as appropriate.
Primary outcomes (critical outcomes)	Themes will be identified from the literature. The committee identified the following potential themes (however, not all of these themes may be found in the literature, and additional themes may be identified): • Acceptability of means of, and barriers to, accessing information (e.g. product, portal, literature) • Avoidance of use of medical jargon • Co-production of healthcare information with children and families • Developmentally-relevant, culturally-appropriate information • Lack of accessibility (e.g. for people whose first language is not English; for people who have a sensory impairment) • Quality, quantity, type and pace of information provided (including too much information) • Role of charities, support groups, social media and social networks in finding and accessing information

Field	Content
	• Source and mode of information (e.g. website, charity, social media page; digital apps, online videos, pamphlets, podcasts, websites) The following themes will not be covered in this review despite relating to supporting participation in usual activities: • Barriers to and facilitators of accessing healthcare services (reviewed in RQ 8.1) • Factors that promote continuity of care (reviewed in RQ 8.2) • Physical healthcare environment (reviewed in RQ 6.1)
Secondary outcomes (important outcomes)	Not applicable
Data extraction (selection and coding)	• All references identified by the searches and from other sources will be uploaded into STAR and de-duplicated. Titles and abstracts of the retrieved citations will be screened to identify studies that potentially meet the inclusion criteria outlined in the review protocol. • Duplicate screening will not be undertaken for this question. • Full versions of the selected studies will be obtained for assessment. Studies that fail to meet the inclusion criteria once the full version has been checked will be excluded at this stage. Each study excluded after checking the full version will be listed, along with the reason for its exclusion. A standardised form will be used to extract data from studies, including study reference, research question, theoretical approach, data collection and analysis methods used, participant characteristics, second-order themes, and relevant first-order themes (i.e. supporting quotes). One reviewer will extract relevant data into a standardised form, and this will be quality assessed by a senior reviewer.
Risk of bias (quality) assessment	Risk of bias of individual qualitative studies will be assessed using the CASP Qualitative checklist. Risk of bias of systematic reviews of Qualitative studies will be assessed using the CASP (Critical Skills Appraisal Programme) Systematic Review checklist. See Appendix H in Developing NICE guidelines: the manual for further details. The quality assessment will be performed by one reviewer and this will be quality assessed by a senior reviewer.
Strategy for data synthesis	• Extracted second-order study themes and related first-order quotes will be synthesised by the reviewer into third-order themes and related sub-themes. • The GRADE-CERQual (Confidence in the Evidence from Reviews of Qualitative research; Lewin 2015) approach will be used to summarise the confidence in the third-order themes or sub-themes synthesized from the qualitative evidence. The overall confidence in evidence about each theme or sub-theme will be rated on four dimensions: methodological limitations, coherence, adequacy, and relevance. • Methodological limitations refer to the extent to which there were problems in the design or conduct of the studies and will be assessed with the CASP checklist for qualitative studies or systematic reviews as appropriate. Coherence of findings will be assessed by examining the clarity of the data. Adequacy of data will be assessed by looking at the degree of richness and quantity of findings. Relevance of evidence will be assessed by determining the extent to which the body of evidence from the primary studies are applicable to the context of the

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

Field	Content		
	Risk of bias (quality) assessment		
	Data analysis		
Named contact	**5a. Named contact** National Guideline Alliance **5b. Named contact e-mail** Infant&younghealth@nice.org.uk **5c. Organisational affiliation of the review** National Institute for Health and Care Excellence (NICE) and National Guideline Alliance		
Review team members	NGA Technical Team		
Funding sources/sponsor	This systematic review is being completed by the National Guideline Alliance, which receives funding from NICE.		
Conflicts of interest	All guideline committee members and anyone who has direct input into NICE guidelines (including the evidence review team and expert witnesses) must declare any potential conflicts of interest in line with NICE's code of practice for declaring and dealing with conflicts of interest. Any relevant interests, or changes to interests, will also be declared publicly at the start of each guideline committee meeting. Before each meeting, any potential conflicts of interest will be considered by the guideline committee Chair and a senior member of the development team. Any decisions to exclude a person from all or part of a meeting will be documented. Any changes to a member's declaration of interests will be recorded in the minutes of the meeting. Declarations of interests will be published with the final guideline.		
Collaborators	Development of this systematic review will be overseen by an advisory committee who will use the review to inform the development of evidence-based recommendations in line with section 3 of Developing NICE guidelines: the manual. Members of the guideline committee are available on the NICE website: https://www.nice.org.uk/guidance/indevelopment/gid-ng10119/documents		
Other registration details	-		
Reference/URL for published protocol	https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=145425		
Dissemination plans	NICE may use a range of different methods to raise awareness of the guideline. These include standard approaches such as: • notifying registered stakeholders of publication • publicising the guideline through NICE's newsletter and alerts • issuing a press release or briefing as appropriate, posting news articles on the NICE website, using social media channels, and publicising the guideline within NICE.		
Keywords	Access; accessibility; babies; children; experience; healthcare; infants; information; qualitative; views; young people		

Field	Content	
Details of existing review of same topic by same authors	Not applicable	
Current review status	☒	Ongoing
	☐	Completed but not published
	☐	Completed and published
	☐	Completed, published and being updated
	☐	Discontinued
Additional information		
Details of final publication	www.nice.org.uk	

CASP: critical appraisal skills programme; CCTR/CENTRAL: Cochrane controlled trials register); CDSR: Cochrane database of systematic reviews; GRADE-CERQual: grading of recommendations assessment, development and evaluation – confidence in the evidence from reviews of qualitative research; NGA: National Guideline Alliance; NHS: National health service; NICE: National Institute for Health and Care Excellence; PRESS: peer review of electronic search strategies

Appendix B – Literature search strategies

Literature search strategies for review question: How do children and young people, and the parents or carers of babies and young children, prefer to access healthcare information?

Databases: Embase/Medline/PsycINFO

Date searched: 29/07/2020

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

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

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

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

Database: Cochrane Library

Date searched: 29/07/2020

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

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

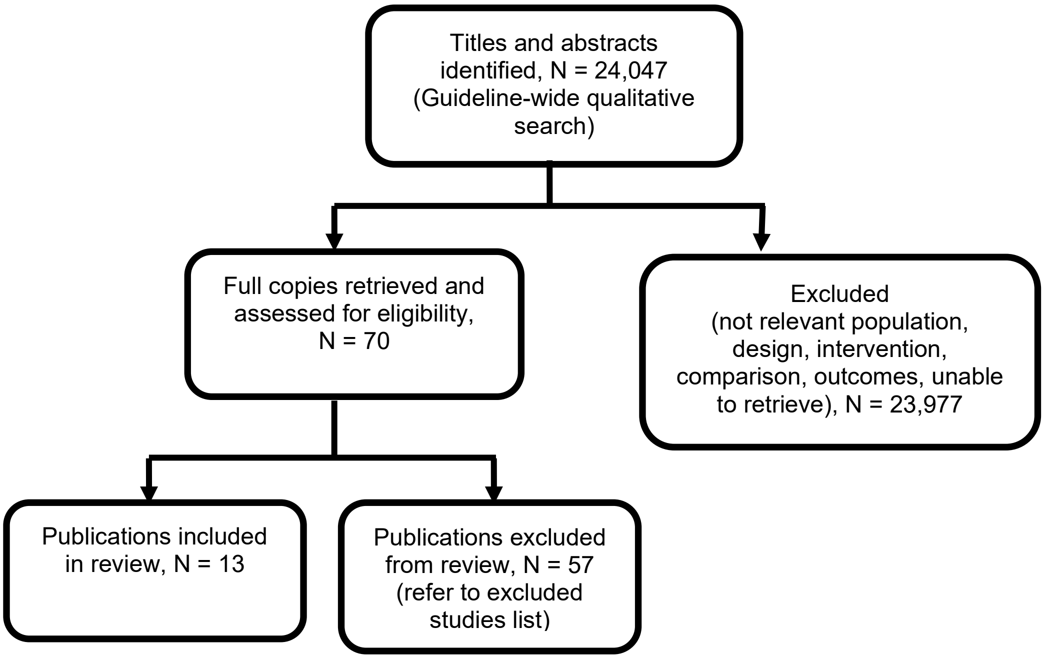
#	Search
100	(ethnograph*):ti,ab,kw
101	(ethnonursing):ti,ab,kw
102	(phenomenol*):ti,ab,kw
103	(life stor* or women* stor*):ti,ab,kw
104	(grounded near (theor* or study or studies or research or analys*s)):ti,ab,kw
105	((data near/1 saturat*) or participant observ*):ti,ab,kw
106	(field near (study or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

#	Search
135	#133 OR #134
136	#132 not #135
137	#125 not #136
138	#115 AND #137 with Cochrane Library publication date Between Jan 2009 and Aug 2020

Appendix C – Clinical evidence study selection

Study selection for: How do children and young people, and the parents or carers of babies and young children, prefer to access healthcare information?

Figure 2: Clinical evidence study selection flow chart



Appendix D – Clinical evidence tables

Evidence tables for review question: How do children and young people, and the parents or carers of babies and young children, prefer to access healthcare information?

Table 6: Evidence Tables

Study details	Participants	Methods	Themes and findings	Limitations
Full citation Alderdice, F., Gargan, P., McCall, E., Franck, L., Online information for parents caring for their premature baby at home: A focus group study and systematic web search, Health Expectations, 30, 30, 2018 **Ref Id** 773609 **Country/ies where the study was carried out** Belfast, Northern Ireland, UK **Study type** Focus group; qualitative **Aim of the study** To explore what parents deem important after returning home from	**Sample size** N=23 parents (21 mothers and 2 fathers) of premature infants **Characteristics** Age of babies: Born at <37 weeks gestation Gender of babies: not reported **Inclusion criteria** • Parent of baby born at less than 37 weeks' gestation who has been discharged from hospital **Exclusion criteria** • Unable to adequately understand verbal explanations in English	**Setting** Community, online **Recruitment** Eligible participants identified by Northern Ireland premature and sick baby charity, TinyLlife, through parents on their mailing list and through social media (Facebook page). Invitation letter sent by email and post and interested participants contacted TinyLife contact, who arranged convenient time and location for participation and informed research team. **Data collection** Three focus groups were conducted in three different locations in Northern Ireland to reflect urban and rural area using neutral venue. A total of 23 parents took part in a focus group (10 in focus group 1, eight in focus group 2 and five in focus group 3). Informed consent obtained upon arrival and complete short	**Author's themes:** • Web information: How parents wanted the information delivered **Findings** Parents reported using terms not solely related to prematurity but also more general newborn topics, such as feeding and digestion. Six websites were specifically mentioned. (Best Beginnings, Bliss, Babycentre, NHS direct and Netmums). The sixth was a breast-feeding website. General parenting websites were seen as attractive as they have larger communities of parents from different backgrounds and much more information on key issues such as feeding and nutrition, although this content was not always relevant to premature	**Limitations (assessed using the CASP checklist for qualitative studies).** *Q1: Was there a clear statement of the aims of the research?* Yes. *Q2: Was a qualitative methodology appropriate?* Yes. *Q3: Was the research design appropriate to address the aims of the research?* Yes. *Q4: Was the recruitment strategy appropriate to the aims of the research?* Probably not. Recruitment by online platform and through one charity may limit the applicability of findings to larger population *Q5: Were the data collected in a way that addressed the research issue?* Yes. focus groups justified and audio-recording mentioned.

Study details	Participants	Methods	Themes and findings	Limitations
hospital with their premature baby **Study dates** April 2016 **Source of funding** Funded by TinyLife Charity, Belfast, Northern Ireland	• Special communication needs	demographic/health questionnaire. Group rules explained and two researchers present for each group, one to facilitate and one to take notes. Open-ended questions asked and notes taken on flip chart to prompt discussion. Parents identified top-5 priorities. Sessions audio-recorded for transcription, which were professionally transcribed verbatim, cross-referenced by the researcher and analysed by hand along with field notes and flip charts. Participants received travel expenses and £20 for child care cover. **Analysis** The first stage of the content analyses was conducted during the focus group with topics being written on a flip chart as the topic was raised. Data analysis of the transcripts was undertaken using conventional content analysis following Morse and Field. Transcripts read by 2 researchers who identified and coded topics, and then categorised and compared to flip chart to ensure consistency and to identify gaps, and final themes agreed.	babies. Parents recognized that some websites gave information that caused further concern. Parents reported that they valued information from other parents and health professionals and they felt that ideally a website should have both perspectives. They were keen to hear other parents' stories on topics that were of concern to them but equally they also wanted to hear from health professionals to further inform and consolidate recommendations. A balanced approach, including content from both parents and health professionals, was preferred. Parents reported no preference for the mode of delivery of the information but felt a combination of video clips and text would appeal to more parents.	*Q6: Has the relationship between researcher and participants been adequately considered?* No. No description of potential bias/influence between researcher and participants. *Q7: Have ethical issues been taken into consideration?* Yes. Participant consent obtained, ethical approval obtained from Lancaster NRES (IRAS project id: 187383). *Q8: Was the data analysis sufficiently rigorous?* Yes. Clear and explicit findings presented and discussed in relation to the original research question. *Q9: Is there a clear statement of findings?* Yes. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* Yes. 1. Yes but very brief discussion of results in context of extant literature. 2. Possibly yes but small sample size and online recruitment through one charity limits the transferability of the research. *Overall judgement of quality:* Moderate concerns

Study details	Participants	Methods	Themes and findings	Limitations
Full citation 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 **Ref Id** 986875 **Country/ies where the study was carried out** South England, UK **Study type** Focus group; qualitative **Aim of the study** To explore young people's experiences, views and preferences regarding school-based sexual health and school nursing to inform commissioning and	**Sample size** N=74 children and young people **Characteristics** Age (range): 11-19 years • 11-13 years, n=16 • 14-15 years, n=40 • 16-17 years, n=17 • 18-19 years, n=1 Gender (M/F): 43/31 **Inclusion criteria** • Attending educational school-based institution (e.g. school, academy, youth centre) in one of 5 districts/boroughs in a South England local authority area **Exclusion criteria** None reported	**Setting** School **Recruitment** Purposeful sampling of school year groups from range of educational-based school settings in all 5 districts/boroughs of South England local authority, taking into account urban/rural location, deprivation scores, and demographic characteristics (gender, ethnicity, disability). Recruited schools sent letters to parents providing information on the project and giving parents the opportunity to "opt-out" via a slip that could be returned to the school. Other schools explicitly required parents to "opt-in" by returning a signed slip to the school. For youth groups and recruitment sites, the same procedures were followed as with schools, with a youth leader or equivalent acting as the gatekeeper and *locus parentis.* **Data collection** Data collected using participatory focus groups, ~ 1 hour duration during school day or in evening as appropriate, and topic guides on sexual health and health improvement/school nursing. Focus groups were single-sex andAll	**Author's themes:** • Visible sexual health education • Invisible school nursing **Findings** Young people were aware of the existence of local sexual health clinics (but not necessarily how to access them); however, they raised concerns about being seen by others when attending. Consequently, discussions over alternative means of accessing information and advice in school were mentioned, including leaflets, but importantly, there were suggestions for an individual anonymous question and answer service by text message. Furthermore, a number of young people saw online services as a means of accessing information when required, being available 24/7 and as a means of guaranteeing anonymity. In terms of preferences regarding future content of sex and relationship education, students mentioned many of the topics already covered in	**Limitations (assessed using the <u>CASP checklist for qualitative studies</u>).** *Q1: Was there a clear statement of the aims of the research?* Yes. *Q2: Was a qualitative methodology appropriate?* Yes. *Q3: Was the research design appropriate to address the aims of the research?* Yes. *Q4: Was the recruitment strategy appropriate to the aims of the research?* Yes. *Q5: Were the data collected in a way that addressed the research issue?* Yes. Single-sex focus groups given topic of sexual health, also risk assessment and safeguarding procedures in place during study. *Q6: Has the relationship between researcher and participants been adequately considered?* Yes. *Q7: Have ethical issues been taken into consideration?* Yes. Assent/consent obtained as appropriate. Research/ethical approval obtained from Local Authority's Research Governance Panel and

Study details	Participants	Methods	Themes and findings	Limitations
delivery for an English local authority area **tudy dates** 02/2015 to 03/2015 **Source of funding** Funded by a local authority in the South of England		activities using focus groups/interviews were recorded on a digital voice recorder and allocated a unique identifying number. Audio files transcribed verbatim, by an University-approved external supplier. All transcripts anonymised and NVivo 10 used. Consent obtained before and after session and participants received £10 voucher. **Analysis** A combination of thematic analysis (focus groups, interviews) and content analysis (e.g. post-it notes from interactive activities, data from kites and balloons activities) was used. Data analysed and coded, themes developed and triangulated by research team, including blind checks on data interpretation.	school. The isolated exceptions to this were recommendations for more information on sexting (sexual text messaging); the consequences of not following sexual health advice (e.g., becoming pregnant at a young age); and for young women, managing young men's boasting of sexual exploits by, for example, using an initiative known as the "C-Card" for contraception, more for status than for condom use. Overall, young people's awareness of school nurse, their role, what they did/could offer was poor. For example, young people demonstrated little awareness or knowledge of neither their school nurse nor related initiatives facilities or provision available in their respective schools. Young people commonly recounted that they did not know whom the school nurse was, or where he/she was located. For one young man, this lack of visibility translated into a lesser likelihood of ever	University Research Ethics and Governance Committee *Q8: Was the data analysis sufficiently rigorous?* Yes. Iterative approach of analysis involving research team. *Q9: Is there a clear statement of findings?* Yes. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* Yes. 1. Yes, discusses findings in context of literature and clinical practice. 2. Yes, although there is lack of ethnic minority and other White participants, as well as demographic information for some groups (gender in particular). *Overall judgement of quality:* Minor concerns

Study details	Participants	Methods	Themes and findings	Limitations
			seeing the nurse, given that she was so unfamiliar, even though he knew she was present in the school. Many young people were not aware of the range of health opportunities available to them via the school nurse (such as the C-Card initiative), viewing a school nurse as somewhere to go only if injured, feeling unwell or to be inoculated (jabs), rather than as an opportunity to actively improve and promote health (e.g., via advice, information and strategies on key health issues such as healthy eating, anxiety, alcohol, sexual health, relationships,). This lack of visibility and poor awareness of the range of health opportunities available via the school nurse meant young people did not feel connected to the service and that they were less likely to access this, even if they felt they needed to; when asked where they would go for help or advice on health in school, say on a sexual matter, and whether they might go to the school nurse, they were mostly	

Study details	Participants	Methods	Themes and findings	Limitations
			unsure. Anxiety over privacy was another key concern, especially regarding the location of the office. These fears over discretion and confidentiality were also raised in a mixed focus group, where several young women reflected on the process of receiving their human papilloma virus (HPV) vaccination. Although the next quote recognises the constraints on school nurses to deliver large numbers of vaccinations to young people, as well as privacy, it also raises important issues over consent, lack of information and understanding for/by young people, as well as issues of sexual health stigma and power, whereby young women experience little control over their own health or bodies: In response to these concerns, some male students again cited the use of technology to post anonymous questions as preferable to face-to-face contact. This preference for anonymity and use of the Internet was, however, conditional; for some young people reported	

Study details	Participants	Methods	Themes and findings	Limitations
			that their phones were monitored by their parents, or that Internet access in the home was limited or firewalled by parents. This meant that in reality online information regarding sex or sexual health was actually quite difficult to access.	
Full citation Arnott, J., Hesselgreaves, H., Nunn, A. J., Peak, M., Pirmohamed, M., Smyth, R. L., Turner, M. A., Young, B., Enhancing Communication about Paediatric Medicines: Lessons from a Qualitative Study of Parents' Experiences of Their Child's Suspected Adverse Drug Reaction, Plos one, 7 (10) (no pagination), 2012 **Ref Id** 1052885 **Country/ies where the study was carried out** North-West England, UK **Study type**	**Sample size** N=45 parents of 44 children (41 mothers and 4 fathers) Data from parents of children over-5 years were not extracted nor included in this review **Characteristics** Age of child (range): 0-17 years Gender of child (M/F): 24/20 **Inclusion criteria** • Parents of children who had a suspected adverse drug reaction identified on hospital admission, during in-patient treatment, or reported by parents using the Yellow Card **Exclusion criteria**	**Setting** Recruited from other studies **Recruitment** Participants recruited from 2 cohort studies (unplanned admission; admission for 48 hours or more) within the Adverse Drug Reaction (ADRIC) programme at a UK regional paediatric hospital and from the Yellow Card Scheme (a UK drug surveillance system allowing reporting of suspected adverse drug reactions [ADR]). In latter case, MHRA invited participants by letter detailing study to all parents who had submitted Yellow Card on behalf of child under 17 years; after 6 months, restricted to parents submitting cards for suspected ADRs linked to vaccines; parents contacted researchers if interested and interview arranged.	**Author's themes:** • How parents become aware that their child may be experiencing an ADR they were prescribed • Criticism about ADR management and communication • Parents of children with cancer were positive about ADR communication • How parents thought communication about suspected ADRs should be handled **Findings** Parents also spoke about the information sources that they drew on when making attributions about their child's symptoms. This included their personal experience with medicines, media coverage of problems	**Limitations (assessed using the <u>CASP checklist for qualitative studies).</u>** *Q1: Was there a clear statement of the aims of the research?* Yes. *Q2: Was a qualitative methodology appropriate?* Yes. *Q3: Was the research design appropriate to address the aims of the research?* Yes. *Q4: Was the recruitment strategy appropriate to the aims of the research?* Yes. *Q5: Were the data collected in a way that addressed the research issue?* Yes. *Q6: Has the relationship between researcher and participants been adequately considered?* Yes. Field notes in conjunction with transcripts consulted, whilst modified grounded theory

Study details	Participants	Methods	Themes and findings	Limitations
Semi-structured interview; qualitative **Aim of the study** To identify unmet information and communication needs of parents whose child has had a suspected adverse drug reaction **Study dates** Not reported **Source of funding** The United Kingdom Institute for Health Research	- Currently experiencing pronounced distress - Child protection concerns	**Data collection** Face-to-face or telephone semi-structured interviews, ~60 min average duration, conducted with use of topic guides by interviewers independent from researchers/MHRA; most interviews were audio recorded and all available were transcribed (some lost due to equipment failure). Transcripts included indicators of hesitation, repetition, dysfluency and sub verbal vocalisations and were checked by the interviewer who removed all identifying details before analysis. Field notes also recorded detailing context and observations. **Analysis** Modified (interpretative) grounded theory using constant comparison and constructivist interpretation of latent and manifest content. Multi-disciplinary triangulation attempted with one researcher analysing data and developing framework and two other researchers supporting analysis and discussion of issues, including emerging themes, deviant cases, coherence, and potential for practice.	with medicines and the concerns of friends and family. Information on the Internet could be a source of considerable anxiety for parents. Parents' communication needs could be extensive. However, parents' accounts indicated that clinicians' communication about a child's suspected ADR was often poorly matched to parents' needs. They reported communication as being contradictory and poorly coordinated, with some clinicians attributing the child's symptoms to a medicine, while other clinicians attributed the same symptoms to different causes. Parents remarked that the way in which clinicians managed and communicated uncertainty surrounding an ADR's identification did little to reassure them. Parents also described how they found clinicians' communication was poorly timed and paced, with parents receiving detailed information at times when they were anxious (e.g. when a child was critically unwell or	approach puts emphasis on participants' narrative. *Q7: Have ethical issues been taken into consideration?* Informed consent obtained and ethical approval from UK National Health Service research ethics committee (Northwest 3 Research Ethics Committee 08/H1002/7). *Q8: Was the data analysis sufficiently rigorous?* Yes. Three researchers involved in analysis and development of framework. *Q9: Is there a clear statement of findings?* Yes. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* Yes. 1. Yes, discusses findings in context of literature. 2. Findings plausibly generalisable to other acute situations, although study includes ~66% parents of children over-5 years old. *Overall judgement of quality:* Minor concerns **Other information** Note that only ~33% sample are parents of children <5 years; only

Study details	Participants	Methods	Themes and findings	Limitations
			immediately prior to surgery) and it was hard to absorb information, and receiving little or no information at times when they were less anxious and better able to absorb information. Commenting on how he/she felt overwhelmed with information at the height of his child's illness but received little support when his/her daughter's condition improved. Some parents were intensely critical and one parent, who was frustrated during a visit to outpatients when clinicians could not explain what was happening to his/her child spoke of feeling that he/she was being lied to by clinicians. More commonly, parents emphasized how their concerns had been ignored or dismissed by clinicians. Parents felt clinicians had dismissed the possibility that a child's symptoms could be related to a medicine with little exploration of parents' concerns or explanation of the reasons for ruling out an ADR. Despite the life-threatening nature of the illness and the	quotes from this group have been extracted.

Study details	Participants	Methods	Themes and findings	Limitations
			risks of cancer treatment, parents of children with cancer felt well supported by how clinicians communicated with them about medicines. There was a sense from the accounts of these parents that clinicians took ADRs seriously, were adept in communicating about them and had well-developed systems in place for the management of ADRs: Parents pointed to how clinicians discussed possible ADR symptoms and how to respond before an ADR happened, so that parents were clear about what to look out for and what action to take in the event of a suspected ADR. Consequently, parents felt that clinicians communicated about medicines and ADRs in a way that was ordered, timely and reassuring. Other parents reflected on the implications of poor communication about medicines and suspected ADRs. Parents commented on how a lack of information about potential ADRs at the time of prescription had	

Study details	Participants	Methods	Themes and findings	Limitations
			prevented them from being involved in decisions about their child's care. While parents sometimes thought clinicians were unwilling to discuss ADRs, none blamed clinicians for their child's problems or said they intended to formally complain, and only one expressed a slight ''loss of trust'' (YC8) in clinicians. However, a few parents explained that their trust in medicines had diminished. Alongside their wish for dialogue with clinicians about ADRs, Several parents also wanted accessible and reliable written information about ADRs.	
Full citation Best, Paul, Gil-Rodriguez, Elena, Manktelow, Roger, Taylor, Brian J., Seeking help from everyone and no-one: Conceptualizing the online help-seeking process among adolescent males, Qualitative health research, 26, 1067-1077, 2016	**Sample size** N=56 young people **Characteristics** Age (range): 14-15 years Gender (M/F): 56/0 **Inclusion criteria** • Young person aged 14-15 in school **Exclusion criteria** Not reported	**Setting** School **Recruitment** Focus groups conducted as part of larger study. Seven schools in Northern Ireland were recruited to participate in this study using cluster-based sampling (by school). Education level (secondary/grammar) and gender composition (single gender or co-educational) also considered in selection of schools. Researcher	**Author's themes:** • Search strategies • Pathways for help-seeking **Findings** Informal online help-seeking pathways increased opportunity for social support and reduced stigma but also included loss of control and reduced anonymity. Formal pathways offered increased anonymity but concerns were raised	**Limitations (assessed using the <u>CASP checklist for qualitative studies).</u>** *Q1: Was there a clear statement of the aims of the research?* Yes. *Q2: Was a qualitative methodology appropriate?* Yes. *Q3: Was the research design appropriate to address the aims of the research?* Yes.

Study details	Participants	Methods	Themes and findings	Limitations
Ref Id 1053374 **Country/ies where the study was carried out** Northern Ireland, UK **Study type** Semi-structured focus group; qualitative **Aim of the study** To conceptualize the process of online help-seeking by exploring how adolescent males locate and access support online **Study dates** Study conducted in 2014 **Source of funding** Lead author funded to conduct this work as part of UK Department of Education and Learning (DEL) PhD studentship		attempted to randomly select at least one pupil for each class in a school using a code assigned to each pupil on the relevant attendance registers. Teacher was also consulted to avoid internal conflict between pupils in focus groups; also emphasised to school officials importance of having range of pupils of mixed abilities to achieve representative sample of school population. Written consent from young person and child obtained prior to focus groups. **Data collection** Eight semi-structured focus groups of between 6 and 8 participants conducted in school assembly hall and library with designated teacher present. Topic guide developed, including on: online vs. offline help-seeking; use of social network sites to seek help; role of online/offline friends; positive and negative aspects of online help-seeking. Lead author present for all interviews. To facilitate disclosure, a modified photo-elicitation technique used - four A-4 sized cards of logos and home page screenshots from websites of 4 healthcare organisations: Samaritans, NHS Direct, CHildline, and Cancer Research UK, which were placed on table for length of	regarding participants' ability to locate and appraise the quality of information online. Search strategies Young men employ various strategies to assess quality of online mental health information, including comparative strategies, evaluating position of links on results page, and appraising general appearance of websites/information. However, while some discrimination is employed when selecting which search engine results to follow up, there is a lack of understanding among men as to what constitutes indicators of quality and how they should go about assessing the quality of websites and the information they provide. Moreover, they appeared to express "blind faith" in Google as a filter that will perform some element of evaluation for them. Nonetheless, there is evidence of some discernment from these groups in terms of weighing up which websites are of good quality and therefore worth investigating further.	*Q4: Was the recruitment strategy appropriate to the aims of the research?* Yes. *Q5: Were the data collected in a way that addressed the research issue?* Yes. Uses photo-eliciation technique and vignette, as well as targeted sampling of participants, to offset potential concerns over discussion of mental health issues in focus group format. *Q6: Has the relationship between researcher and participants been adequately considered?* Yes. *Q7: Have ethical issues been taken into consideration?* Yes. Written pupil and parental consent obtained prior to sessions and ethical approval granted by Ulster University's Research Ethics Committee (REC/12/0199). *Q8: Was the data analysis sufficiently rigorous?* Yes. *Q9: Is there a clear statement of findings?* Yes. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* Yes. 1. Yes, discusses results in detail and in context of literature.

Study details	Participants	Methods	Themes and findings	Limitations
		groups. Written vignette used if elicitation technique did not generate sufficient discussion. All groups audio-recorded and transcribed at semantic level using orthographic/verbatim style. Transcripts checked for accuracy, data anonymised and stored on secure university computer, and NVivo 10 used. **Analysis** Inductive thematic analysis assuming critical realist position and epistemological contextualism. Coding and analysis primarily at a semantic level, with participants' words taken at face value so that meanings explicitly stated in the data are captured. Three researchers from different instituitions familiarised themselves with data, making notes; then systematic coding data set using inductive and bottom-up approach; themes identified and structure agreed. Fourth researcher supervised process.	Informal pathway for help-seeking: Young men are in a double bind: Informal pathways not only appear to facilitate emotional expression and disclosure of personal issues to some degree on one hand but also limit it on the other due to confidentiality concerns. This pathway can provide a beneficial level of control and management of the disclosure process, but the very features that support disclosure (ease of access, immediacy, written disclosure as opposed to verbal) can also serve to discourage it. Formal pathway for help-seeking: Using formal pathways can lead individuals to improve their levels of control and management over the disclosure process, and of their image, as personal information is revealed in confidence. These have the potential to facilitate emotional expression and disclosure of personal issues in young men due to the additional level of trust ascribed to their	2. Yes, good sample size and reasonably representative of UK 14-15 year-old population. *Overall judgement of quality:* No or very minor concerns

Study details	Participants	Methods	Themes and findings	Limitations
			professional nature and it's independence from the individual's social network.	
Full citation Chaney, D., Coates, V., Shevlin, M., Carson, D., McDougall, A., Long, A., Diabetes education: What do adolescents want?, Journal of clinical nursing, 21, 216-223, 2012 **Ref Id** 1054207 **Country/ies where the study was carried out** Northern Ireland, UK **Study type** Semi-structured focus group; qualitative **Aim of the study** To establish adolescents' beliefs about the need for a structured diabetes education programme and their views on how it should be organised and what topics need to be addressed.	**Sample size** N=21 young people with Type I diabetes **Characteristics** Age of child (range): 13-19 years Gender of child (M/F): not reported **Inclusion criteria** • Patient between 13-19 years • At least 1 year diagnosis of Type I Diabetes • Able to communicate in English **Exclusion criteria** • Previously diagnosed psychiatric disorder	**Setting** Specialist clinic **Recruitment** Participants recruited from diabetes clinic lists of three Northern Irish acute Hospital Trusts. Purposive sampling from diabetes register according to age, gender and duration of diabetes to ensure diversity of participants. Sixteen participants invited to attend each focus group; 80 participants invited across 3 sites. **Data collection** Five semi-structured focus groups lasting 40-90 min, conducted by researcher and note-taker diabetes care team, conducted across 3 hospitals. Groups were preceded by short presentation of Berger structured diabetes education programme (for adults). Topic guide and list of questions used overing learning needs, session timing, delivery methods, and post-education support. Sessions held at 3 sites; where 2 groups held on 1 site, one was for 13-15 year-old and the other for 16-19 year-olds.	**Author's themes:** **Themes** • Practical and engaging • Frequency of delivery, timing, and location • Follow-up • Parental involvement **Findings** Engaging programme for young people is essential with use of practical sessions very important for learning by doing. Lectures about the subject areas to be addressed were discouraged with many adolescents stating that they would simply 'turn off' or not return after the first session. Group discussion, practical demonstrations and fun activities were identified as best way to deliver programme for this age group. Majority of adolescents willing to attend one session per week for a maximum of four weeks with some indicating should be away	**Limitations (assessed using the CASP checklist for qualitative studies).** *Q1: Was there a clear statement of the aims of the research?* Yes. *Q2: Was a qualitative methodology appropriate?* Yes. *Q3: Was the research design appropriate to address the aims of the research?* Yes. *Q4: Was the recruitment strategy appropriate to the aims of the research?* Yes. *Q5: Were the data collected in a way that addressed the research issue?* Yes but no demographic data collected. *Q6: Has the relationship between researcher and participants been adequately considered?* Unclear. Little discussion of this. Note taker was from participant's diabetes care team and notes used in analysis, so possibility of researcher bias. However use of topic guides may have obviated this to some extent.

Study details	Participants	Methods	Themes and findings	Limitations
Study dates Not reported **Source of funding** Completed as part of Fellowship award to lead author from Royal Belfast Hospital for Sick Children		With permission of participants and parents, each focus group digitally recorded using dictaphone, and transcribed verbatim. **Analysis** Thematic content analysis including of notes taken during focus groups, involving verbatim transcription, identification of themes, open coding, development of categories, and finally alignment of themes and categories.	from the hospital if possible, which might make the programme more accessible to those who may not attend for hospital appointments currently and make it congruent with normal life. School days should be avoided as this was seen as lengthening the school day. Varied opinions amongst participants about when to run programme. As many would rely on their parents for transport to the programme, mid to late evening was considered to be most appropriate. Follow-up was important for reassurance and guidance as well as support. Many adolescents did not wish to be contacted when with their friends or during school hours with text messaging indicated as the preferred means of contact by majority of participants. This allowed the adolescent to express difficulties without actually speaking to the health care professional, encouraging openness and honesty. Also allows them to keep information for future reference.	*Q7: Have ethical issues been taken into consideration?* Yes. Reports all usual ethical safeguards applied and ethical approval obtained from Office for Research Ethics Committee of Northern. *Q8: Was the data analysis sufficiently rigorous?* Unclear. Reports following 6-stage process of thematic content analysis of Newell and Burnard and appears (though not explicitly stated in main text) to be conducted by 2 researchers. *Q9: Is there a clear statement of findings?* Yes. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* Yes. 1. Yes, discusses findings in context of literature. 2. Yes, but limited to one health condition and lack of demographic info limits generalisability. *Overall judgement of quality:* Moderate concerns

Study details	Participants	Methods	Themes and findings	Limitations
			Majority of participants discouraged the involvement of parents in the education programme with need to be independent of parents emphasised throughout all focus groups. The exception to this was a minority of younger adolescents (13–15 years) who had no objection to their parents being involved but would not actively seek such involvement. The need to provide information for parents in respect of the education programme was acknowledged and encouraged. It was suggested this could be via an information leaflet or booklet.	
Full citation Harvey, M. E., Nongena, P., Gonzalez-Cinca, N., Edwards, A. D., Redshaw, M. E., Parents' experiences of information and communication in the neonatal unit about brain imaging and neurological prognosis: A qualitative study, Acta Paediatrica, International Journal of	**Sample size** N=18 parents (13 mothers and 5 fathers) of 15 neonates **Characteristics** Age of parents (range; median): 21-49 years; 34.5 years Age of neonate: Born at <33 weeks gestation Gender of neonate (M/F): 8/7	**Setting** Neonatal unit **Recruitment** Purposeful sampling of eligible parents in a tertiary neonatal unit. All participants gave informed consent and 2 parents decided not to participate. Babies born between 23+2 and 32+3 weeks gestation with birthweights ranging between 650 and 1720 g (median 1230 g); 9 Caesarean sections; 10	**Author's themes:** • Being passive recipients • The information-givers • Trying to gain control **Findings** In a few situations, parents found the lack of information distressing. Nurses were reported as reluctant to comment about the results	**Limitations (assessed using the CASP checklist for qualitative studies).** *Q1: Was there a clear statement of the aims of the research?* Yes. *Q2: Was a qualitative methodology appropriate?* Yes. *Q3: Was the research design appropriate to address the aims of the research?* Yes.

Study details	Participants	Methods	Themes and findings	Limitations
Paediatrics, 102, 360-365, 2013 **Ref Id** 470390 **Country/ies where the study was carried out** London, UK **Study type** Semi-structured interview; qualitative **Aim of the study** To explore information and communication needs of parents during their baby's care in the neonatal unit, focusing on brain imaging and neuro-logical prognosis **Study dates** Not reported **Source of funding** National Institute of Health and Research (NIHR)	**Inclusion criteria** • Parent aged 16 years or more • Infant born <33 weeks gestation approaching discharge or transfer at time of interview • Parent able to give informed consent • Parent able to take part in interview conducted in English **Exclusion criteria** None reported	births on site and others transferred in; At time of interview, babies were 4-53 days-old (median 15 days). Recruitment continued until data saturation reached. **Data collection** Experienced qualitative researcher conducted semi-structured interviews in a private room in the neonatal unit. Topic guide was used with key questions and possible follow-up questions or 'probes'. Audio recordings were made with parental consent to allow transcription and analysis with all data anonymised. All parents given information sheet about sources of support after interview. **Analysis** Grounded theory using constant comparative method. Data collection, transcription and data analysis was carried out concurrently in NVivo 7, with text coded into themes/subthemes. Study continued until data saturation reached and then participant recruitment terminated. Coding framework initially created by one researcher and reviewed and finalised in conjunction with two other researchers.	of investigations, and doctors were often unavailable as illustrated by a mother who had been told that her babies may have problems with cognitive development. Most parents felt the ward round was particularly valuable and often organised their day to attend, feeling involved in the discussions and reporting that exchanging information in this way helped them to learn more about their baby. Parents found update meetings with senior medical staff to be very useful. These were initiated either by the medical staff or the parents themselves. Discussion took place at the cot-side or in a quiet, private room in the NNU. The latter enabled parents to ask more detailed questions and raise specific concerns. Parents also accessed information from charts, nursing notes and other documentation. Some were unsure if they were 'allowed' to access this sort of information, although looked at them anyway.	*Q4: Was the recruitment strategy appropriate to the aims of the research?* Yes. Purposeful sample of parents. *Q5: Were the data collected in a way that addressed the research issue?* Yes. *Q6: Has the relationship between researcher and participants been adequately considered?* Can't tell. Insufficient details reported to determine although three researchers involved so likely some reflexivity occurred. *Q7: Have ethical issues been taken into consideration?* Yes. Ethical approval from Outer North London Research Ethics Committee (09/H0724/24). Impact of interview also monitored during it. *Q8: Was the data analysis sufficiently rigorous?* Yes. Three researchers involved in constant comparison and construction of themes. *Q9: Is there a clear statement of findings?* Yes. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)*

Study details	Participants	Methods	Themes and findings	Limitations
			Parents sometimes felt they had difficulty obtaining updated information, particularly about their baby's developmental prognosis. Nurses were the main providers of information about the equipment and daily updates about the baby. Whilst most parents were comfortable with this, they valued opportunities to speak with senior medical staff, even when this reinforced what they had previously been told by nursing staff or more junior doctors. Some parents felt they had limited control over information and communication processes because they were unable to initiate or influence discussion with healthcare professionals. This was most common during the days following their baby's NNU admission, whilst adjusting to the situation. Mothers who were unable to visit their baby for several days because of their own health problems, had to rely on members of the healthcare team or partners to bring information about	Yes. 1. Yes, findings discuss in context of literature. 2. Restriction to tertiary neonatal unit may limit transferability but attempted to capture range of neonatal unit experiences. *Overall judgement of quality:* Minor concerns

Study details	Participants	Methods	Themes and findings	Limitations
			the baby. During their baby's subsequent care, there were occasions when parents had limited control over information they received. This was particularly so with investigations such as brain imaging. Parents were commonly not told about ultrasound scans until they had been carried out sometimes finding out by chance. Parents mostly thought NNU staff were aware of the emotional impact of the information they gave. They were described as 'reassuring', 'understanding', 'caring', 'responsive', 'supportive' and 'encouraging'. Information received from medical staff about their baby's initial problems and possible outcome was felt to be straightforward and honest. Most parents preferred this style: 'You shouldn't be left in this little bubble thinking everything's rosy'. However, a few thought this approach was too candid and felt it was unnecessarily negative. In contrast, a few parents felt medical staff were oversensitive about the	

Study details	Participants	Methods	Themes and findings	Limitations
			emotional impact of the information they gave	

Full citation
Huby, K., Swallow, V., Smith, T., Carolan, I., Children and young people's views on access to a web-based application to support personal management of long-term conditions: a qualitative study, Child: care, health and development, 43, 126-132, 2017
Ref Id
1057170
Country/ies where the study was carried out
North England, UK
Study type
Semi-structured age-appropriate participatory activities; qualitative
Aim of the study
To explore children's and young people's views on the content of a proposed application to support
	Sample size
	N=26 children and young people with chronic kidney disease
	Characteristics
	Age (range): 5-17 years
	• 5-10 years, n=7
	• 11-15 years, n=10
	• 16+, n=9
	Gender (M/F): 14/12
	Inclusion criteria
	• Child or young person with chronic kidney disease stage 3-5
	Exclusion criteria
	None reported
		Setting
		Specialist clinic
		Recruitment
		Patients with CKD stages 3–5 identified from hospital records using purposive sampling based on age, sex, ethnicity and CKD stage. Study information provided was age-/developmentally-appropriate. Written signed consent (16+ years) or verbal assent/parental consent (child aged 5-15 years) obtained when appropriate.
		Data collection
		Children aged 5-10 years were encouraged to 'draw and tell'; those aged 11-15 years were engaged in face- to-face discussion; young people aged over-16 years were interviewed in a semi-structured way and addressed as adults. Specific topic guides were developed and used for all age groups and included: health information needs, problems with health information, and sources of health information, suggested formats for receiving of health information. interviews conducted by one researcher at convenient
			Author's themes:
			• Access (general theme)
			  ○ Access –Accessibility
			  ○ Access – information
			  ○ Access- Normalcy
			Findings
			The respondents were clear that an online information and support resource (resource) would only be useful if it were accessible on all platforms, on any device and in the presence of a Wi-Fi signal. Information needed to be clear, condition specific and accurate. The respondents did not want to navigate through pages of information to find what they were looking for. They wanted quick access to relevant key information. This influenced not only the type of information but also how the information was displayed. The participants stated that information needed to be age appropriate, acknowledge different learning styles and be secure. Accessibility could
				Limitations (assessed using the CASP checklist for qualitative studies).
				Q1: Was there a clear statement of the aims of the research? Yes.
				Q2: Was a qualitative methodology appropriate? Yes.
				Q3: Was the research design appropriate to address the aims of the research? Yes.
				Q4: Was the recruitment strategy appropriate to the aims of the research? Yes.
				Q5: Were the data collected in a way that addressed the research issue? Yes.
				Q6: Has the relationship between researcher and participants been adequately considered? Yes.
				Q7: Have ethical issues been taken into consideration?
				Yes. Ethical approval obtained from NHS Research Ethics Committee (Reference: 11/N/W/0268) and NHS Trust Research and Development Department

Study details	Participants	Methods	Themes and findings	Limitations
personal management of chronic kidney disease **Study dates** Not reported **Source of funding** Not reported		location (e.g. home, hospital quiet space) with all digitally recorded, transcribed verbatim and anonymised. **Analysis** Thematic (Framework) analysis assuming self-efficacy theory, involving two researchers, used. Five stages include familiarisation of data, developmental of theoretical framework, indexing, charting, and finally mapping/interpretation.	be increased by providing information in age-appropriate ways. Dividing the website into age-appropriate sections would also make finding appropriate information easier the use of colours and games was considered essential to engage younger children in contrast to young people themselves who were more concerned that the information was stated clearly. The presentation of information depended not only on individuals' ages but also on their learning styles. There was a recognition that some people liked to read a lot, whereas others preferred videos, cartoons or interactive games. The information delivered affected the way it should be presented, with many feeling that videos would be useful when learning new skills. Being able to refer to videos would enhance, not replace, the face-to-face teaching currently received from healthcare professionals. For those that travelled some distance to receive their treatment, it may	*Q8: Was the data analysis sufficiently rigorous?* Yes. Two researchers involved in framework analysis. *Q9: Is there a clear statement of findings?* Yes. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* Yes. 1. Yes, contextualises findings in existing literature. 2. Yes, limited to one type of condition but findings likely to apply to online self-management of other conditions. *Overall judgement of quality:* No or very minor concerns

Study details	Participants	Methods	Themes and findings	Limitations
			reduce travelling. Some thought that information relating to potential procedures and treatments may reduce some of the associated fear. However, some felt that too much information could cause anxiety. Concern was expressed about following advice from certain websites due to uncertainty about the accuracy of information: The proposed resource would only be used if the information was trustworthy and checked for accuracy by health professionals.	
Full citation Ingram, J., Cabral, C., Hay, A. D., Lucas, P. J., Horwood, J., Parents' information needs, self-efficacy and influences on consulting for childhood respiratory tract infections: a qualitative study, BMC family practice, 14, 106, 2013 **Ref Id** 989892	**Sample size** N=60 parents (58 mothers, 2 fathers) *Focus group only,* n=30 mothers *Semi-structured interview only*, n=23 parents (21 mothers and 2 fathers) *Focus group and semi-structured interview*, n=7 mothers Data from parents of children over 5 years were not extracted nor included in this review **Characteristics**	**Setting** General practice **Recruitment** Purposeful sampling of eligible parents for the interviews were identified through a search of patient records, in six GP practices, for those who had consulted in the previous 3 months for a child with a respiratory infection. When more than 60 parents initially identified in a practice, 30 letters sent to most frequent users of practice (for any reason) and 30 to least frequent users of practice. Seven younger mothers recruited for focus groups	**Author's themes:** • Illness information **Findings** Parents sought information and advice about coughs from a range of sources including lay and professional people within their social network (family, friends, health visitors, nursery workers and pharmacists), written information and advice available on websites, books and leaflets. No single	**Limitations (assessed using the CASP checklist for qualitative studies).** *Q1: Was there a clear statement of the aims of the research?* Yes. *Q2: Was a qualitative methodology appropriate?* Yes. *Q3: Was the research design appropriate to address the aims of the research?* Yes. *Q4: Was the recruitment strategy appropriate to the aims of the research?* Yes.

Study details	Participants	Methods	Themes and findings	Limitations
Country/ies where the study was carried out Bristol, UK **Study type** Focus group and/or semi-structured interview; qualitative **Aim of the study** To explore what parents' think about their support and information needs prior to consulting when their children have respiratory tract infections with cough, and to identify the facilitators and barriers to consulting primary care. **Study dates** 10/2010 to 05/2011 **Source of funding** Programme Grant for Applied Research, National Institute for Health Research (NIHR)	Age of child (range): 5 months-17 years Gender of child (M/F): not reported **Inclusion criteria** • Parent of child between 3 months old and 12 years old • Consulted 1 of 6 GP practices for their child's respiratory infection **Exclusion criteria** • Parent of child less than 3 months-old	also recruited for interviews to increase diversity. **Data collection** Seven focus groups, ~6--85 min duration, conducted in range of non-clinical setting (e.g. home) and 30 semi-structured interviews, ~30-90 min, conducted with parents of children aged 5-mo to 17 years from range of socio-economic backgrounds. Groups were stratified according to Socio-Economic Status and age of children (with only mother volunteering for focus group). Written/verbal information provided and written informed consent obtained. Focus group facilitated by three researchers, with one leading discussion, one taking flip chart notes, and one audio-recording sessions. Separate topic guides informed by Health Belief model were used for groups (parents' pre-consultation beliefs and behaviours) and interviews (parents' perceptions and experiences of primary care consultations when their child had a cough). Discussions were audio-recorded, and transcribed, anonymised, and checked for accuracy. **Analysis**	information source was used by all parents and they often referred to multiple sources before deciding what to do, if anything. When assessing the trustworthiness of information sources, parents felt that 'professional' sources were more credible. NHS branded websites were generally more trusted than other internet sources, as were people in their social network with some health training. However, those with extensive personal experience of children's illness were also trusted. Contradictory information or advice was likely to contribute to a decision to consult.	*Q5: Were the data collected in a way that addressed the research issue?* Yes. *Q6: Has the relationship between researcher and participants been adequately considered?* Can't tell. Insufficient information reported. *Q7: Have ethical issues been taken into consideration?* Yes. Written informed consent obtained and ethical approval from Southmead Local Research Ethics Committee 10/H0102/55. *Q8: Was the data analysis sufficiently rigorous?* Can't tell. Validation of coding on 2 focus group and 2 interviews conducted by two researchers, and mention of discrepancies discussed within research team, but unclear how many researchers involved in coding/analysis. *Q9: Is there a clear statement of findings?* Yes. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* Yes. 1. Yes, discusses findings in context of existing literature. 2. Yes. Although limited

Study details	Participants	Methods	Themes and findings	Limitations
		Thematic analysis using constant comparison method. Focus group data collection and analysis continued in parallel until data saturation reached and no new themes emerged. Findings from previous groups raised with later groups for discussion. NVivo 8 used to analyse interviews and groups transcriptions. Line-by-line coding of data conducted by 2 researchers with revisions made as appropriate. Coding consensus achieved through discussion with research team. Comparison of themes by Socio-Economic Status using parents' post codes also conducted.		to respiratory infections, some findings plausibly generalisable to other situations. However, only 2 fathers are included in entire sample. *Overall judgement of quality:* Minor concerns
Full citation Neill, S. J., Jones, C. H., Lakhanpaul, M., Roland, D. T., Thompson, M. J., Parent's information seeking in acute childhood illness: what helps and what hinders decision making?, Health expectations : an international journal of public participation in health care and health policy, 18, 3044-3056, 2015 **Ref Id**	**Sample size** N=27 parents (24 mothers and 3 fathers) of children aged less than 5 years old **Characteristics** Age of children: under-5 years Gender of children (M/F): not reported Age of parents: • <20 years, n=1 • 20-29 years, n=5 • 30-39 years, n=16 • 40-49 years, n=5 Ethnicity of parents:	**Setting** Community **Recruitment** Purposeful sampling of eligible parents were recruited from South Asian and Gypsy/Travelling communities, a Sure Start Children's Centre (community centre supporting families of children under 5 years age), and a private sector day nursery. **Data collection** Five focus groups (2-8 parents) and 3 semi-structured interviews conducted together and separately, respectively, by two researchers.	**Author's themes:** • Sources of information: Independent information seeking: delivery systems • Personal contact: Lay sources and health service use as source of information • Factors influencing information received • Factors influencing information access and information use **Findings**	**Limitations (assessed using the CASP checklist for qualitative studies).** *Q1: Was there a clear statement of the aims of the research?* Yes. *Q2: Was a qualitative methodology appropriate?* Yes. *Q3: Was the research design appropriate to address the aims of the research?* Yes. *Q4: Was the recruitment strategy appropriate to the aims of the research?* Yes.

Study details	Participants	Methods	Themes and findings	Limitations
1060151 **Country/ies where the study was carried out** East Midlands, UK **Study type** Focus group and semi-structured interview; qualitative **Aim of the study** To explore how parents use information resources at home to make decisions about their child's acute illness **Study dates** 05/2012 to 12/2012 **Source of funding** National Institute for Health Research (NIHR) under its Programme Grants for Applied Research funding scheme (RP-PG-0407-10347)	• Travelling community, n=6 • South Asian community, n=11 • White British community, n=10 **Inclusion criteria** • Parent of at least one child under 5 years old **Exclusion criteria** None reported	Duration ~1-2 hours in community centres, day nursery or parents' home. Topic guide used with open question and four prompts about finding information and making decisions. Discussions audio recorded, transcribed verbatim and anonymised. Demographic information also collected via questionnaire. **Analysis** Modified grounded theory using constant comparative method and NVivo 10. Descriptive coding transformed into substantive codes, which then informed theoretical sampling and future data collection in subsequent groups/interviews to clarify/refute themes. Coding developed by two researchers and discussed with research team.	Parents reported using three different information delivery systems: digital, hard copy and broadcast media. The internet was reported by most parents to be their default information source. However, this was not their first port of call when a child was acutely ill as it is too time-consuming and too difficult to use a keyboard with a distressed child. Parents reported being more likely to search the internet for information once they had a diagnosis. Searching to find out 'what things could be' (Gypsy/Travelling Family FG Mother) or for symptoms was not perceived to produce useful results. Parents reported usually starting searches from Google, even when intending to use NHS Direct (UK health service advice on-line (also available as telephone helpline). Open internet searching generated conflicting information adding to uncertainty about the nature and severity of their child's illness and increasing anxiety for some parents. This uncertainty was associated with a	*Q5: Were the data collected in a way that addressed the research issue?* Yes. *Q6: Has the relationship between researcher and participants been adequately considered?* Yes. Researcher's own roles and assumptions discussed. *Q7: Have ethical issues been taken into consideration?* Yes. Written informed consent obtained; ethical approval obtained from East Midlands–Nottingham 2 NHS Research Ethics Committee (REC reference 12/EM/0076), a well as from research and development officers of each local Trust and the managers of the day nursery and community centres. *Q8: Was the data analysis sufficiently rigorous?* Yes. Two researchers developed coding/themes, resolved disagreements, and discussed with research team. *Q9: Is there a clear statement of findings?* Yes. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* Yes. 1. Yes, discusses findings

Study details	Participants	Methods	Themes and findings	Limitations
			feeling of being bombarded with information, although internet searching was also reported by some parents to decrease anxiety. Internet forums appeared to supplement physical social networks, particularly in the White British community where participants described their friends being geographically dispersed. They provide access to social support during antisocial hours. Although parents said they might not trust information from these sources, they felt that it was reassuring Parents reported using Smartphone apps for information. One mother liked the ease of use and implied that because apps limit the information presented on any one screen this helps to prevent information overload. One mother had tried to use the NHS Direct app but stopped before getting the information she was looking for as there were too many questions. This suggests that parents expect Smartphones to provide	in context of literature and implications for practice. 2. Yes, wide range of socio-economic/ethnic groups of parents recruited although fathers not well represented. *Overall judgement of quality:* No or very minor concerns. **Other information** Data from this study also published in Neil et al. 2016

Study details	Participants	Methods	Themes and findings	Limitations
			faster access to simplified information than the web. Importantly, digital media were not an effective medium for those with limited literacy, including participants in the Gypsy/Travelling and South Asian communities. These parents referred to others in their local communities for advice, who were able to read or write in English or in their first language. Television was a valued source of information for parents either within programmes or within health promotion campaign advertisements (e.g. Meningitis 'glass test'), particularly for parents with low levels of literacy in English. Parents reported using various hard copy presentations of information including books, maternity information packs (known as the Bounty pack), the personal child health record (the red book), flash cards, leaflets and posters. Personal contact with others was the preferred option for some parents as it was only through such contacts that they felt reassured. Others	

Study details	Participants	Methods	Themes and findings	Limitations
			turned to personal contact when the use of information accessed independently did not meet their needs Posters in the hospital setting provided key messages on what to 'look out for'. Most parents were unaware of childhood illness information contained within sources of general information on child health such as the Birth to Five book. Parents perceived that there were four factors which influenced the information they were given by HCPs. Firstly, perceived demands on HCP time created pressure; parents felt that time pressures limited the information doctors could provide, describing their consequent use of the internet to supplement it. Secondly, some parents felt that HCPs' attitudes towards them, and the information they provided, were influenced by whether or not HCPs themselves were parents. For example, parents reported feeling that becoming a parent made HCPs more sympathetic. Thirdly, parents perceived	

Study details	Participants	Methods	Themes and findings	Limitations
			that HCPs altered their response according to their assessment of the parents' competence. For example, they described reduced information provision to parents of more than one child (an assumption of knowledge). Fourthly, parents reported that the social distance between parents and HCPs limited information they felt able to give and, consequently, the information HCPs provided in response. Some parents felt intimidated by and/or feared criticism from HCPs indicating that parents position themselves as subservient to the HCP illustrating perceptions of doctors' superior location within the social hierarchy. The unequal power distribution in such relationships can result in communication dominated by those with the most power such as HCPs, consequently inhibiting parents' ability to communicate their concerns. Fathers described particular problems accessing hard copy or verbal information,	

Study details	Participants	Methods	Themes and findings	Limitations
			due to their traditional roles in British society as they continue to be the parent most likely to be in full-time employment. They struggled to access health information about their children as many information delivery systems are designed around daytime attendance, including consultations with GPs, child health clinics and community education events. Fathers explained that they were reluctant to access these at weekends because this would eat into time when they could be with their children. Low levels of literacy also created problems for both fathers and mothers, as described above. Stress, created by the child's illness, was also described as reducing parents' ability to understand instructions or to recall information. Parents talked about the timing of information provision. Before the birth of their child, the mother's main focus was on the developing baby and the birth, rather than the possibility of childhood illness thereafter.	

Study details	Participants	Methods	Themes and findings	Limitations
			Information provided immediately after the birth was valued at the time but later not used. When parents did consult a doctor with their child, some were given information during the consultation, usually verbally and often only in response to questions from the parents themselves.	
Full citation Neill, S. J., Jones, C. H., Lakhanpaul, M., Roland, D. T., Thompson, M. J., Parents' help-seeking behaviours during acute childhood illness at home: A contribution to explanatory theory, Journal of child health care : for professionals working with children in the hospital and community, 20, 77-86, 2016 **Ref Id** 991707 **Country/ies where the study was carried out** East Midlands, UK **Study type**	**Sample size** N=27 parents (24 mothers and 3 father) of children less than 5 years-old **Characteristics** Age of children: under 5 years Gender of children (M/F): not reported Age of parents: • <20 years, n=1 • 20-29 years, n=5 • 30-39 years, n=16 • 40-49 years, n=5 Ethnicity of parents: • Travelling community, n=6 • South Asian community, n=11 • White British community, n=10	**Setting** Community **Recruitment** Purposeful sampling of eligible parents were recruited from South Asian and Gypsy/Travelling communities, a Sure Start Children's Centre (community centre supporting families of children under 5 years age), and a private sector day nursery. **Data collection** Five focus groups (2-8 parents) and 3 semi-structured interviews conducted together and separately, respectively, by two researchers. Duration ~1-2 hours in community centres, day nursery or parents' home. Topic guide used with open question and four prompts about finding information and making	**Author's themes:** • Social support and its impact on help-seeking behaviours • Access to health services • Trust in service provider and effect on help-seeking behaviour • Social expectations and their influence on parents' help-seeking behaviour **Findings** Adequate information, /education and experience in managing acute illnesses determined parental confidence in accessing services or not. First-time parents were more likely to check minor health problems with healthcare professionals.	**Limitations (assessed using the CASP checklist for qualitative studies).** *Q1: Was there a clear statement of the aims of the research?* Yes. *Q2: Was a qualitative methodology appropriate?* Yes. *Q3: Was the research design appropriate to address the aims of the research?* Yes. Qualitative design using interviews and focus groups using key elements of grounded theory were used to explore the qualitative approach the concept, focusing on participant-defined problems and explanatory power. *Q4: Was the recruitment strategy appropriate to the aims of the research?* Yes. Sampling targeted parents in communities with differing social, economic

Study details	Participants	Methods	Themes and findings	Limitations
Focus group and semi-structured interview; qualitative **Aim of the study** To explore barriers and facilitators to parental help-seeking and access of healthcare services in several different socio-economic groups. **Study dates** 05/2012 to 12/2012 **Source of funding** Supported by Programme Grants from Applied Research and a Career Development Fellowship from National Institute for Health Research.	**Inclusion criteria** • Parent of at least one child under 5 years-old **Exclusion criteria** None reported	decisions. Discussions audio recorded, transcribed verbatim and anonymised. Demographic information also collected via questionnaire. **Analysis** Modified grounded theory using constant comparative method and NVivo 10. Descriptive coding transformed into substantive codes, which then informed theoretical sampling and future data collection in subsequent groups/interviews to clarify/refute themes. Coding developed by two researchers and discussed with research team.	Access to NHS111, NHS Direct web pages or online parent forums were highlighted as increasing access to healthcare information and out-of-hours services. Alternative convenient options such as walk-in centres and going to their local Accident and Emergency department were mentioned Lack of flexible appointment times or difficulties booking appointments that did not clash with family life were barriers to accessing healthcare services. For example, appointments are offered at a young child's bedtime, or parents are required to telephone or queue for an appointment at 8 a.m. when preparing for school and work. Lack of trust in healthcare services was moderated by developing a relationship between parents and healthcare professionals. Previous bad experiences with healthcare professionals meant parents resorted to other strategies to obtain healthcare information.	and ethnic profiles. Recruitment was facilitated by assistance from the Comprehensive Local Research Network and community centre leaders" was provided. *Q5: Were the data collected in a way that addressed the research issue?* Yes. Focus groups were conducted with parents, which would facilitate in-depth content. *Q6: Has the relationship between researcher and participants been adequately considered?* No. Descriptions of potential bias/influence between researcher and participants was not described. Field notes were incorporated into the analysis and not necessarily indicating reflexivity. *Q7: Have ethical issues been taken into consideration?* Yes. Written informed consent given by all participants and ethical approval was obtained from both East Midlands and Nottingham NHS Research Ethics Committees (and relevant NHS Trusts). *Q8: Was the data analysis sufficiently rigorous?* Can't tell. Information on how themes were

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				developed or use of independent researchers to develop categories using an iterative approach; resolve disagreements and contrary statements were not described. But input from the wider team was mentioned. *Q9: Is there a clear statement of findings?* Yes. The study findings were adequately described; multiple views were considered from the focus groups. The findings were well situated within the study aims and current literature on attitudes and beliefs of young people. Credibility, reflexivity, trustworthiness and triangulation were not discussed, but limitations were acknowledged. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* Yes. 1. Yes. Details how the study findings fit in with current literature and the UK population, and how they can be used to inform best practice. Ideas and directions for future research presented. 2. Yes. Good population size for qualitative study and sample had a wide age range for parents, with broad findings applicable to

Study details	Participants	Methods	Themes and findings	Limitations
				general, minority or deprived populations. *Overall judgement of quality:* Serious concerns **Other information** Reports additional data from study originally published in Neil et al. 2015.
Full citation Nightingale, R., Hall, A., Gelder, C., Friedl, S., Brennan, E., Swallow, V., Desirable Components for a Customized, Home-Based, Digital Care-Management App for Children and Young People With Long-Term, Chronic Conditions: A Qualitative Exploration, Journal of medical Internet research, 19, e235, 2017 **Ref Id** 786356 **Country/ies where the study was carried out** UK	**Sample size** N=36 • n=17 children and young people • n=12 parents (10 mothers, 2 fathers) • n=7 healthcare professionals Data from parents and healthcare professionals were not extracted nor included in review **Characteristics** Age (range): • 5-10 year olds, n=6 • 11-14 year old, n=6 • 15-18 year old, n=5 Gender (M/F): 9/8 **Inclusion criteria**	**Setting** Specialist clinic **Recruitment** Potential participants were identified by 2 researchers in 1 of 2 UK paediatric kidney units using purposeful sampling according to the child's age, developmental stage, ethnicity, and sex until theoretical data saturation reached. **Data collection** Once verbal consent for researcher to contact participants obtained, appropriate information sent to participants. Informed consent and assent/parental consent obtained where appropriate. Nineteen semi-structured interviews and 8 focus groups conducted, as preferred by	**Results summarised under the following themes:** • Gaps in current information and support • Suggestions for a digital care-management app **Findings** Concern was expressed about whether websites contained accurate information and, therefore, whether they could be relied upon to promote mastery, although those from recognized organizations (eg, NHS Choices and the National Kidney Foundation) were viewed as more trustworthy.	**Limitations (assessed using the CASP checklist for qualitative studies).** *Q1: Was there a clear statement of the aims of the research?* Yes. *Q2: Was a qualitative methodology appropriate?* Yes. *Q3: Was the research design appropriate to address the aims of the research?* Yes. *Q4: Was the recruitment strategy appropriate to the aims of the research?* Yes. *Q5: Were the data collected in a way that addressed the research issue?* Yes. *Q6: Has the relationship between researcher and participants been adequately considered?* Yes.

Study details	Participants	Methods	Themes and findings	Limitations
Study type Participatory-based focus group and semi-structured interview; qualitative **Aim of the study** To explore the views of children with chronic kidney disease, their parents, and health care profession-als to inform future develop-ment of a child-focused, care-management mobile app **Study dates** Not reported **Source of funding** Research award from the British Renal Society and the British Kidney Patient Association	• Child or young person with chronic kidney disease, their parents or related health professionals **Exclusion criteria** None reported	participants in child-friendly setting (e.g. home). Joint interviews with parent and child concentrated on child's views. Interviews used topic guides developed by researchers in cooperation with a virtual advisory group. Children's views on strengths and limitations of existing web and mobile resources related to chronic kidney disease or general health issues explored using age- and developmentally appropriate methods, including demonstrating existing web resources and mobile apps to facilitate discussion. Views of 5-10 year-olds could also be elicited through use of 'Draw and tell' method if participant preferred. **Analysis** Thematic (Framework) analysis using iterative process of data collection, theme identification, coding/labelling data, category/pattern identification and seeking interpretations. Four researchers involved in discussion and resolution of themes.	Young people expressed concerns about the accessibility of online information, reporting difficulties with searching for, and finding, information. Though some reported that professionals had recommended specific websites, for others the preference was to ask their professional, rather than “trawl” through information online. For some young people, searching online was considered much less accessible than using a mobile app.	Research involved patient and public throughout project and virtual advisory group composed of young people with CKD and parents advised on study management, topic guides, web resources used, data analysis and dissemination. *Q7: Have ethical issues been taken into consideration?* Yes. Ethical approval obtained from the Health Research Authority, a National Health Service (NHS) Research Ethics Committee (reference No. 16/NW/0227), and NHS Trust Research and Development Departments. *Q8: Was the data analysis sufficiently rigorous?* Yes. Four researchers involved in development of themes until consensus reached. *Q9: Is there a clear statement of findings?* Yes. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* 1. Discusses in context of literature, practice. 2. Yes, wide range of age groups involved at all stages of project.

Study details	Participants	Methods	Themes and findings	Limitations
				Overall judgement of quality: No or very minor concerns **Other information**
Full citation Reen, G. K., Muirhead, L., Langdon, D. W., Usability of Health Information Websites Designed for Adolescents: Systematic Review, Neurodevelopmental Model, and Design Brief, Journal of medical internet research, 21, e11584, 2019 **Ref Id** 1061288 **Country/ies where the study was carried out** Various **Study type** Systematic review **Aim of the study** To determine the preferences of	**Sample size** K=25 studies with total of 2621 participants **Characteristics** Age (range; mean) of participants in included studies: 11-25 years; 15.2 years Participants from non-clinical population: 2074/2621 (79.1%) Participants from clinical population: • Adolescents diagnosed with diabetes: 322/2621 (12.3%) • Juvenile idiopathic arthritis: 54/2621 (2.1%) • Haemophilia: 47/2621 (1.8%) • Depression: 42/2621 (1.6%) • Participants with other conditions (all <1%): Cancer; Cystic Fibrosis,	PRISMA guidelines followed to present review, which was not previously published or registered. **Search strategy** Uniform search terms developed and used in systematic search of PubMed, PsychInfo, and Education Resources Information Center (ERIC) databases. **Data extraction** Following details were extracted from included studies: • Participant demographics (age, gender, clinical or nonclinical population) • Specific health information website including topic of website and characteristics • Currently availability of website on the internet • Method used to evaluate usability of website • Any data on children's and young people's feedback on usability **Quality assessment of included studies**	**Features of included studies** **Analysis** Studies were broadly qualitative in study design as they collected interview data or used ad hoc surveys. Narrative synthesis based on qualitative findings of studies. Results were categorised into appearance (e.g. visual appearance, organisation of information, and screen size), burdens (e.g. barriers to navigation), delivery of content (e.g. animations, videos, illustrations, vignettes, and testimonials), message source (eg, credibility and age-appropriateness of the website), and participation (e.g. the degree of interaction by users), based on Ritterband's work on usability of websites. Results further categorised by clinical and non-clinical status of user, by age (≤14	**Limitations assessed using Critical Skills Appraisal Programme (CASP) Systematic Review checklist.** *Q1: Did the review address a clearly focused question?* Yes. *Q2: Did the authors look for the right type of papers?* Yes. *Q3: Do you think all the important, relevant studies were included?* Can't tell, but search strategy and eligibility criteria should have picked up relevant articles. *Q4: Did the review's authors do enough to assess quality of the included studies?* Yes. CASP qualitative checklist used and assessed by 2 independent researchers, with disagreements resolved through discussion. *Q5: If the results of the review have been combined, was it reasonable to do so?* Not applicable. Narrative synthesis conducted.

Study details	Participants	Methods	Themes and findings	Limitations
adolescent regarding the usability of specific health information websites and to identify the difficulties they face when attempting to access these sites. **Study dates** Search conducted from 2000 to April 2018 **Source of funding** None reported	Migraines, recent kidney transplant (~3%) **Inclusion criteria** • Peer-reviewed original articles published in English about health information website for any health topic (i.e. those that predominantly provide information about specific health topic or provide general health guidance) • Study included some (clinical or non-clinical) participants aged between 13 and 17 years • Study conducted some form of usability testing of website from perspectives of children and young people • Any study design if previous criteria met **Exclusion criteria** • Study only includes participants 18 years or older, or younger than 13 years • Studies on other forms of web-based health content (e.g. information on social media platforms, web-	CASP checklist used to evaluate each study by 2 reviewers independently but not to exclude studies. Discrepancies between reviewers were slight and resolved after discussion.	years-old, >14 years-old), and gender. **Participants** Participants in the included studies were recruited from a range of sources, including: • middle and secondary schools • specialist clinics • online • youth services • those who had participated in other studies • those already accessing the relevant website **Themes** • *Website characteristics* Majority of websites studied were designed for specific health topics and intended for older children and young people (i.e. adolescents). Websites evaluated included those about: weight management, physical activity and diet, organ transplants, transition from paediatric to adult services, human papillomavirus, diabetes, depression, cancer, chronic pain, migraines and anxiety. General health websites	*Q6: What are the overall results of the review?* Adolescents preferred interactive (e.g. games, quizzes) and multimedia content (e.g. video, images. audio clips, animations) on websites, with a preference for communicating with peers with same condition and learning through real stories/testimony. Difficulties using websites due to bad user interface design (e.g. too much text, cluttered look). *Q7: How precise are the results?* Narrative synthesis conducted; review does not report country in which study was conducted nor overall data regarding gender of participants. *Q8: Can the results be applied to the local population?* Yes. Websites accessible to local population and although includes studies from other countries, reasonable to assume some homogeneity in the experience of children and young people across the world regarding use of health-related websites. Future health-related websites should be designed with the adolescent neuro-developmental profile, and users' specific preferences and skills, in mind.

Study details	Participants	Methods	Themes and findings	Limitations
	based courses, short-term education modules, tools to collect patient data) • Studies that evaluate usability of health websites that do not predominately provide information about health topics • Studies that focus on changing adolescent behaviour • Studies that only describe health information website, did not evaluate usability from user feedback, or only describe protocol • Studies evaluating non-health related information websites		included topics on mental health, diet, drugs and alcohol, contraception and sleep patterns. Four websites were evaluated by more than one study. • *User feedback* Studies in clinical and non-clinical population collected usability feedback using variety of methods, including: surveys, interviews, website visits essays. Several studies in clinical population also used 'think aloud' procedures, recording users thoughts as they use website, whilst one study in non-clinical population also used focus groups. • *Visual appearance* Participants in clinical population liked websites that were simple and used bright colours (both younger and older adolescents), and did not like websites with lots of blank space on webpage (older adolescents). In non-clinical population, did not websites to be too dull or boring or had lots of blank space on	*Q9: Were all important outcomes considered?* Yes. Concentrates on usability of websites using established framework for development of health-related websites. *Q10: Are the benefits worth the harms and costs?* Yes. Tailoring website design to its users should clearly improve their experience in a digital world without appreciable risks. *Overall judgement of quality:* Minor concerns **Other information**

Study details	Participants	Methods	Themes and findings	Limitations
			webpage. Excessive text was not considered visually appealing. • *Navigation burden* Ten studies recorded how easy it was to navigate websites. Websites generally easy to navigate for people in clinical population although suggestions for improvements included search bar, drop down menus, information at top of page, hyperlinks in text. In non-clinical population, 2 studies showed generally easy and 1 study mixed (all female participants). Slow loading times or difficult log-in procedure not liked. • *Delivery of content* Participants in clinical population strongly expressed their preference for content delivered using videos images , audio clips , and animations. However, adolescents also wanted videos to be clearly visible controls on videos and animations to be clearly displayed, “cheesy” images	

Study details	Participants	Methods	Themes and findings	Limitations
			to be removed and all content delivery to be accessible and easy to comprehend. Adolescents did not like images that were too difficult to understand and stated that medical images on the website should have labels to improve clarity. Adolescents really liked seeing real stories and testimonials from other adolescents who had the same health issues especially when presented in a video format, and if the stories were positive in nature. Adolescents also liked content that was generated by other users. • *Message source* Three studies in clinical population reported participants found website to be age-appropriate although all were over-14. Non-clinical participants aged 13-18 in 1 study showed website to be age-appropriate. Suggestions by older adolescents included to improve message source were making logo and website name clearer and more suitable for target	

Study details	Participants	Methods	Themes and findings	Limitations
			audience. Pages from one website were thought to be 'too girly' or to contain too much information about what boys like. • *Participation* Interactive features of websites generally favoured, which should be easy to navigate and use. Participants in clinical populations liked games and quizzes, journal feature, and ability to personalise website. One study provided access to medical records, which many found useful though for some it was overwhelming. Health websites that allow interaction with peers and health professionals appreciated although not always most used feature. Social networking features also favoured. However, anonymity during social interaction was important. Similarly, non-clinical population wanted more interactive features, including games, quizzes, ability to set goals or customise website, scrapbook feature, incentive	

Study details	Participants	Methods	Themes and findings	Limitations
			point-based system, or interactive demonstration of health information. Social networking features, e.g. discussion boards, chat rooms, phone support, favoured.	

Full citation
Waite-Jones, J. M., Majeed-Ariss, R., Smith, J., Stones, S. R., Van Rooyen, V., Swallow, V., Young People's, Parents', and Professionals' Views on Required Components of Mobile Apps to Support Self-Management of Juvenile Arthritis: Qualitative Study, JMIR MHealth and UHealth, 6, e25, 2018
Ref Id
1063452
Country/ies where the study was carried out
North England, UK
Study type
Semi-structured interview and focus group; qualitative
	Sample size
	N=25
	• n=9 young people
	• n=8 parents/carers
	• n=8 healthcare professionals
	Data from parents, carers and healthcare professionals were not extracted nor included in this review
	Characteristics
	Age of young person (range): 10-17 years
	• 10 years-old, n=1
	• 11 years-old, n=1
	• 13 years-old, n=2
	• 14 years-old, n=2
	• 15 years-old, n=2
	• 17 years-old, n=1
	Gender (M/F): 2/7
	Inclusion criteria
	• Aged 10-18 years
		Setting
		Specialist clinic
		Recruitment
		Purposeful sampling of young people aged 10-18 years from paediatric rheumatology clinic database of large teaching hospital in north England, catering for juvenile arthritis, by rheumatology nurse specialist according to age, developmental stage, disease type and duration, ethnicity, sex, socioeconomic status and treatment type. Parents/carers, and relevant professionals (e.g. consultants, psychologist, youth worker), invited by nurse specialist. Verbal and written information (e.g. developmentally-appropriate topic guides, info sheets; assent/consent forms) provided to potential recruits.
		Data collection
		Participatory semi-structured interviews and focus groups, ~35-
			Author's themes:
			• *Purpose*
			  ○ App ownership
			  ○ Monitoring chronic rheumatic diseases and information sharing
			  ○ Facility for reminders
			• *Components and content*
			  ○ Desired components
			  ○ Essential content
			  ○ Practical considerations
			• *App-enabled social support*
			  ○ Access and signposting to existing support networks
			  ○ Secure peer support
			  ○ Understanding from others without juvenile arthritis
			  ○ Parent support network
			Despite differences in emphasis on essential content, general agreement between young people with
				Limitations (assessed using the CASP checklist for qualitative studies).
				Q1: Was there a clear statement of the aims of the research? Yes.
				Q2: Was a qualitative methodology appropriate? Yes.
				Q3: Was the research design appropriate to address the aims of the research? Yes.
				Q4: Was the recruitment strategy appropriate to the aims of the research? Yes. Purposeful sampling from paediatric clinic database.
				Q5: Were the data collected in a way that addressed the research issue? Yes.
				Q6: Has the relationship between researcher and participants been adequately considered? Yes. Five researchers involved in triangulation of data and user ambassador involved at every stage of research.
				Q7: Have ethical issues been taken into consideration? Ethical approval obtained from National Health Service Health Research

Study details	Participants	Methods	Themes and findings	Limitations
Aim of the study To examine the views of young people with Juvenile Arthritis, their parents or carers, and health care professionals (HCPs) as to what a mobile app to facilitate young people's self-management of chronic Juvenile Arthritis should include **Study dates** Not reported **Source of funding** Funding competitively awarded through University of Leeds Pump Priming Programme	• Diagnosed with chronic rheumatic disease **Exclusion criteria** None reported	60 min duration, using developmentally-appropriate topic guides to structure discussion and four self-management apps (chosen by 'user ambassador') were demonstrated two for adults with rheumatoid arthritis; one for adults with chronic pain; one for younger people with type II diabetes mellitus). Young people with parents/carers were interviewed (one young person was interviewed on their own due to time constraints), whilst professionals attended group. Topic guides used to explore participants' views of self-management apps, including existing apps, barriers./facilitators to app use, design, data sharing; participants also given opportunity to offer additional comments. Young people sent £10 thank you voucher and support group information after interviews. All groups and interviews digitally recorded and transcribed. **Analysis** Thematic (Framework) analysis by 5 experienced child health researchers, including consultation with user ambassador at all stages of project. Two transcripts initially coded and 4 themes and related subthemes emerged. All transcripts	Juvenile Arthritis and their parents or carers, and professionals, that self-management mobile app would be useful. underlying themes was prerequisite that young people are enabled to feel sense of ownership and control of app, and that it be an interactive, engaging resource that provides developmentally-appropriate information, reminders, and that it enable them to monitor their symptoms and access social support.	Authority (reference no: 193786). *Q8: Was the data analysis sufficiently rigorous?* Yes. Five researchers involved in framework analysis. *Q9: Is there a clear statement of findings?* Yes. Q10: Is the research valuable for the UK? Yes. (1. Contribution to literature and 2. Transferability) 1. Yes, discusses findings in context of literature. 2. Possibly yes, potentially generalisable to other conditions though note lack of male participants and ethnic minority participants. *Overall judgement of quality:* No or very minor concerns. **Other information**

Study details	Participants	Methods	Themes and findings	Limitations
		analysed using preliminary framework and displayed in MS Excel. Themes then discussed, refined and critically evaluated. All final themes/subthemes/quotations reviewed and consensus reached.		

Appendix E – Forest plots

Forest plots for review question: How do children and young people, and the parents or carers of babies and young children, prefer to access healthcare information?

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

Appendix F – GRADE-CERQual tables

GRADE-CERQual tables for review question: How do children and young people, and the parents or carers of babies and young children, prefer to access healthcare information?

Table 7: Evidence summary (GRADE-CERQual) for theme 1: Searching for relevant healthcare information

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
Sub-theme 1.1: Evaluating quality of information							
8 (Alderdice 2018, Arnott 2012, Best 2016, Harvey 2013, Huby 2017, Ingram 2013, Neill 2015/2016, Nightingale 2017)	Focus group; semi-structured interview; focus group and semi-structured interview; participatory-based activities	Data from 8 studies showed that children and young people, and parents of children under 5 years, often find it difficult to evaluate the quality of healthcare information, especially that gained from searching online. The numerous potential sources of information available, which is often conflicting, can present a decision problem for them about what to believe and lead to confusion, worry or anxiety, especially for parents. Official sources of information, such as NHS helplines and websites, appear to be trusted by parents of children under 5 and used as a point of reference to evaluate healthcare information acquired from other sources and decide whether further action should be taken. Although children and young people may be aware to some extent of how search engines work, they may lack the skills to discern the reliability of websites and the information they	Minor concerns[1]	No or very minor concerns	Minor concerns[2]	No or very minor concerns	MODERATE

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	**Design**		**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
		contain and exhibit a 'blind faith' in the quality of the presented search results. *Researcher: '. . . how do you decide which link to hit [on a Google search result page]?'* *Participant: '[I go for] The first normally . . . Google tells ya. . . puts it first for a reason. Most viewed.'* *Participant: 'Yeah, first one is usually the best for a reason, like 'cause everyone has actually used it or give it good reviews'. (Best 2016, page 1071)*					
Sub-theme 1.2: Knowing where to find information							
9 (Aranda 2018, Alderdice 2018, Arnott 2012, Best 2016, Harvey 2013, Huby 2017 Ingram 2013, Neill 2015, Nightingale 2017)	Focus group; semi-structured interview; focus group and semi-structured interview	Data from 9 studies showed that children and young people, and parents of children under 5 years, typically consult multiple formal and informal sources of information when attempting to learn more about a health issue, whether generally or for a specific health reason. These can include formal pathways such as using official NHS or other reputable information resources and informal pathways such as their extended social network (peers, friends and family). Searching online appears to be ubiquitous for those with internet access, with search engines and 'non-official' websites often being the first port of call, except in times of perceived emergencies where other means of accessing reliable health	Minor concerns[1]	No or very minor concerns	Minor concerns[2]	No or very minor concerns	MODERATE

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	**Design**		**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
		information (e.g. telephone helpline) or health services are perceived to be more direct and convenient. For children and young people in a non-clinical population, although informal pathways for seeking help online may to some extent facilitate emotional expression and disclosure of personal issues due to its apparent confidentiality, doubts about online security may also discourage these. For parents, members of their extended social network, such as their own parents or grandparents, or friends with some existing healthcare knowledge, may often be consulted before making a further decision to seek more information and/or contact services. In addition, this input is valued as it can provide reassurance and emotional support. *Researcher: 'And if you were going online to find out about a personal problem, how would you go about that?'* *Participant: 'Probably Google'. (Focus group [FG] 6)* *Participant: 'Google, anything you need you just type into Google'. (FG6)* *Participant: 'You probably get the most options to help on Google'. (FG6)* *Participant: 'I always do that like I always just Google it. I wouldn't go through Facebook or anything but I would just Google it sure no one is*					

Study information		**Description of Theme or Finding**	**CERQUAL Quality Assessment**				
Number of studies	**Design**		**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
		going to see it unless they're in your phone or history then ya remove that as well'. (FG7) (Best 2016, page 1071) *"But sometimes it comes up with (…) worrying stuff (…) it can make it a bit scary sometimes just using Google, I reckon. And then when you look on the NHS it's something like totally different. So I do try and tend to stick to the NHS one". (Low-socioeconomic status mother of 2 children aged 10 mo & 5 years, Ingram 2013, page 5)*					

1 Evidence was downgraded for methodological limitations as per CASP qualitative checklist
2 Evidence was downgraded for relevance because studies were conducted in variety of settings and populations/age groups

Table 8: Evidence summary (GRADE-CERQual) for theme 2: Means of accessing healthcare information

Study information		**Description of Theme or Finding**	**CERQUAL Quality Assessment**				
Number of studies	**Design**		**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
Sub-theme 2.1: Mobile phone/web-based apps							
4 (Huby 2017 Neill 2015 Nightingale 2017, Waite-Jones 2018)	Participatory-based activities; focus group and semi-structured interview	Data from 4 studies showed that children and young people, and parents of children under 5 years, value accessing health information using mobile phone or web-based apps due to their ease of use, accessibility, and interactivity, compared to health information presented on websites. For children and young people in a clinical population using an app to manage a health condition, ownership of it (in the	No or very minor concerns	Moderate concerns[1]	No or very minor concerns	Moderate concerns[2]	MODERATE

Study information			CERQUAL Quality Assessment				
Number of studies	**Design**	**Description of Theme or Finding**	**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
		sense of having a measure of control over its personalised use) may be valued. However, being able to access it on all platforms (i.e. operating systems) and devices (e.g. phone, tablet, laptop) at any time using wi-fi is important as mobile phone data plans can be expensive and may not always be available to the user. *'I think an app would probably be better, rather than going on a website to do it, because apps are more convenient. You don't have to type anything up and you can just click on it' (Nightingale 2017, page 6)*					
Sub-theme 2.2: Structured education programme							
1 (Chaney 2012)	Focus group	Data from 1 study shows that children and young people from a clinical population may be willing to attend structured education programmes if they are engaging, and easy and convenient to attend. These programmes could be conducted in non-hospital settings, preferably not on a school day, should be personalised (i.e. tailored to their needs), and should include group discussion, practical demonstrations, and fun activities. Follow up, which could be by mobile phone text, is important as it can provide reassurance, guidance, and support.	Moderate concerns[3]	No or very minor concerns	Moderate concerns[4]	Serious concerns[5]	VERY LOW

Study information			CERQUAL Quality Assessment				
Number of studies	**Design**	**Description of Theme or Finding**	**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
		'In life you're not sitting there just listening you're actually doing things, so it's good to apply things you do throughout your day…' (Chaney 2012, page 219)					
Sub-theme 2.3: Text message							
2 (Aranda 2018, Chaney 2012)	Focus group	Data from 2 studies showed that children and young people may value accessing health information via mobile phone text message as it allows them to do so without requiring direct contact with a healthcare professional. This means of accessing health information could be used generally for an anonymous question and answer service or as a means of following up progress in a clinical context. *'Interviewer: "So something like that maybe in school where you could text questions and get a response".* *Male 1: "Yeh, just like a text back."* *Male 2: "Even if it's anonymous, you could just type it and they could type back and then you know it's you but other people just think-"'(Aranda 2018, page 381)*	Minor concerns[3]	Moderate concerns[6]	Moderate concerns[7]	Serious concerns[8]	VERY LOW
Sub-theme 2.4: Traditional forms of access							
3 (Arnott 2012, Ingram 2013, Neill 2015)	Focus group; focus group and semi-structured interview	Data from 3 studies showed that parents of children under 5 years still use traditional means of accessing health information such as books, leaflets, posters, television, and	Minor concerns[3]	Minor concerns[9]	Minor concerns[10]	Moderate concerns[11]	MODERATE

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
		telephone help lines for learning about health issues, health programmes or promotion, or for reference, depending on the type and depth of health information being communicated. Although the internet is a default information source, parents value accessible and reliable written information, which can be referred to conveniently, e.g. after consultations. However, although parents may be aware of and use specific health information provided by health services (e.g. after birth of a child), they may not be aware of the wealth of information on child health generally that is available to them. In addition, parents often find that they have to prompt healthcare professionals to provide further information, which is also typically provided only verbally. Television appears to be particularly valued by parents with low levels of literacy, whilst telephone helplines such as NHS Direct are valued as they afford a quick and direct means of accessing health information, especially before deciding whether to seek a consultation. *'It would be handy to have it [printed information], I prefer that anyway, I prefer to have, look down and then it's always there to look back on, you know.' (Neill 2015, parental proxy, page 3048)*					

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	**Design**		**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
Sub-theme 2.5: Websites							
7 (Alderdice 2018, Aranda 2018, Best 2016, Harvey 2013, Huby 2017, Neill 2015/2016 Nightingale 2017)	Focus group; semi-structured interview; focus group and semi-structured interview; participatory-based activities	Data from 7 studies showed that children and young people, and parents of children under-5 years, value accessing health information via websites for their convenience, with searching the internet using search engines to identify relevant websites appearing ubiquitous. However, in addition, children and young people appear to value accessing some kinds of healthcare information online as it can afford anonymity and distance from their own social network, which may encourage emotional expression and written disclosure. Doubts about confidentiality - i.e. the online safety of personal information - may serve to discourage the use of more informal pathways, which may include contact (albeit virtual) with members of their own social network. For parents, formal resources (e.g. NHS websites) appear to be trusted with more informal resources (e.g. online forums) often serving to act as a check as to whether consulting health services is appropriate or as a supplement to any information received already. In addition, parents prefer health information content to include the perspectives of both other parents and healthcare professionals.	No or very minor concerns	Minor concerns[12]	Minor concerns[13]	Minor concerns[14]	MODERATE

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
		'I know I think that's just a place where you can go where you don't have to broadcast to everyone that you want to know more. Some people might feel really self-conscious about asking about it or they don't like talking, then they might just be able to access their computer at home or just go on there with a friend that they want to and just have a look at it with someone if they want to…' (Aranda 2018, page 380)					

1 Evidence was downgraded for coherence because not all studies specifically examined reasons for valuing mobile- or web-based apps
2 Evidence was downgraded for adequacy because studies together offered some rich data
3 Evidence was downgraded for methodological limitations as per CASP qualitative checklist
4 Evidence was downgraded for relevance because study was about children's and young people's views on need for, as well as the structure and organisation of, a structured diabetes education programme, so only indirectly relevant.
5 Evidence was downgraded for adequacy because study did not offer rich data
6 Evidence was downgraded for coherence because data were limited and use of text discussed only in passing
7 Evidence was downgraded for relevance because 1 study was about children's and young people's views on need for, as well as the structure and organisation of, a structured diabetes education programme, so only indirectly relevant.
8 Evidence was downgraded for adequacy because studies together did not offer rich data
9 Evidence was downgraded for coherence because data were limited and reasons for use of traditional media not always explored
10 Evidence was downgraded for relevance because one of the included studies includes >66% parents of children over-5 years-old.
11 Evidence was downgraded for adequacy because studies together offered some rich data
12 Evidence was downgraded for coherence because data is complex and reasons for use of websites not always explored
13 Evidence was downgraded for relevance because there are differences in study populations/settings, with one study including adolescent males only
14 Evidence was downgraded for adequacy because studies together offered moderately rich data

Table 9: Evidence summary (GRADE-CERQual) for theme 3: Features of how healthcare information is delivered

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
Sub-theme 3.1: Connecting with others							
6 (Alderdice 2018,	Focus group; semi-structured interview;	Data from 5 studies and 1 systematic review showed that children, young people, and parents or carers of	Minor concerns[1]	Minor concerns[2]	Moderate concerns[5]	Moderate concerns[4]	LOW

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
Harvey 2013, Huby 2017, Neill 2016, Reen 2019, Waite-Jones 2018)	systematic review of qualitative studies	children under 5 years, value connecting with others when accessing healthcare information. Learning about the experiences of peers in similar situations, through stories and first-hand accounts - in addition to the medical information typically provided by healthcare professionals, whether through their own extended social network or using digital resources (e.g. online chat rooms, internet forums) – can help them to understand the presented information and provide them with emotional support (i.e. encouragement, reassurance) during their healthcare experience, which can also be lonely or isolating. Children and young people from both clinical and non-clinical populations like stories and testimonials from their peers, especially if they are positive in nature and show the person successfully coping with their health condition. Relatedly, they also value user-generated content - including blogs, vlogs and photos. However, not all children and young people may feel comfortable contributing their own experiences. General online parents' forums are valued by parents of children under 5 for the variety of experiences and backgrounds that can be represented in them and may provide a check for parents before they decide whether a					

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	**Design**		**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
		consultation with health services is merited. *'It would be really good to see what other people have gone through and if I can relate to them' (Waite-Jones 2018, page 7)*					
Sub-theme 3.2: Interactivity							
4 (Chaney 2012, Nightingale 2017, Reen 2019, Waite-Jones 2018)		Data from 3 studies and 1 systematic review showed that that children and young people want to be engaged when accessing healthcare information and value interactivity in the way it is presented and used. This might include: interactive demonstrations of healthcare information; gamifying healthcare information (e.g. how the kidney works) or using elements of game design (e.g. scoring points) to present it; journals; personalising or customising how websites or mobile apps appear or function; provision for contacting healthcare professionals; practical learning sessions; social networking features (e.g. online peer forums); quizzes. However, information should still be clear and accessible. *'If you made it into a game like, if you had a character to help you learn it more and help you and stuff you could make it give you information and then you could feed and bath*	Minor concerns[1]	Minor concerns[2]	Minor concerns[3]	Moderate concerns[4]	LOW

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
		your pet and stuff. And, it answers your questions and it gives you like notifications every day to feed it and wash it and stuff and you can put your pain scales in and stuff like that. And, as well it takes your mind off of your pain as well.' (Waite-Jones 2018, page 6)					
Sub-theme 3.3: Privacy, anonymity, online safety and security							
6 (Aranda 2018 Best 2016, Chaney 2012, Nightingale 2017, Reen 2019, Waite-Jones 2018)	Focus group; focus group and semi-structured interview; systematic review	Data from 5 studies and 1 systematic review showed that children and young people prefer to be able to access some kinds of health information in a way that affords them privacy and anonymity, and if online, safety and security. In particular, in-person services may discourage them from accessing information available from health services, for example on sexual health, because they afford no or little privacy and are not anonymous. The use of electronic devices (e.g. mobile phone, computer) to access online healthcare information is seen as a way of avoiding this risk and of guaranteeing anonymity if wanted, as well as affording users with ease of access, immediacy and the opportunity for written disclosure of personal issues. However, there should be some provision for ensuring online safety and security of personal information.	Minor concerns[1]	Minor concerns[2]	Minor concerns[3]	Moderate concerns[4]	LOW

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
		'It's kind of awkward because her [school nurse] office is in reception so she works with, like she's around everyone else so it's not really the person you want to talk to considering there's all the gossip going on and they're on their computers' (Aranda 2018, page 381)					
Sub-theme 3.4: Role of parents and carers							
3 (Aranda 2018, Chaney 2012, Waite-Jones 2018)	Focus group, focus group and semi-structured interview	Data from 3 studies showed that children and young people may not want their parents or carers to be involved in accessing healthcare information as it may be considered private or impact their independence in coping with a health condition. However, they may also appreciate the need for parents or carers to have access to their healthcare information in certain circumstances, e.g. in emergencies or when child is younger. For children in a clinical population, provision for a parent support network may be appropriate. *'Something for parents in addition to young people so they can monitor and support their child' (Waite-Jones 2018, page 7)*	Minor concerns[1]	Moderate concerns[6]	Moderate concerns[7]	Serious concerns[8]	VERY LOW
Sub-theme 3.5: Video content							
3 (Alderice 2018, Huby 2017, Reen 2019)		Data from 2 studies and 1 systematic review showed that children and young people, and parents of children under 5 years, like healthcare information to be	Minor concerns[1]	Minor concerns[2]	Minor concerns[3]	Moderate concerns[4]	LOW

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
		presented in a video format, especially when accessing it online or learning new skills. Children and young people in both clinical and non-clinical populations, like especially seeing real stories told or testimony given by their peers. However, whilst video content is conveniently accessible and enhances learning opportunities, it should not replace face-to-face meetings with healthcare professionals nor be the only way information is presented. *'Yeah, had to come over quite a lot of times and it's quite far as well…so if we did have videos it would be much better'* (Huby 2017, page 130)					

1 Evidence was downgraded for methodological limitations as per CASP qualitative checklist or CASP systematic review checklist as appropriate
2 Evidence was downgraded for coherence because not all studies examined theme in detail
3 Evidence was downgraded for relevance because studies conducted in various populations/settings
4 Evidence was downgraded for adequacy because studies together offer some rich data
5 Evidence was downgraded for relevance because only 1 study includes children and young people from a non-clinical population, whilst the systematic review although focusing on young people aged 13-19 years includes studies with participants older than 18 years.
6 Evidence was downgraded for coherence because not all studies examined role of parents and carers in detail
7 Evidence was downgraded for relevance because populations/settings and focus of studies varied
8 Evidence was downgraded for adequacy because study does not offer rich data

Table 10: Evidence summary (GRADE-CERQual) for theme 4: Barriers and facilitators to accessing healthcare information

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
Sub-theme 4.1: Appropriateness of information							

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	**Design**		**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
4 (Huby 2017, Nightingale 2017, Reen 2018, Waite-Jones 2018)	Focus group; participatory-based activities; focus group and semi-structured interview; systematic review of qualitative studies	Data from 3 studies and 1 systematic review showed that children and young people, and parents of children under 5 years, want digital health information to be presented using a multimedia format. Whilst parents do not appear to have a strong preference for this, children and young people from both clinical and non-clinical populations appear to strongly prefer content to be age-appropriate and delivered using a combination of videos, images, and animation. Healthcare information intended for children and young people, however it is presented, should be age-appropriate, concise (i.e. digestible with small chunks of information), not too cluttered, and should be easy to understand relative to the user's age, development and learning style. This could be achieved, for example, by allowing customisation according to age and diagnosis or dividing health information into different sections for specific age groups, which may also afford users from a clinical population the facility to use such information to educate others. For children in a clinical population, gamifying health information using elements of game design – for example, scoring points, progressing through levels, and/or having a leader board - may encourage them to engage with the	Minor concerns[1]	Minor concerns[2]	Moderate concerns[3]	Moderate concerns[4]	LOW

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	**Design**		**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
		relevant health information and provide them with an incentive to access and learn about it. However, gamifying health information may not be appropriate for older children and young people, who may prefer health information to be presented more straightforwardly using text. *'…a section for younger kids, which is more games and stuff to help them learn, and then a part for older people, more my age, that would obviously read a bit more…' (Huby 2017, page 129)*					
Sub-theme 4.2: Control of online access							
2 (Aranda 2018, Huby 2017)	Focus group; participatory-based activities	Data from 2 studies showed that children and young people may not have full control over whether they can access online resources thus curtailing their freedom to learn about health issues or access healthcare-related information. Children and young people's means of accessing online information resources is often controlled and monitored by their parents, which can make it difficult for them to research more sensitive issues (e.g. sexual health). Although mobile data can be used to access online information when in locations where Wi-Fi access is unavailable or only available for a free, it is often expensive and, as above, access to it may not be under their direct control,	No or very minor concerns	Moderate concerns[4]	Minor concerns[5]	Serious concerns[6]	LOW

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
		which may also limit children and young people's ability to stay in contact with friends and family. *'It would just be really good because I Skype with my friends…so I don't feel that I can't see any of my friends or talk to them' (Huby 2017, page 5)*					
Sub-theme 4.3: In-person services and relationship with healthcare professional							
7 (Aranda 2018, Arnott 2012 Chaney 2012, Harvey 2013, Huby 2017, Neill 2015/2016, Reen 2017)	Focus group; semi-structured interview; focus group and semi-structured interview; participatory-based activities	Data from 6 studies and 1 systematic review showed that the way children and young people, and parents of children under 5, access healthcare information, both in general and when seeking or receiving treatment from healthcare services, can be substantially affected by whether they want contact with a healthcare professional, and if they do, how they perceive the quality of the ensuing relationship between them (in particular whether they trust them). For children and young people, accessing certain kinds of healthcare information such as sexual health in an in-person context (e.g. school nurse, GP consultation, drop-in service) may not provide children and young people with sufficient privacy and anonymity, especially when there are other means that can (e.g. online, text message service) and there is little or no pre-existing relationship with the relevant healthcare professional or service.	Minor concerns[1]	Minor concerns[7]	Minor concerns[8]	No or very minor concerns	MODERATE

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
		For children with a pre-existing health condition, although use of web-based apps to access healthcare information is acceptable, in-person contact with healthcare professionals is still valued as part of ongoing care and education. For parents' of children under 5, their need to access information and their perception of whether they have received adequate information can be substantially affected by when and the manner in which the information is delivered, the amount and consistency of information received from healthcare professionals, whether healthcare professionals afforded them sufficient time to ask questions or were parents themselves, whether they themselves had more than one child, and by their own perception of the authority of the healthcare professional. In particular, information not being provided during treatment of their child in a timely and at an appropriate time prevents them from being both fully engaged in the information being communicated and fully involved in their care, can be emotionally distressing, and may lead them to searching, especially online, for other sources of information. For fathers of children under 5, certain kinds of information about their child are only available					

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
		during in-person consultations, which are typically only accessible during the day, a time in which many of them are working and unable to attend. Even when printed materials are provided or alternative sessions (e.g. during the weekend), fathers may not be motivated to access them, preferring instead to spend time with their child. *'I know I think that's just a place where you can go where you don't have to broadcast to everyone that you want to know more. Some people might feel really self-conscious about asking about it or they don't like talking, then they might just be able to access their computer at home or just go on there with a friend that they want to and just have a look at it with someone if they want to.' (Aranda 2018, page 380)*					

1 Evidence was downgraded for methodological limitations as per CASP qualitative checklist
2 Evidence was downgraded for relevance because studies conducted in different populations
3 Evidence was downgraded for adequacy of data because studies together offer moderately rich data
4 Evidence was downgraded for coherence because data was limited and not discussed in detail
5 Evidence was downgraded for relevance because studies conducted in different populations
6 Evidence was downgraded for adequacy because studies together do not offer rich data
7 Evidence was downgraded for coherence because not all studies examined relationship with healthcare professional in detail
8 Evidence was downgraded for relevance because studies conducted in different populations and one study includes >66% participants over-18 years

Appendix G – Economic evidence study selection

Economic evidence study selection for review question: How do children and young people, and the parents or carers of babies and young children, prefer to access healthcare information?

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

Appendix H – Economic evidence tables

Economic evidence tables for review question: How do children and young people, and the parents or carers of babies and young children, prefer to access healthcare information?

No economic evidence was identified for this review

Appendix I – Economic evidence profiles

Economic evidence profiles for review question: How do children and young people, and the parents and carers of babies and young children, prefer to be involved and supported in planning their healthcare and making informed, shared decisions about their health?

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

Appendix J – Economic analysis

Economic evidence analysis for review question: How do children and young people, and the parents or carers of babies and young children, prefer to access healthcare information?

No economic analysis was conducted for this review question.

Appendix K – Excluded studies

Excluded studies for review question: How do children and young people, and the parents or carers of babies and young children, prefer to access healthcare information?

Clinical studies

Table 11: Excluded studies and reasons for their exclusion

Study	Reason for Exclusion
Aicken, C. R., Fuller, S. S., Sutcliffe, L. J., Estcourt, C. S., Gkatzidou, V., Oakeshott, P., Hone, K., Sadiq, S. T., Sonnenberg, P., Shahmanesh, M., Young people's perceptions of smartphone-enabled self-testing and online care for sexually transmitted infections: qualitative interview study, BMC public health, 16, 974, 2016	Population and phenomenon of interest not in protocol - Aged 16-24 years. The themes informed by quotes of 16-17 year olds in the study do not relate to access to healthcare information.
Alifrangis, C., Koizia, L., Rozario, A., Rodney, S., Harrington, M., Somerville, C., Peplow, T., Waxman, J., The experiences of cancer patients, Qjm, 104, 1075-81, 2011	Population not in protocol - Adults >20 years.
Aljafari, A. K., Scambler, S., Gallagher, J. E., Hosey, M. T., Parental views on delivering preventive advice to children referred for treatment of dental caries under general anaesthesia: A qualitative investigation, Community dental health, 31, 75-79, 2014	Population not in protocol - Parents of 3-10 year olds with data not presented separately for target population.
Allison, D. G., Higginson, P., Martin, S., Antibiotic resistance awareness: a public engagement approach for all pharmacists, International journal of pharmacy practice, 25, 93-96, 2017	Phenomenon of interest not in protocol - Themes do not relate to access to healthcare information.
Alur, P., Cirelli, J., Goodstein, M., Bell, T., Liss, J., Audiovisual Presentations on a Handheld PC are Preferred As an Educational Tool by NICU Parents, Applied Clinical InformaticsAppl Clin Inform, 1, 142-8, 2010	Country: USA
Anderson, C., Lupfer, A., Shattuck, P. T., Barriers to receipt of services for young adults with autism, Pediatrics, 141, S300-S305, 2018	Country: USA
Anzinger, H., Elliott, S. A., Hartling, L., Comparative Usability Analysis and Parental Preferences of Three Web-Based Knowledge Translation Tools: Multimethod Study, Journal of medical Internet research, 22, e14562, 2020	Country: Canada
Arai, L., Bettany-Saltikov, J., Hamilton, S., Findings from a small-scale, exploratory content analysis of information provided to AIS patients and their parents from NHS Scoliosis Hospital Clinics, Scoliosis. Conference: 9th International Conference on Conservative Management of Spinal Deformities SOSORT, 8, 2012	Conference abstract
Armoiry, Xavier, Sturt, Jackie, Phelps, Emma Elizabeth, Walker, Clare-Louise, Court, Rachel, Taggart, Frances, Sutcliffe, Paul, Griffiths, Frances, Atherton, Helen, Digital clinical communication for families and caregivers of children or young people with short- or long-term conditions: Rapid review, Journal of Medical Internet Research Vol 20(1), 2018, ArtID e5, 20, 2018	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Aston, Hermione J., Lambert, Nathan, Young people's views about their involvement in decision-making, Educational Psychology in Practice, 26, 41-51, 2010	Phenomenon of interest not in protocol - Themes do not relate to access to healthcare information.

Study	Reason for Exclusion
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 - Themes do not relate to access to healthcare information.
Aston, J., Wilson, K. A., Terry, D. R. P., The treatment-related experiences of parents, children and young people with regular prescribed medication, International journal of clinical pharmacy, 41, 113-121, 2019	Population not in protocol - Parents views with data not presented separately for target population.
Atherton, H., Pappas, Y., Heneghan, C., Murray, E., Experiences of using email for general practice consultations: A qualitative study, British journal of general practice, 63, e760-e767, 2013	Phenomenon of interest not in protocol - Themes do not relate to access to healthcare information.
Aventin, A., French, R., Young, H., McDaid, L., Lewis, R., Warren, E., McConnon, L., Lohan, M., Acceptability of an interactive film-based intervention targeting adolescent boys to prevent sexual risk-taking: findings from the JACK cluster randomised controlled trial process evaluation, The Lancet, 394, S5, 2019	Conference abstract
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 - Themes do not relate to access to healthcare information.
Davison, Jo, Zamperoni, Victoria, Stain, Helen J., Vulnerable young people's experiences of child and adolescent mental health services, Mental Health Review Journal, 22, 95-110, 2017	Phenomenon of interest not in protocol - Themes do not relate to access to healthcare information.
Elwell, L., Grogan, S., Coulson, N., Adolescents living with cancer: the role of computer-mediated support groups, Journal of health psychology, 16, 236-248, 2011	Phenomenon of interest not in protocol - Themes do not relate to access to healthcare information.
Fairbrother, H., Curtis, P., Goyder, E., Making health information meaningful: Children's health literacy practices, SSM - Population Health, 2, 476-484, 2016	Phenomenon of interest not in protocol - Themes do not relate to access to healthcare information.
Fortier, M. A., Chorney, J. M., Rony, R. Y. Z., Perret-Karimi, D., Rinehart, J. B., Camilon, F. S., Kain, Z. N., Children's desire for perioperative information, Anesthesia and Analgesia, 109, 1085-1090, 2009	Country: USA
Fortier, Michelle A., Chorney, Jill MacLaren, Rony, Rachel Yaffa Zisk, Perret-Karimi, Danielle, Rinehart, Joseph B., Camilon, Felizardo S., Kain, Zeev N., Childrenâ□™s Desire for Perioperative Information, Anesthesia & Analgesia, 109, 2009	Country: USA
Gatt, Albert, Portet, Francois, Reiter, Ehud, Hunter, Jim, Mahamood, Saad, Moncur, Wendy, Sripada, Somayajulu, From data to text in the Neonatal Intensive Care Unit: Using NLG technology for decision support and information management, AI Communications, 22, 153-186, 2009	Phenomenon of interest not in protocol - Themes do not relate to access to healthcare information.
Goodwin, J., Savage, E., Horgan, A., Adolescents' and Young Adults' Beliefs about Mental Health Services and Care: A Systematic Review, Archives of psychiatric nursing, 30, 636-644, 2016	Phenomenon of interest not in protocol - Themes do not relate to access to healthcare information.
Gray,N.J., Boardman,H.F., Symonds,B.S., Information sources used by parents buying non-prescription medicines in pharmacies for preschool children, International Journal of Clinical Pharmacy, 33, 842-848, 2011	Phenomenon of interest not in protocol - No themes related to access to healthcare information.

Study	Reason for Exclusion
Grist, Rebecca, Porter, Joanna, Stallard, Paul, Mental health mobile apps for preadolescents and adolescents: A systematic review, Journal of medical internet research, 19, 153-166, 2017	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Hartling, L., Scott, S., Pandya, R., Johnson, D., Bishop, T., Klassen, T. P., Storytelling as a communication tool for health consumers: development of an intervention for parents of children with croup. Stories to communicate health information, BMC pediatrics, 10, 64, 2010	Country: Canada
Henderson, E. M., Keogh, E., Rosser, B. A., Eccleston, C., Searching the internet for help with pain: adolescent search, coping, and medication behaviour, British journal of health psychology, 18, 218-232, 2013	Phenomenon of interest not in protocol - No themes related to access to healthcare information.
Hulin, J., Baker, S. R., Marshman, Z., Albadri, S., Rodd, H. D., Development of a decision aid for children faced with the decision to undergo dental treatment with sedation or general anaesthesia, International journal of paediatric dentistry, 27, 344-355, 2017	Phenomenon of interest not in protocol - No themes related to access to healthcare information.
Jansen, R., Reid, M., Caregivers of adolescents with mental health issues using communication technology: a systematic review, JMIR mHealth and uHealth, 2020	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Kauer, S. D., Mangan, C., Sanci, L., Do online mental health services improve help-seeking for young people? A systematic review, Journal of medical internet research, 16, e66, 2014	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Kayyali, R., Hesso, I., Ejiko, E., Nabhani Gebara, S., A qualitative study of Telehealth patient information leaflets (TILs): are we giving patients enough information?, BMC health services research, 17, 362, 2017	Population not in protocol - Adults >20 years
Kean, S., Children and young people's strategies to access information during a family member's critical illness, Journal of Clinical Nursing, 19, 266-274, 2010	Phenomenon of interest not in protocol - Themes do not relate to access to healthcare information.
Krska, J., Morecroft, C. W., Informing patients about medicines--a hospital in-patient survey in England, Patient Education & Counseling, 90, 276-8, 2013	Population not in protocol - Adult population
Lea, S., Martins, A., Morgan, S., Cargill, J., Taylor, R. M., Fern, L. A., Online information and support needs of young people with cancer: A participatory action research study, Adolescent Health, Medicine and Therapeutics, 9, 121-135, 2018	Population not in protocol - Aged 13-24 years with data not presented separately for target population.
Low, J. K., Manias, E., Use of Technology-Based Tools to Support Adolescents and Young Adults With Chronic Disease: Systematic Review and Meta-Analysis, JMIR MHealth and UHealthJMIR Mhealth Uhealth, 7, e12042, 2019	Population and phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Lucassen, M., Samra, R., Iacovides, I., Fleming, T., Shepherd, M., Stasiak, K., Wallace, L., How LGBT+ Young People Use the Internet in Relation to Their Mental Health and Envisage the Use of e-Therapy: Exploratory Study, JMIR Serious Games, 6, e11249, 2018	Phenomenon of interest not in protocol - No themes related to access to healthcare information.
Martin-Kerry, J. M., Knapp, P., Atkin, K., Bower, P., Watt, I., Stones, C., Higgins, S., Sheridan, R., Preston, J., Horton Taylor, D., Baines, P., Young, B., Supporting children and young people when making decisions about joining clinical trials: Qualitative study to inform multimedia website development, BMJ open, 9 (1) (no pagination), 2019	Phenomenon of interest not in protocol - Themes do not relate to access to healthcare information.

Study	Reason for Exclusion
Masoumi, M., Shahhosseini, Z., Self-care challenges in adolescents: A comprehensive literature review, International Journal of Adolescent Medicine and Health, 31, 0152, 2019	Systematic review. References checked for possible included studies - none were identified.
Mousavi Jazayeri, S. M. H., Jamshidnezhad, A., Top mobile applications in pediatrics and children's health: Assessment and intelligent analysis tools for a systematic investigation, Malaysian Journal of Medical Sciences, 26, 5-14, 2019	Systematic review with no potential studies meeting the inclusion criteria
Neill, S., Roland, D., Jones, C. H. D., Thompson, M., Lakhanpaul, M., Information resources to aid parental decision-making on when to seek medical care for their acutely sick child: A narrative systematic review, BMJ open, 5 (12) (no pagination), 2015	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Nickels, A., Dimov, V., Innovations in technology: Social media and mobile technology in the care of adolescents with asthma, Current Allergy and Asthma Reports, 12, 607-612, 2012	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Nightingale, R., Friedl, S., Swallow, V., Parents' learning needs and preferences when sharing management of their child's long-term/chronic condition: A systematic review, Patient Education and Counseling, 98, 1329-1338, 2015	Population of included studies not in protocol. Included studies checked for inclusion.
Nightingale, R., Wirz, L., Cook, W., Swallow, V., Collaborating With Parents of Children With Chronic Conditions and Professionals to Design, Develop and Pre-pilot PLAnT (the Parent Learning Needs and Preferences Assessment Tool), Journal of pediatric nursing, 35, 90-97, 2017	Population not in protocol - Parents of children of all ages with data not presented separately for target poulation.
Nik-Hussin, N. M. H., Saleem, Y., Sivayoham, E., Rothera, M. P., A survey of parent's attitudes towards viewing intraoperative photographs used as an educational tool, International journal of pediatric otorhinolaryngology, 73, 585-588, 2009	Phenomenon of interest not in protocol - Themes do not relate to access to healthcare information.
Park, Eunhee, Kwon, Misol, Health-related internet use by children and adolescents: Systematic review, Journal of Medical Internet Research Vol 20(4), 2018, ArtID e120, 20, 2018	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Pretorius, C., Chambers, D., Coyle, D., Young People's Online Help-Seeking and Mental Health Difficulties: Systematic Narrative Review, Journal of Medical Internet Research, 21, e13873, 2019	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Redshaw, M. E., Harvey, M. E., Explanations and information-giving: Clinician strategies used in talking to parents of preterm infants, BMC Pediatrics, 16 (1) (no pagination), 2016	Population not in protocol - Healthcare professionals
Robards, F., Kang, M., Usherwood, T., Sanci, L., How Marginalized Young People Access, Engage With, and Navigate Health-Care Systems in the Digital Age: Systematic Review, Journal of Adolescent Health, 365-381, 2018	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Sayal, Kapil, Mills, Jonathan, White, Kate, Merrell, Christine, Tymms, Peter, Predictors of and barriers to service use for children at risk of ADHD: Longitudinal study, European child & adolescent psychiatry, 24, 545-552, 2015	Study design not in protocol - Quantitative study
Sharkey, S., Lloyd, C., Tomlinson, R., Thomas, E., Martin, A., Logan, S., Morris, C., Communicating with disabled children when inpatients: barriers and facilitators identified by parents and professionals in a qualitative study, Health expectations : an international journal of public participation in health care and health policy, 19, 738-750, 2016	Phenomenon of interest not in protocol - Themes do not relate to access to healthcare information.
Slater, H., Campbell, J. M., Stinson, J. N., Burley, M. M., Briggs, A. M., End User and Implementer Experiences of mHealth	Phenomenon of interest of included studies not in protocol.

Study	Reason for Exclusion
Technologies for Noncommunicable Chronic Disease Management in Young Adults: Systematic Review, Journal of medical internet research, 19, e406, 2017	Included studies checked for inclusion.
Stenberg, U., Haaland-Overby, M., Koricho, A. T., Trollvik, A., Kristoffersen, L. G. R., Dybvig, S., Vagan, A., How can we support children, adolescents and young adults in managing chronic health challenges? A scoping review on the effects of patient education interventions, Health expectations : an international journal of public participation in health care and health policy, 2019	Scoping review. References checked for possible included studies - none were identified.
Sutcliffe, P., Martin, S., Sturt, J., Powell, J., Griffiths, F., Adams, A., Dale, J., Systematic review of communication technologies to promote access and engagement of young people with diabetes into healthcare, BMC endocrine disorders, 11 (no pagination), 2011	Study design of included studies not in protocol. Included studies checked for inclusion.
Sutton, P., Woodruff, T. J., Risk communication and decision tools for children's health protection, Birth Defects Research Part C - Embryo Today: Reviews, 99, 45-49, 2013	Country: USA
Swallow, V., Carolan, I., Smith, T., Webb, N. J., Knafl, K., Santacroce, S., Campbell, M., Harper-Jones, M., Hanif, N., Hall, A., A novel Interactive Health Communication Application (IHCA) for parents of children with long-term conditions: Development, implementation and feasibility assessment, Informatics for health & social care, 41, 20-46, 2016	Population not in protocol - Parents of children of all ages with data not presented separately for target poulation.
Turnbull, J., Pope, C., Martin, D., Lattimer, V., Do telephones overcome geographical barriers to general practice out-of-hours services? Mixed-methods study of parents with young children, Journal of Health Services & Research Policy, 15, 21-7, 2010	Phenomenon of interest not in protocol - Themes do not relate to access to healthcare information.
Ulph, F., Cullinan, T., Qureshi, N., Kai, J., Informing children of their newborn screening carrier result for sickle cell or cystic fibrosis: qualitative study of parents' intentions, views and support needs, Journal of Genetic Counseling, 23, 409-20, 2014	Phenomenon of interest not in protocol - Themes do not relate to access to healthcare information.
Yonker, Lael M., Zan, Shiyi, Scirica, Christina V., Jethwani, Kamal, Kinane, T., "Friending" teens: Systematic review of social media in adolescent and young adult health care, Journal of medical internet research, 17, No Pagination Specified, 2015	Phenomenon of interest not in protocol - Themes do not relate to access to healthcare information.

Economic studies

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

Appendix L – Research recommendations

Research recommendations for review question: How do children and young people, and the parents or carers of babies and young children, prefer to access healthcare information?

No research recommendations were made for this review question.

Appendix M – Evidence from reference groups and focus groups

Reference group and focus group evidence for review question: How do children and young people, and the parents or carers of babies and young children, prefer to access healthcare information?

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 12: Evidence from reference groups and focus groups

Age < 7 years	Age 7-11 Years	Age 11-14 years	Overall quality of the evidence
There was no evidence from this group for this question.	There was no evidence from this group for this question.	How do you prefer to access healthcare information? • Have helplines • Don’t make it overwhelming Sources of information [children would use] if didn't understand or didn't feel able to ask a question: • Tiktok - video of young person explaining • Video of adult explaining • Books • 'My favourite way to get answers would be from my mum' • Alexa? Not very comfortable asking Alexa question about health - much more comfortable asking Google • Google • Leaflet from hospital/school etc.	• Low

Appendix N – Evidence from national surveys

Evidence from national surveys for review question: How do children and young people, and the parents or carers of babies and young children, prefer to access healthcare information?

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

Table 13: Evidence from national surveys

Survey	Findings	Overall quality of the evidence
Association for Young People's Health. Young people's views on involvement and feedback in healthcare 2014	• No relevant findings were identified for this question	• N/A
Care Quality Commission. Children and young people's inpatient and day case survey 2018	INFORMATION AROUND SURGERY: • 93% of children 8 to 15 years old said that staff explained pre-operative information • 76% said that they were informed how the procedure had gone • 90% of parents said staff explained the procedure in a way they could understand	• Low
Child Outcomes Research Consortium. Child- and Parent-reported Outcomes and Experience from Child and Young People's Mental Health Services 2011-2015	INFORMATION ABOUT MENTAL HEALTH HELP AVAILABLE: • 74.4% of children and young people said they were given enough explanation about the help available	• Moderate
Health and Social Care Information Centre. Children's Dental Health Survey 2013. (Country specific report for England, published 2015)	• No relevant findings were identified for this question	• N/A
HM Inspectorate of Prisons. Children in Custody 2016-2017	• No relevant findings were identified for this question	• N/A
National Children's Bureau.	• No relevant findings were identified for this question	• N/A

Survey	Findings	Overall quality of the evidence
Listening to children's views on health provision 2012		
Opinion Matters. Declare your care survey 2018	LACK OF INFORMATION: • Of young people who had raised a concern or made a complaint, in 48% the subject had been lack of information about a health condition or treatment options not being well explained	• Low
Picker Institute. Children and Young People's Patient Experience Survey 2018.	• No relevant findings were identified for this question	• N/A
Picker Institute. Paediatric Emergency Department Survey 2015 and Children and Young People's Outpatient Survey 2015	INFORMATION ABOUT OUTPATIENT VISIT: • 55% of children and young people aged 8-16 years did not know before their visit to hospital what was going to happen to them while they were there	• Low
Picker Institute/NHS England/Bliss. Neonatal Survey 2014 *Results for individual questions were converted into scores on a scale of 1 to 100, with 100 representing the best possible outcome (the scores are not percentages).*	INFORMATION BEFORE BIRTH: • Before your baby was born did a member of staff from the neonatal unit talk to you about what to expect after the birth? Score = 54 INFORMATION ABOUT THE NEONATAL UNIT: • Were you given enough information about the neonatal unit (such as rules, procedures, facilities for parents)? Score = 76 • Was the purpose of the machines, monitors and alarms used in the neonatal unit clearly explained to you? Score = 73 • Were infection control practices explained to you, such as hand washing and procedures for visitors? Score = 85 INFORMATION ABOUT YOUR BABY: • If you asked questions about your baby's condition and treatment, did you get answers you could understand? Score = 88	• Moderate

Survey	Findings	Overall quality of the evidence
	• Were you given enough written information to help you understand your baby's condition and treatment? Score = 53 INFORMATION ABOUT OTHER SUPPORT: • Were you given enough information about help you could get with expenses related to your baby's stay in the neonatal unit (such as travelling/ parking expenses, hardship fund or food vouchers)? Score = 41 • Did staff give you any information about parent support groups such as Bliss or other local groups? Score = 53	
Word of Mouth Research and Point of Care Foundation. An options appraisal for obtaining feedback on the experiences of children and young people with cancer 2018	• No relevant findings were identified for this question	• N/A

N/A: not applicable