National Institute for Health and Care Excellence

Draft for consultation

Babies, children and young people's experience of healthcare

[O] Accessing healthcare

NICE guideline <tbc>

Evidence reviews underpinning recommendations 1.10.1 to 1.10.9 in the NICE guideline

March 2021

Draft for consultation

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

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Accessing healthcare

Review question

What are the facilitators of, and barriers to, babies, children and young people in accessing healthcare services?

Introduction

The ease with which babies, children and young people can access healthcare services may be a major determinant of their overall healthcare experience and poor experiences can lead to lack of engagement or re-attendance. The design and provision of some healthcare services, particularly those serving both adults and children (for example, emergency departments, GP surgeries and urgent care centres) may be focused around the needs of adults, and there may be opportunities to make these services more accessible and friendly for children and young people to use.

There may be a number of factors which can impact on this initial contact with healthcare services and ease of access, and these factors may impact variably on individuals with different needs (for example, those from minority communities, or who do not have parents or carers to help them navigate the healthcare system) and lead to inequalities in access. Understanding the factors that can facilitate access or act as barriers allows recommendations to be made that can improve access in the future.

The aim of this review is to identify barriers that may impair access to healthcare services and facilitators that may aid ease of access.

Summary of the protocol

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

Table 1: Summary of the protocol

Population	• People <18 years-old who have experience of healthcare • Studies that use the views of parents or carers as proxies will be included only if they are responding on behalf of their child or charge, and ○ The baby or child of the parent or carer is under-5 years-old, or ○ There is a clear rationale provided as to why the study is using parents' or carers' views on and experiences of healthcare as proxies for their child.
Phenomenon of interest	Experience of healthcare, in particular of accessing healthcare services (defined as the initial point of contact with a specific healthcare service for a particular condition).
Primary outcome	Themes will be identified in 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): • Awareness and knowledge of available healthcare services • Concerns about privacy and confidentiality • Convenience of time, location and setting in which healthcare is delivered • Distrust of healthcare services • Fear or stigma related to accessing services • Impact on parents' or carers' personal financial means

	• Impact of parents' or carers' lives on healthcare received by their child or charge • Lack of age- or developmentally-appropriate services • Lack of knowledge about the availability of services • Provision of services that are sensitive to the (for example physical, cultural, religious) needs of the baby, child or young person • Safeguarding • Use of medical jargon • Use of electronic technology to increase ways of accessing healthcare

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

Methods and process

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

Clinical evidence

Included studies

This was a qualitative review with the aim of:

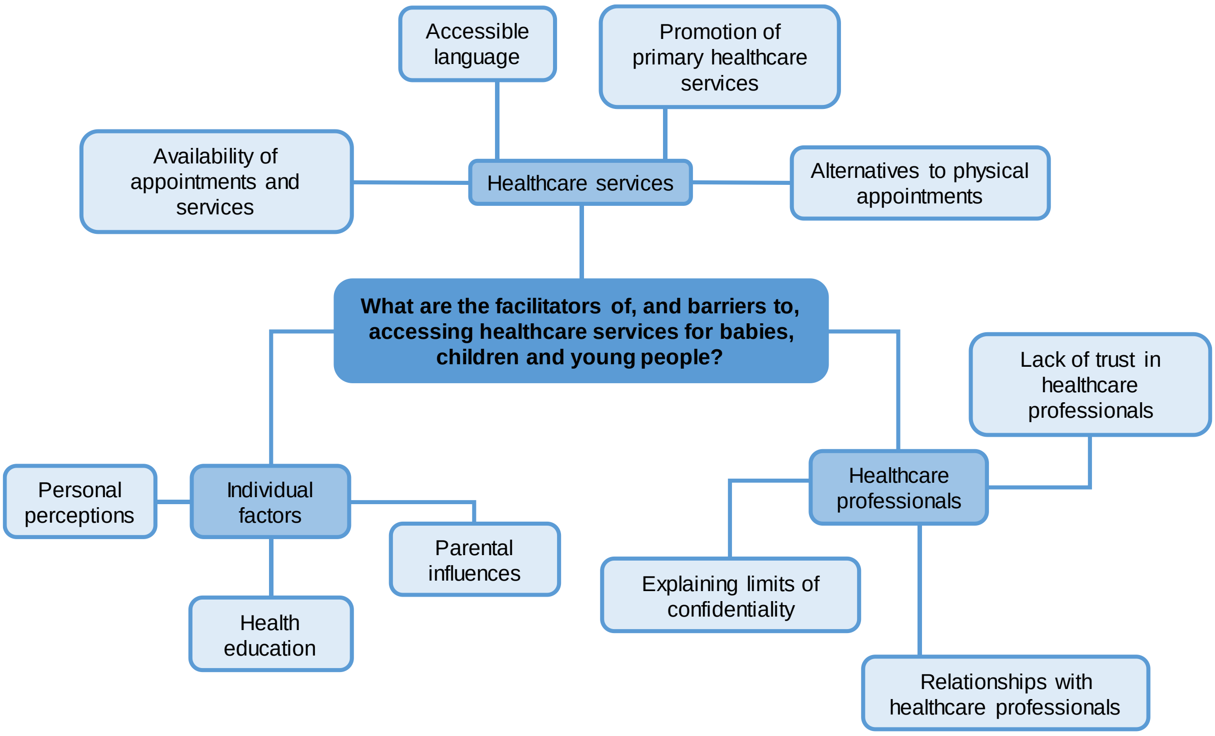
- Understanding the factors that may facilitate access to healthcare for babies, children and young people, or that can act as barriers that prevent them from accessing healthcare.

A systematic review of the literature was conducted using a combined search. Fourteen studies were included in this evidence review: 3 studies used focus groups (Ali 2017, Best 2016, Leavey 2011); 7 used semi-structured interviews (Dickson 2015, Diwakar 2019, Fargas-Malet 2018, Haig-Ferguson 2019, Heath 2015, Walsh 2011, Whittle 2012); 1 used a mixed-method including semi-structured interviews (Turnbull 2010); 2 used a combination of focus groups and semi-structured interviews (Neill 2016, Sime 2014); and 1 was a systematic review including qualitative, quantitative and mixed-methods studies (Robards 2018). With the exception of Robards 2018, which included studies from the US, Australia, Canada, New Zealand and Portugal, the remaining 13 studies were conducted in the UK.

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

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

Table 2: Summary of included studies

Study	Participants	Methods	Themes
Ali 2017 **Study design** Focus group **Aim of the study** To explore UK Pakistani young people's views of barriers and facilitators to accessing mental health services in Peterborough, as well as designing actions to improve access to these services.	N=33 young people **Characteristics** Age (range): 11-19 years • It was not possible to establish how many participants were ≥18 years old. • Themes have been downgraded for relevance where applicable. Gender (M/F): 17/16	**Recruitment** Recruited from local schools, madrasas (Islamic religious education institutions) and youth groups **Data collection** Focus groups **Analysis** Framework approach	• Individual factors: Personal perceptions • Individual factors: Health education • Healthcare professionals: Lack of trust in healthcare professionals • Healthcare services: Promotion of primary healthcare services

Study	Participants	Methods	Themes
Peterborough, UK			
Best 2016 **Study design** Focus group **Aim of the study** To explore how adolescent males locate and access healthcare support online. Northern Ireland, UK	N=56 young people **Characteristics** Age (range): 14-15 years Gender (M/F): 56/0	**Recruitment** Purposive sampling of secondary schools **Data collection** Focus groups **Analysis** Thematic analysis	• Individual factors: Personal perceptions • Healthcare professionals: Lack of trust in healthcare professionals • Healthcare professionals: Managing expectations of confidentiality
Dickson 2015 **Study design** Semi-structured interview **Aim of the study** To explore parents' perceptions of factors influencing the dental registrations of their children. Northern Ireland, UK	N=8 parental proxies (8 mothers) of children under 5 years old **Characteristics** Age of children (range): 1 month – 3 years Gender of children: not reported	**Recruitment** Purposive sampling of 'Sure-Start Play' database **Data collection** Semi-structured face-to-face interviews **Analysis** Phenomenological framework approach	• Individual factors: Parental influences • Healthcare professionals: Lack of trust in healthcare professionals
Diwakar 2019 **Study design** Semi-structured interview **Aim of the study** To explore the experiences of babies, children and young people in accessing regional allergy services. West Midlands, UK	N=18 parental proxies ○ Only the views of parents of children under the age of 5 years old are included in this review. **Characteristics** Age of children: • <1 year, n=3 • 1-5 years, n=9 • 5-10 years, n=1 • 10-15 years, n=4 • >15 years, n=1	**Recruitment** Purposive sampling of 2 paediatric allergy clinics. **Data collection** Semi-structured interviews **Analysis** Framework approach (including 2 interim analyses)	• Healthcare services: Availability of appointments and services
Fargas-Malet 2018 **Study design**	N=25 young people **Characteristics**	**Recruitment** Through carers of looked-after children and	• Individual factors: Personal perceptions

Study	Participants	Methods	Themes
Mixed-methods including semi-structured interview **Aim of the study** To explore the barriers to help-seeking for looked after children and young people, as well as their carers and social work practitioners, in order to improve their engagement with mental health services. Northern Ireland, UK	Age: 12 years or older Gender: not reported	young people that took part in study. **Data collection** Semi-structured interviews **Analysis** Content analysis	• Healthcare services: Availability of appointments and services • Healthcare services: Promotion of healthcare services
Haig-Ferguson 2019 **Study design** Semi-structured interviews **Aim of the study** To explore the views of children and young people, their parents, and healthcare professionals of treatment delivered by video-conferencing in a specialist paediatric chronic fatigue syndrome clinic. South-west England, UK	N=12 children and young people **Characteristics** Age (range): 9-18 years Gender (M/F): 3/9	**Recruitment** Purposive sampling of a paediatric chronic fatigue syndrome clinic **Data collection** Semi-structured interviews **Analysis** Inductive thematic analysis	• Individual factors: Personal perceptions • Healthcare professionals: Explaining limits of confidentiality • Healthcare services: Alternatives to physical appointments
Heath 2015 **Study design** Semi-structured interview **Aim of the study** To explore paediatric outpatient care as experienced by patients and	N=14 children and young people • n=8 hospital outpatient • n=6 community clinic outpatient **Characteristics** Not reported	**Recruitment** Purposive sampling of families in waiting area of paediatric clinic **Data collection** Semi-structured interviews **Analysis**	• Healthcare professionals: Relationships with healthcare professionals • Healthcare services: Availability of appointments and services

Study	Participants	Methods	Themes
parents, focusing on the impact of healthcare setting. Birmingham, UK/West Midlands, UK		Descriptive phenomenology	
Leavey 2011 **Study design** Mixed methods including focus group **Aim of the study** To explore young people's attitudes to their family doctors, in the context of seeking help for mental and physical health concerns. A secondary aim was to understand the more general help-seeking concerns and beliefs of secondary school pupils. London, UK	N=298 young people • n=48 young people (who participated in focus groups) included in this review **Characteristics** Age (range): 14–15 years Gender (M/F): not reported	**Recruitment** Convenience sampling of secondary schools in North London. **Data collection** Single-sex focus groups **Analysis** Content analysis	• Healthcare professionals: Explaining limits of confidentiality • Healthcare services: Promotion of primary healthcare services
Neill 2016 **Study design** Focus group and semi-structured interview **Aim of the study** To explore barriers and facilitators to parental help-seeking and access of healthcare services in several different socio-economic groups. East Midlands, UK	N=27 parental proxies (3 fathers and 24 mothers) of children under 5 years old **Characteristics** Age of children: not reported but inclusion criteria states at least 1 child aged 1-<5 years per parent Gender of children: not reported	**Recruitment** Purposive sampling of a low socio-economic, urban area (2 community centres and a private day nursery) **Data collection** Focus groups and semi-structured interviews **Analysis** Comparative analysis	• Individual factors: Parental influences • Healthcare professionals: Lack of trust in healthcare professionals • Healthcare professionals: Relationships with healthcare professionals • Healthcare services: Alternatives to physical appointments • Healthcare services: Availability of appointments and services

Study	Participants	Methods	Themes
Robards 2018 **Study design** Systematic review **Aim of the study** To access engagement with and navigation through healthcare systems for marginalised young people in the digital age. Multiple countries	K=68 studies Range of sample size: N=3 to 1388 **Characteristics** Type of study: • Qualitative, k=44 • Quantitative, k=16 • Mixed-methods, k=8 ○ This study incorporated all their results (qualitative and quantitative) into a narrative summary, which was then used in the findings of this review. Participants: • Young people, k=61 • Professionals, k=11 • Parents, k=7 ○ Although the study notes that their themes were identified by all the participants in their population (marginalised young people up to age 24 years old, parents and healthcare professionals), views of people > 18 years old, parents and health professionals will also have been included in their results. Our findings have been downgraded for relevance where applicable.	**Recruitment** Not applicable **Data collection** Systematic literature search **Analysis** Data extraction, quality appraisal of studies and thematic analysis	• Individual factors: Personal perceptions • Healthcare professionals: Lack of trust in healthcare professionals • Healthcare professionals: Explaining limits of confidentiality • Healthcare professionals: Relationships with healthcare professionals • Healthcare services: Promotion of primary healthcare services
Sime 2014 **Study design** Mixed methods including focus groups and family case study interviews **Aim of the study**	N=105 children, young people, parents and healthcare professionals • n=86 children and young people • n=19 parents and healthcare professionals ○ Only the views of children and young	**Recruitment** Service providers were recruit potential participants **Data collection** Focus groups and family case studies using participatory-based activities	• Individual factors: Parental influences • Healthcare services: Accessible language • Healthcare services: Promotion of primary healthcare services

Study	Participants	Methods	Themes
To explore the experiences of recently migrated Eastern-European children when accessing UK healthcare services. Scotland, UK	people were included in this review. *Focus group* N=57 children and young people *Family case studies* N=29 children and young people **Characteristics** Age (range): 5–16 years Gender (M/F): 40/46	**Analysis** Grid analysis and thematic coding	
Turnbull 2010 **Study design** Mixed-method including semi-structured interview **Aim of the study** To explore the experiences of parents of young children when using an out-of-hours telephone-based healthcare delivery service. Devon, UK	N=8 parental proxies of children under 5 years old **Characteristics** Age of children (range): 0-4 years Gender of children (M/F): not reported	**Recruitment** Purposive sampling **Data collection** Semi-structured interviews by telephone or face-to-face **Analysis** Framework approach	• Healthcare services: Availability of appointments and services
Walsh 2011 **Study design** Mixed- method including semi-structured interview **Aim of the study** To explore young offenders' views on their mental health needs and support when accessing mental health services. Suffolk, UK	N=6 young people **Characteristics** Age (range): 13-17 years Gender (M/F): 4/2	**Recruitment** Purposive sampling of participants from the geographical area of Suffolk **Data collection** Initial questionnaire phase of study followed by semi-structured face-to-face interviews in subset of participants **Analysis** Thematic analysis	• Individual factors: Health education

Study	Participants	Methods	Themes
Whittle 2012 **Study design** Semi-structured interview **Aim of the study** To inform the development of a DVD capturing views of young people in custody about health issues and their experiences of coping while in custody. Northern and Southern England, UK	N=28 young people **Characteristics** Age (range): 16-18 years Gender (M/F): 23/5	**Recruitment** Not reported **Data collection** Semi-structured face-to-face interviews **Analysis** Constant comparative method	• Healthcare services: Accessible language • Healthcare services: Availability of appointments and services

F: female; K: number of studies; M: male; N: number of participants

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 themes below. For each of the sub-themes the overall confidence was judged to be:

Main theme 1: Individual factors

- Sub-theme 1.1: Personal perceptions. The overall confidence in this sub-theme was judged to be high.
- Sub-theme 1.2: Heath education. The overall confidence in this sub-theme was judged to be low.
- Sub-theme 1.3: Parental influences. The overall confidence in this sub-theme was judged to be moderate.

Main theme 2: Healthcare professionals

- Sub-theme 2.1: Lack of trust in healthcare professionals. The overall confidence in this sub-theme was judged to be moderate.
- Sub-theme 2.2: Explaining limits of confidentiality. The overall confidence in this sub-theme was judged to be high.
- Sub-theme 2.3: Relationships with healthcare professionals. The overall confidence in this sub-theme was judged to be low.

Main theme 3: Healthcare services

- Sub-theme 3.1: Accessible language. The overall confidence in this sub-theme was judged to be very low.

- Sub-theme 3.2: Alternatives to physical appointments. The overall confidence in this sub-theme was judged to be moderate.
- Sub-theme 3.3: Availability of specialist appointments and services. The overall confidence in this sub-theme was judged to be very low.
- Sub-theme 3.4: Promotion of primary healthcare services. The overall confidence in this sub-theme was judged to be low.

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

Evidence from reference groups and focus groups

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

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

Age groups	• <7 years • 7-11 years • 11-14 years
Areas covered	• Access to health services, including barriers and solutions
Illustrative quotes	• Who is someone you go to if you are not feeling very well? ○ 'A doctor/surgeon' ○ 'Daddy' ○ 'Dentist' • What makes it easier to access health services? ○ 'Not missing a lot of school to see the doctor' ○ 'Swift in and out' ○ 'More doctors so you don't have to wait long' ○ 'Not too much travelling' • What are barriers to accessing healthcare? ○ 'Not being taken seriously by healthcare staff' ○ 'Feeling embarrassed' ○ 'Not enough time/too busy/already have plans – if you have a busy schedule you might not have enough time' • Possible solutions to the barrier 'fear and being scared' ○ 'Having a teddy to hold onto' ○ 'Knowing the risks, knowing it's not going to kill you' ○ 'Worried about fertility with treatment - having information about the risks' ○ 'Having parents there/right there beside me'

See the full evidence summary in appendix M.

Evidence from national surveys

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

Table 4: Summary of the evidence from national surveys

National surveys	• Association for Young People's Health. Young people's views on involvement and feedback in healthcare 2014

	• Child Outcomes Research Consortium. Child- and Parent-reported Outcomes and Experience from Child and Young People's Mental Health Services 2011-2015 • Health and Social Care Information Centre. Children's Dental Health Survey 2013 • HM Inspectorate of Prisons. Children in Custody 2016-2017 • National Children's Bureau. Listening to children's views on health provision 2012 • Opinion Matters. Declare your care survey 2018 • Word of Mouth Research and Point of Care Foundation. An options appraisal for obtaining feedback on the experiences of children and young people with cancer 2018
Areas covered	• Use of different health services • Appointments • Access to NHS dental services • Access to healthcare in custody • Access to healthcare for care-leavers • Choice of hospital
Key findings	• People reported having used a wide variety of health services, such as GPs, pharmacies and hospitals, and most were feeling positive about how these met their needs. The accident and emergency service was used by many, but it was ranked lowest of 7 services for meeting needs • Most were satisfied with the date and time for their appointments, although some made complaints about delays and cancellations • Most parents of children reported being satisfied with access to dental services • The majority of those in custody felt that they were able to see a doctor or a nurse when required, and most reported that health services were 'good' • Care leavers reported that they needed more support to access health services, including more information about the services available, particularly sex education

See the full evidence summary in appendix N.

Economic evidence

Included studies

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

Excluded studies

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

Summary of studies included in the economic evidence review

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

Economic model

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

The committee's discussion of the evidence

Interpreting the evidence

The outcomes that matter most

This review focused on the barriers that may prevent babies, children and young people accessing healthcare, and the facilitators that may help with access. 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:

- Awareness and knowledge of available healthcare services
- Concerns about privacy and confidentiality
- Convenience of time, location and setting in which healthcare is delivered
- Distrust of healthcare services
- Fear or stigma related to accessing services
- Impact on parents' or carers' personal financial means
- Impact of parents' or carers' lives on healthcare received by their child or charge
- Lack of age- or developmentally-appropriate services
- Lack of knowledge about the availability of services
- Provision of services that are sensitive to the (e.g. physical, cultural, religious) needs of the baby, child or young person
- Safeguarding
- Use of medical jargon
- Use of electronic technology to increase ways of accessing healthcare

Not all of these themes were identified in the literature, and there was no evidence on the lack of age- or developmentally-appropriate services. Additional themes were identified relating to parental influences, health literacy and relationships with healthcare professionals.

The quality of the evidence

The systematic review evidence (excluding grey literature and focus group evidence) was assessed using GRADE-CERQual methodology, and the overall confidence in the findings ranged from very low to high. Sub-themes were generally downgraded because of the methodological limitations of the included studies, which was assessed using the Critical Appraisal Skills Programme (CASP) checklist. Examples of these are lack of information regarding recruitment methods or how interviews were conducted. Lack of reflexivity in data analysis was also a common limitation. The evidence was also downgraded due to concerns about the adequacy of data, as some themes only had relatively small amounts of evidence contributing to the finding. Themes were downgraded for coherence in the study findings. For example, the evidence for certain themes were closely interlinked and may have lost some nuances in the synthesis and separation. The evidence was also downgraded due to applicability where some data were generated from participants over 18 years of age. The study in question was nevertheless included because the themes identified in the study were supported by evidence from participants under 18.

Benefits and harms

The committee discussed that the evidence for this review reflected a wide range of diverse groups of children and young people and services. This included looked after children, young people from a minority ethnic background, young offenders, immigrants, parents of babies and young children, and settings included dental, primary care, outpatient, specialist and out of hours services. The committee therefore agreed that the themes identified could be representative across a wide range of healthcare provision.

Based on the evidence from the sub-themes on health education and primary care services, the committee noted that one of the main barriers that prevent children and young people from accessing healthcare was the lack of information about when to access healthcare services, the services available and the role these have in supporting them. The committee therefore made a recommendation that information relating to identifying healthcare needs and the availability of services should be provided to enable access.

Based on the theme of personal perceptions, and on evidence from the focus and reference groups, the committee noted that children and young people may avoid seeking help due to fear of being blamed, labelled or because they are too embarrassed. The committee acknowledged that fear and embarrassment were emotions commonly experienced by children and young people, however they do not always recognise these straightaway, so healthcare professionals may need to encourage them to talk about it by asking questions, and reassure them that is normal to feel afraid or embarrassed, and that healthcare professionals are there to provide help.

The committee were aware from their own experience that much health information and service information is aimed at parents, and so made it clear in the recommendation that there should be specific information for children and young people. There had been no evidence on the development of information resources for children and young people, but the committee used their knowledge and experience to recommend that resources to improve access may need to be co-produced with children and young people and developed in collaboration with appropriate specialists and sectors other than healthcare.

The committee were aware that parents of babies and young children would still need information applicable to them to help them access the right services for their child, and so made a recommendation to that effect.

There was evidence from the themes of explaining limits of confidentiality and lack of trust in healthcare professionals. Children and young people were unsure about what services they could access with or without their parents and whether they had accessed services would be shared with their parents. These were recognised as factors which might diminish their willingness to access services. The committee therefore made recommendations that information clarifying this should be made available.

There was evidence of other barriers from the themes of personal perceptions and accessible language. This included the fear of stigma or judgemental attitudes and gender stereotypes. Complex or jargon-filled information or not having interpreters available may also act as barriers to accessing healthcare. The committee therefore agreed that when delivering services for children and young people their specific needs and wishes should be taken into account. However, the committee agreed that as well as being applicable to the delivery of existing services, it was very important to take these factors into account when reviewing services, and when designing new ones. This was not something that had been identified in this evidence review, but the committee made a cross-reference to the recommendations they had already written on involving children and young people in the design of healthcare services.

The committee recognised that although it was possible to overcome some of the barriers to accessing healthcare for a large proportion of children and young people, there were groups of children and young people who may require additional support. This was confirmed by the evidence from the grey literature review of national surveys, where feedback from care leavers had identified that they would like additional support to help them access primary healthcare services, including advice on when and how often they should see healthcare professionals, how to navigate the system, how to pay for services where necessary or to claim exemptions from payment. The committee agreed this additional support could be provided by a named healthcare professional or a named social care professional such as a social worker, and included this in their recommendation. The committee discussed that a named professional was necessary, as while this support could be provided by a number of different people, there may be a potential harm if no professional involved with a child or young person, sees it as their role and takes that responsibility because they assume that someone else will do it.

There was evidence from the theme of availability of specialist appointments and services that some children and young people found it more difficult to attend appointments – for example those from a rural location who might have to travel long distances or those who did not wish to miss school for appointments scheduled during school hours. The committee therefore made a recommendation that flexible appointments should be offered where possible, and agreed that for some families with several children, appointments in school hours might be easier, for others evenings or weekends were easier, and for children or young people who had regular appointments, not missing school on a regular basis would be preferable. The committee discussed that providing services in locations that were easier to access could help overcome some of the barriers to access, and stated that in a recommendation.

The theme of alternatives to physical appointments provided evidence that virtual appointments, services such as 111 and telephone appointments could help overcome some access issues such as the difficulties of travelling to physical appointments, so the committee recommended these options should be considered in addition to face-to-face healthcare. The committee recognised that a potential harm from this recommendation was that digital access could cause other access issues, for example if children or young people did not have easy access to a computer. Choosing between a number of options available to them to access healthcare may cause problems for children and young people if they do not know which option to select. However, this could be mitigated by clear health education and service information which had been included in their recommendations.

The committee reviewed the evidence from the focus and reference groups. The evidence from the 4-7 year olds showed that although they were aware of a variety of people and services who could provide healthcare they may view accessing healthcare as ‘scary’, and the committee agreed that in their experience this was a barrier for younger children. The older two groups were very aware of a large number of potential barriers that could prevent or discourage children and young people from accessing healthcare. These included embarrassment, not feeling able to explain what was wrong, and not being taken seriously, being afraid of the treatment or its side-effects, being too busy to seek healthcare, or fears about missing out on other activities and school. Both age groups mentioned the difficulty of physically getting to services, and the older age group mentioned capacity issues such as lack of services, thresholds for referral or long waiting times. The committee agreed that the views of the reference groups reinforced the evidence from the systematic literature review, and confirmed the recommendations about promoting and supporting access to healthcare services by providing information and overcoming barriers. There was also evidence that the gender of the healthcare professional could be perceived as a barrier or concern, and as this had not been identified by the systematic review, the committee added to their recommendations that preferences about the gender of the healthcare professional should be accommodated if possible.

Finally, there was no evidence about obtaining feedback from children and young people on accessibility, but based on their experience the committee agreed that this should be highlighted as a specific area on which feedback should be obtained, and made a cross-reference to the section of the guideline on measuring experience of care.

Cost effectiveness and resource use

There was no existing economic evidence for this review. The committee noted that there could be resource implications to develop information and resources to facilitate better access to services. There may also be cost implications in developing flexible services, such as running clinics in the evening or at weekend. The committee was of a view that this may lead to more timely and appropriate care and any additional costs would be outweighed by improvements in outcomes. There may also be cost savings associated with flexible methods of delivering healthcare services, in particular to parents or carers (e.g. less expense associated with travelling to appointments or potentially taking less time out of work). However, flexible methods of delivering healthcare services are unlikely to reduce healthcare professional workload as time will still need to be spent providing a consultation.

Recommendations supported by this evidence review

This evidence review supports recommendations 1.1.1 to 1.10.9 in the NICE guideline.

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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, 21-27, 2010

Walsh 2011

Walsh, J., Scaife, V., Notley, C., Dodsworth, J., Schofield, G., Perception of need and barriers to access: The mental health needs of young people attending a Youth Offending Team in the UK, Health and Social Care in the Community, 19, 420-428, 2011

Whittle 2012

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Appendices

Appendix A – Review protocol

Review protocol for review question: What are the facilitators of, and barriers to, accessing healthcare services for babies, children and young people?

Table 5: Review protocol

Field	Content
PROSPERO registration number	CRD42019145552
Review title	Accessing healthcare services
Review question	What are the facilitators of, and barriers to, accessing healthcare services for babies, children and young people?
Objective	To determine the facilitators of, and barriers to, accessing healthcare services faced by babies, children and young people.
Searches	The following databases will be searched: • CCTR • CDSR • Embase • MEDLINE • MEDLINE IN-Process • PsycINFO One broad, guideline-wide, search will be conducted for qualitative questions, capturing the population and the settings. A UK filter will be applied to identify relevant UK studies, and a systematic review filter will be applied to the remainder of the results to identify relevant reviews that include evidence from non-UK high-income countries. If no systematic reviews of this type are identified, then a more focused search may be conducted to identify studies conducted in the following high-income countries: Australia, Austria, Belgium, Canada Denmark, Finland, France, Germany, Greece, Iceland, Ireland, Italy, Liechtenstein, Luxembourg, Malta, Monaco, Netherlands, New Zealand, Norway, Portugal, Spain, Sweden, Switzerland, and USA. Searches will be restricted by: • Date: 2009 • Language of publication: English language only

Field	Content
	• Publication status: Conference abstracts will be excluded because these do not typically provide sufficient information to fully assess the risk of bias • Standard exclusions filter (animal studies/low-level publication types) will be applied • UK-filter on guideline-wide search and systematic review filter on the remaining citations will also 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's and young people's experience of accessing healthcare
Population	• People <18 years-old who have experience of healthcare Studies that use the views of parents or carers as proxies will be included only if they are responding on behalf of their child or charge, and ○ The baby or child of the parent or carer is under-5 years-old, or ○ There is a clear rationale provided as to why the study is using parents' or carers' views on and experiences of healthcare as proxies for their child. Note: Studies where part of the population is <18 years-old and part of the population is ≥18 years-old will only be included if it is clear that the themes are supported by evidence from the former group only.
Intervention/Exposure/Test	Experience of healthcare, in particular of accessing healthcare services. 'Access to healthcare' will be defined as the initial point of contact with a specific healthcare service for a specific (possibly unidentified) condition (e.g. seeing a GP; booking and attending a hospital appointment). Note: Views on, and experience of, subsequent planning, treatment and referral to other services for a specific disease or condition not related to initially accessing specific services will be treated as continuity of care and reviewed in RQ 8.2
Comparator/Reference standard/Confounding factors	Not applicable
Types of study to be included	• Systematic reviews of qualitative studies • Studies using qualitative methods: focus groups, semi-structured and structured interviews, observations • Surveys conducted using open-ended questions and a qualitative analysis of responses Note: Mixed methods studies will be included but only qualitative data will be extracted, and risk of bias assessed. Systematic reviews that include evidence from countries not listed in the search strategy will be excluded if the sources of the themes and evidence from high-income countries cannot be clearly established. Evidence from individual qualitative studies conducted in the high-income countries listed in the search strategy will be included only if no relevant systematic review evidence is identified.

Field	Content
Other exclusion criteria	STUDY DESIGN • Studies using quantitative methods only (including surveys that report only quantitative data) • Surveys using mainly closed questions or which quantify open-ended answers for analysis TOPIC OF STUDY Studies on the following topics will also be excluded: • Accessing non-NHS commissioned health promotion interventions • Views and experiences of healthcare professionals and service managers • Views and experiences of people reporting only on social care planning and shared decision making Studies that focus explicitly on the following topics rather than focussing on the views on and experiences of babies, children and young people in healthcare will be excluded as they are covered by the following NICE guidelines: • Child abuse and maltreatment: o Child abuse and neglect (NG76) o Child maltreatment: when to suspect maltreatment in under 18s (CG89) • Community engagement o Community engagement (NG44) • Drug misuse in children and young people: o Alcohol: school-based interventions (PH7) o Alcohol-use disorders: diagnosis, assessment and management of harmful drinking and alcohol dependence (CG115) o Alcohol-use disorders: prevention (PH24) o Drug misuse prevention: targeted interventions (NG64) • End of life care for infants, children and young people with life-limiting conditions: planning and management (NG61) • Immunisations: reducing differences in uptake in under 19s (PH21) • Oral health promotion: general dental practice (NG30) • Physical activity and weight management: o Maternal and child nutrition (PH11) o Obesity prevention (CG43) o Physical activity for children and young people (PH17) o Weight management: lifestyle services for overweight or obese children and young people (PH47) • Pregnancy, including routine antenatal, intrapartum or postnatal care:

Field	Content
	○ Antenatal and postnatal mental health: clinical management and service guidance (CG192) ○ Antenatal care for uncomplicated pregnancies (CG62) ○ Intrapartum care for healthy women and babies (CG190) ○ Intrapartum care for women with existing medical conditions or obstetric complications and their babies (NG121) ○ Multiple pregnancy: antenatal care for twin and triplet pregnancies (CG129) ○ Postnatal care up to 8 weeks after birth (CG37) ○ Pregnancy and complex social factors: a model for service provision for pregnant women with complex social factors (CG110) • Self-harm: ○ Self-harm in over 8s: long-term management (CG133) ○ Self-harm in over 8s: short-term management and prevention of recurrence (CG16) • Sexual health and contraception ○ Contraceptive services for under 25s (PH51) ○ Sexually transmitted infections and under-18 conceptions: prevention (PH3) ○ Harmful sexual behaviour among children and young people (NG55) • Smoking prevention: ○ Smoking: preventing uptake in children and young people (PH14) ○ Smoking prevention in schools (PH23) ○ Stop smoking interventions and services (NG92) • The transition from children's to adults' services for young people using health or social care services (NG43)
Context	UK studies from 2009 onwards will be prioritised for decision making by the committee as those conducted in other countries may not be representative of current expectations about either services or current attitudes and behaviours of healthcare professionals. The committee presumes that due to their development, particular circumstances and/or condition, there are some topics that babies, children and young people may not be in a position to pronounce on and that in these circumstances, it may be necessary to treat the 'indirect' views of their parents or carers as proxies for their own views on and experiences of healthcare in order to make recommendations. The guideline committee will be consulted on whether a study should be included if it is unclear why parents' or carer's views are being reported instead of their child or charge, and reasons for exclusion if appropriate will be documented. The topic about which the BCYP are talking about should be generalizable to the wider healthcare context (e.g. a study on the views on and experience of communication with healthcare professionals whilst receiving chemotherapy would be included, whilst a study on experience of chemotherapy would be too narrow and not generalizable to wider healthcare context and therefore excluded). Recommendations will apply to those receiving care in all settings where NHS- or local authority- commissioned healthcare is provided

Field	Content
	(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 relating to facilitators of, and barriers to, accessing healthcare services 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): • Awareness and knowledge of available healthcare services • Concerns about privacy and confidentiality • Convenience of time, location and setting in which healthcare is delivered • Distrust of healthcare services • Fear or stigma related to accessing services • Impact on parents' or carers' personal financial means (e.g. cost of transport to enable use healthcare services) • Impact of parents' or carers' lives on healthcare received by their child or charge (e.g. employer of parent refusing time off to take child to GP) • Lack of age- or developmentally-appropriate services (e.g. young person is seen by adult services rather than paediatric services) • Lack of knowledge about the availability of services • Provision of services that are sensitive to the (e.g. physical, cultural, religious) needs of the baby, child or young person (e.g. interpreter, same-sex healthcare staff) • Safeguarding • Use of medical jargon • Use of electronic technology to increase ways of accessing healthcare (e.g. online booking system, virtual appointments) The following themes will not be covered in this review despite relating to accessing healthcare services: • Accessing healthcare information (will be covered in RQ 2.1) • Advocacy and support (will be covered in RQ 3s) • Architectural, physical or design features of environment in which healthcare is provided (will be covered in RQ 6.1) • Communication with babies, children and young people, and their parents or carers (including issues regarding confidentiality, treatment etc.) (will be covered in RQ 1s) • Using views and experiences of babies, children and young people to improve healthcare services (will be covered in RQ 5.1)

Field	Content
Secondary outcomes (important outcomes)	Not applicable
Data extraction (selection and coding)	• All references identified by the searches and from other sources will be uploaded into STAR and de-duplicated. Titles and abstracts of the retrieved citations will be screened to identify studies that potentially meet the inclusion criteria outlined in the review protocol. • Duplicate screening will not be undertaken for this question. • Full versions of the selected studies will be obtained for assessment. Studies that fail to meet the inclusion criteria once the full version has been checked will be excluded at this stage. Each study excluded after checking the full version will be listed, along with the reason for its exclusion. A standardised form will be used to extract data from studies, including study reference, research question, theoretical approach, data collection and analysis methods used, participant characteristics, second-order themes, and relevant first-order themes (i.e. supporting quotes). One reviewer will extract relevant data into a standardised form, and this will be quality assessed by a senior reviewer.
Risk of bias (quality) assessment	Risk of bias of individual qualitative studies will be assessed using the CASP (Critical Skills Appraisal Programme) Qualitative checklist. Risk of bias of systematic reviews of qualitative studies will be assessed using the CASP (Critical Appraisal Skills Programme) Systematic Review checklist. See Appendix H in Developing NICE guidelines: the manual for further details. The quality assessment will be performed by one reviewer and this will be quality assessed by a senior reviewer.
Strategy for data synthesis	• Extracted second-order study themes and related first-order quotes will be synthesised by the reviewer into third-order themes and related sub-themes. • The GRADE-CERQual (Confidence in the Evidence from Reviews of Qualitative research; Lewin 2015) approach will be used to summarise the confidence in the third-order theme or sub-theme from the qualitative evidence. The overall confidence in evidence about each theme or sub-theme will be rated on four dimensions: methodological limitations, coherence, adequacy, and relevance. • Methodological limitations refer to the extent to which there were problems in the design or conduct of the studies and will be assessed with the CASP checklist for qualitative studies or systematic reviews as appropriate. Coherence of findings will be assessed by examining the clarity of the data. Adequacy of data will be assessed by looking at the degree of richness and quantity of findings. Relevance of evidence will be assessed by determining the extent to which the body of evidence from the primary studies are applicable to the context of the review question.
Analysis of sub-groups	If there is sufficient data, views and experiences will be analysed separately by the following age ranges: • <1-year-old (i.e. 364 days-old or less) • ≥1 to <12 years-old (i.e. 365 days-old to 11 years and 364 days-old • ≥12 to <18 years-old (i.e. 12 years and 0 days-old to 17 years and 364 days old) The committee are aware that children can experience substantial cognitive and developmental change during the ages of 1 and 12, and that there may be (though not necessarily) substantive differences

Field	Content			
	between children in this group depending on the topic about which they are being asked. The committee will, therefore, be consulted regarding whether data regarding further subgroups within this age range (e.g. 1-5, 6-11) should be used. Subgroup analysis according to any of the groups listed in the Equality Considerations section of the scope will be conducted if there is sufficient data.			
Type and method of review	☐	Intervention		
	☐	Diagnostic		
	☐	Prognostic		
	☒	Qualitative		
	☐	Epidemiologic		
	☐	Service Delivery		
	☐	Other (please specify)		
Language	English			
Country	England			
Anticipated or actual start date	13 January 2020			
Anticipated completion date	07 April 2021			
Stage of review at the time of this submission	Review stage		Started	Completed
	Preliminary searches		☑	☑
	Piloting of the study selection process		☑	☑
	Formal screening of search results against eligibility criteria		☑	☑
	Data extraction		☑	☑
	Risk of bias (quality) assessment		☑	☑
	Data analysis		☑	☑
Named contact	**5a. Named contact** National Guideline Alliance **5b. Named contact e-mail**			

Field	Content	
	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=145552	
Dissemination plans	NICE may use a range of different methods to raise awareness of the guideline. These include standard approaches such as: • notifying registered stakeholders of publication • publicising the guideline through NICE's newsletter and alerts • issuing a press release or briefing as appropriate, posting news articles on the NICE website, using social media channels, and publicising the guideline within NICE.	
Keywords	Access; accessibility; babies; children; experience; healthcare; infants; qualitative; services; views; young people.	
Details of existing review of same topic by same authors	Not applicable	
Current review status	☒	Ongoing
	☐	Completed but not published
	☐	Completed and published

Field	Content	
	☐	Completed, published and being updated
	☐	Discontinued
Additional information	[Provide any other information the review team feel is relevant to the registration of the review.]	
Details of final publication	www.nice.org.uk	

CASP: critical appraisal skills programme; CDSR: Cochrane Database of Systematic Reviews; CENTRAL/CCTR: Cochrane Central Register of Controlled Trials; GRADE-CERqual: Grading of Recommendations Assessment, Development and Evaluation - Confidence in the Evidence from Reviews of Qualitative research ; NGA: National Guideline Alliance; NHS: National health service; NICE: National Institute for Health and Care Excellence

Appendix B – Literature search strategies

Literature search strategies for review question: What are the facilitators of, and barriers to, accessing healthcare services for babies, children and young people?

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

#	Searches
14	(hospital patient/ or hospitalized adolescent/ or hospitalized child/ or hospitalized infant/ or hospitalization/ or hospital patient/ or outpatient/) use emez
15	(adolescent, hospitalized/ or child, hospitalized/ or Hospitalization/ or inpatients/ or outpatients/) use ppez
16	(hospitalized patients/ or exp hospitalization/ or outpatients/) use psyh
17	(hospital* or inpatient* or outpatient*).tw.
18	(health* adj3 (care or center* or centre* or clinic* or facility or facilities or service* or setting* or specialist*)).tw.
19	((dental or communit* or emergency or hospital* or home or intensive or high-dependen* or mental* or primary or secondary or tertiary) adj3 (care or health*)).tw.
20	(emergency adj2 room*).tw.
21	(ambulance* or CAMHS or dentist* or dietics or dieti?ian or hospice* or NICU or nutritionist* or orthodont* or ophthalmolog* or (outreach adj2 team*) or pharmacy or pharmacies or physio* or SCBU or SENCO or telemedicine*).tw.
22	((virtual* or online) adj2 (physician* or clinician* or doctor*)).tw.
23	(communit* adj3 (p?ediatric* or nurs*)).tw.
24	(home adj3 visit*).tw.
25	((walk-in or "urgent care") adj2 (centre* or center* or clinic* or service*)).tw.
26	"speech and language therap*".tw.
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

#	Searches
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)
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

#	Searches
	"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
110	case control study/ use emez
111	or/103-110

#	Searches
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

#	Searches
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

#	Search
38	MeSH descriptor: [Mental Health Services] explode all trees
39	MeSH descriptor: [Nutritionists] this term only
40	MeSH descriptor: [Occupational Therapy] this term only
41	MeSH descriptor: [Orthodontists] this term only
42	MeSH descriptor: [Pediatric Nursing] this term only
43	MeSH descriptor: [Pharmacies] this term only
44	MeSH descriptor: [Primary Health Care] this term only
45	MeSH descriptor: [Respite Care] this term only
46	MeSH descriptor: [School Health Services] explode all trees
47	MeSH descriptor: [School Nursing] this term only
48	MeSH descriptor: [Secondary Care] this term only
49	MeSH descriptor: [Telemedicine] this term only
50	MeSH descriptor: [Tertiary Healthcare] this term only
51	MeSH descriptor: [Transportation of Patients] this term only
52	MeSH descriptor: [Adolescent, Hospitalized] this term only
53	MeSH descriptor: [Child, Hospitalized] this term only
54	MeSH descriptor: [Hospitalization] this term only
55	MeSH descriptor: [Inpatients] this term only
56	MeSH descriptor: [Outpatients] this term only
57	(hospital* or inpatient* or outpatient*):ti,ab,kw
58	(health* near/3 (care or center* or centre* or clinic* or facility or facilities or service* or setting* or specialist*)):ti,ab,kw
59	((dental or communit* or emergency or hospital* or home or intensive or high-dependen* or mental* or primary or secondary or tertiary) near/3 (care or health*)):ti,ab,kw
60	(emergency near/2 room*):ti,ab,kw
61	(ambulance* or CAMHS or dentist* or dietics or dieti*ian or hospice* or NICU or nutritionist* or orthodont* or ophthalmolog* or (outreach near/2 team*) or pharmacy or pharmacies or physio* or SCBU or SENCO or telemedicine*):ti,ab,kw
62	((virtual* or online) near/2 (physician* or clinician* or doctor*)):ti,ab,kw
63	(communit* near/3 (p*ediatric* or nurs*)):ti,ab,kw
64	(home near/3 visit*):ti,ab,kw
65	((walk-in or "urgent care") near/2 (centre* or center* or clinic* or service*)):ti,ab,kw
66	("speech and language therap*"):ti,ab,kw
67	(general practice*):ti,ab,kw
68	(health* and (nursery or nurseries or school*)):ti,ab,kw
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

#	Search
77	MeSH descriptor: [Patient Preference] this term only
78	MeSH descriptor: [Attitude to Death] this term only
79	MeSH descriptor: [Health Knowledge, Attitudes, Practice] this term only
80	MeSH descriptor: [Patient Advocacy] this term only
81	MeSH descriptor: [Consumer Advocacy] this term only
82	MeSH descriptor: [Narration] this term only
83	MeSH descriptor: [Focus Groups] this term only
84	MeSH descriptor: [Professional-Patient Relations] explode all trees
85	(attitude* or choice* or dissatisf* or expectation* or experienc* or inform* or opinion* or perceive* or perception* or perspective* or preferen* or priorit* or satisf* or thought* or view*):ti,ab,kw
86	((adolescen* or baby or babies or child* or infant* or patient* or teen* or young person*) near/4 (decisi* or decid* or involv* or participat*)):ti,ab,kw
87	("informed choice" or "shared decision making"):ti,ab,kw
88	(empowerment):ti,ab,kw
89	(patient-focused or patient-cent*red):ti,ab,kw
90	(advocate or advocacy):ti,ab,kw
91	((aversion or barrier* or facilitat* or hinder* or obstacle* or obstruct*) near/2 (care or health* or intervention* or pathway* or program* or service* or therap* or treat*)):ti,ab,kw
92	#72 OR #73 OR #74 OR #75 OR #76 OR #77 OR #78 OR #79 OR #80 OR #81 OR #82 OR #83 OR #84 OR #85 OR #86 OR #87 OR #88 OR #89 OR #90 OR #91
93	MeSH descriptor: [Qualitative Research] this term only
94	MeSH descriptor: [Interview] this term only
95	(interview*):ti,ab,kw
96	(theme* or thematic):ti,ab,kw
97	(qualitative):ti,ab,kw
98	(questionnaire*):ti,ab,kw
99	(ethnological research):ti,ab,kw
100	(ethnograph*):ti,ab,kw
101	(ethnonursing):ti,ab,kw
102	(phenomenol*):ti,ab,kw
103	(life stor* or women* stor*):ti,ab,kw
104	(grounded near (theor* or study or studies or research or analys*s)):ti,ab,kw
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

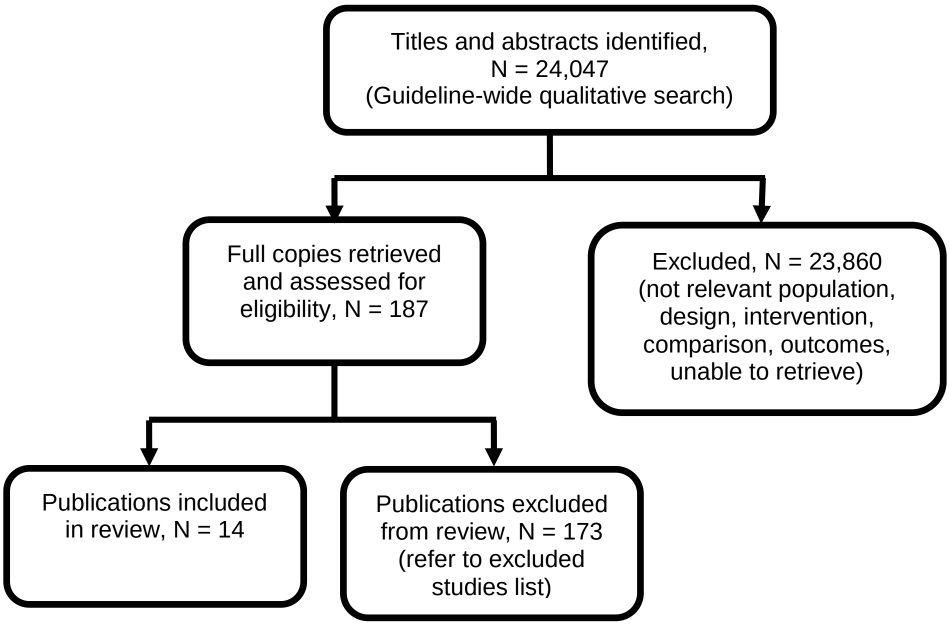
#	Search
115	#11 AND #71 AND #92 AND #114 with Cochrane Library publication date Between Jan 2009 and Aug 2020
116	MeSH descriptor: [United Kingdom] explode all trees
117	(national health service* or nhs*):ti,ab,kw
118	(english not ((published or publication* or translat* or written or language* or speak* 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
135	#133 OR #134
136	#132 not #135

#	Search
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: What are the facilitators of, and barriers to, accessing healthcare services for babies, children and young people?

Figure 2: Study selection flow chart



Appendix D – Clinical evidence tables

Evidence tables for review question: What are the facilitators of, and barriers to, accessing healthcare services for babies, children and young people?

Table 6: Evidence tables

Study details	Participants	Methods	Themes and findings	Limitations
Full citation Ali, Nasreen, McLachlan, Niel, Kanwar, Shama, Randhawa, Gurch, Pakistani young people's views on barriers to accessing mental health services, International Journal of Culture and Mental Health, 10, 33-43, 2017 **Ref Id** 1052663 **Country/ies where the study was** carried out Peterborough, UK **Study type** Qualitative **Aim of the study**	**Sample size** N 33 children and young people **Characteristics** Age (range): 11-19 years • It was not possible to establish how many participants were ≥ 18 years old. • Themes have been downgraded for relevance where applicable. Gender (M/F): 17/16 Ethnicity: all Pakistani origin **Inclusion criteria** Participants had to: • Be aged 11-19 years • Be of Pakistani origin (held or were descended	**Setting** Mental health services in Peterborough **Sample selection** Participants recruited from local schools, madrasas (Islamic religious education institutions) or youth groups and done by personal communication with one of the researchers. **Data collection** 4 single-sex focus groups (lasting 60-90 mins) were held, facilitated by a discussion guide. This was developed from a variety of literature and included semi-structured questions on religion, knowledge about mental health, awareness of local mental health services and suggestions for changes. **Data analysis**	**Author's themes:** • Awareness of mental health services and treatment options • The role of religion on the perceptions of risk factors and treatment options for mental illness • Stigma associated with accessing mental health services and treatment **Findings** Participants reported a lack of information on how to access local mental health services as a barrier. Although relevant services for mental health were mentioned. Participants said that the internet was the first point of reference for information about mental health services. In other cases, Islamic teachers were also approached for guidance. Other contributory factors to accessing mental health services were lack of trust (even within	**Limitations <u>(assessed using the CASP checklist for qualitative studies)</u>.** *Q1: Was there a clear statement of the aims of the research?* Yes. *Q2: Was a qualitative methodology appropriate?* Yes. *Q3: Was the research design appropriate to address the aims of the research?* Yes. Qualitative design and focus groups both justified for the topic area that was explored. *Q4: Was the recruitment strategy appropriate to the aims of the research?* No. Personal communication used for recruitment. This was justified by the researcher having good links to Peterborough Pakistani community but introduced the potential for bias which cannot be overlooked.

Study details	Participants	Methods	Themes and findings	Limitations
To explore UK Pakistani young people's views of barriers and facilitators to accessing mental health services in Peterborough, as well designing actions to improve access to these services. **Study dates** 2012-2013 **Source of funding** This study received support from Cambridgeshire and Peterborough NHS Foundation Trust.	from those who held Pakistani passport) - Reside in Peterborough **Exclusion criteria** None reported.	Framework analysis. Discussions were audio-recorded and transcribed. Researchers met regularly to discuss and develop themes via group consensus. Influence practice.	schools), feelings of embarrassment and shame/stigma. children and young people suggested providing tailored, culturally sensitive education on risk factors of mental illness and providing more social activity for young people.	*Q5: Were the data collected in a way that addressed the research issue?* Probably. Focus groups conducted in community settings for ease and privacy. Single-sex focus groups used to be more culturally sensitive. Discussion guide used during focus groups, which was informed by existing policy, current literature and study aim as well as designed via consensus with 4 researchers.an element of recall bias in the data. *Q6: Has the relationship between the researcher and participants been adequately considered?* No. No description of potential bias/influence between researcher and participants (particularly an issue with Q4). An incentive (£20 voucher and light refreshments were given to the participants at the end of the focus group. No discussion regarding how that may impact findings. *Q7: Have ethical issues been taken into consideration?* Yes. The study was approved by the University of Bedfordshire ethics board. Consent (parental for under 16s and individual for over 16s) process described and obtained. *Q8: Was the data analysis sufficiently rigorous?* Can't tell.

Study details	Participants	Methods	Themes and findings	Limitations
				Reports that a framework approach was used, and that the research team met regularly to discuss emerging patterns and themes. Themes were finalised via consensus. Multiple quotes to support and contradictory data is presented and considered. However, no mention of how many researchers were involved in analysis (at any of the time points), or how raw data quotes were chosen for reporting. No examination of bias in the study. *Q9: Is there a clear statement of findings?* Probably. Results are well described, with discussion of multiple views and experiences that were captured in the focus groups—related to both original research question and current literature. Credibility not discussed. *Q10: Is the research valuable for the UK?* (1. Contribution to literature and 2. Transferability) Probably. 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. 2. Can't tell. Authors mention the small sample size as a possible reason for lack of transferability to the rest of UK Pakistani young people.

Study details	Participants	Methods	Themes and findings	Limitations
				Overall judgement of quality: Serious concerns **Other information** At the end of each focus group, participants were given some light refreshments, and each participant received a £20 voucher for WHSmith as a goodwill gesture.
Full citation Best, Gil-Rodriguez, Manktelow and Taylor, Seeking Help From Everyone and No-One: Conceptualizing the Online Help-Seeking Process Among Adolescent Males, Qualitative Health Research, 26, 1067-1077, 2016 **Ref Id** 1053374 **Country/ies where the study was carried out** Northern Ireland, UK **Study type** Qualitative **Aim of the study**	**Sample size** N=56 young people (from 7 schools) **Characteristics** Age (range): 14-15 years Gender (M/F): 56/0 Ethnicity: not reported **Inclusion criteria** Not reported. **Exclusion criteria** Not reported.	**Setting** Secondary schools in Northern Ireland **Sample selection** Purposive cluster sampling of schools. Schools were purposively chosen using education level (secondary or grammar) and gender composition (single-gender or co-educational). Other factors included school size, class size and composition. At least 1 pupil per class was randomly selected from attendance registers. **Data collection** Eight semi-structured focus group sessions, lasting 45-60 minutes. Focus group data were audio-recorded and transcribed at a semantic level utilizing an orthographic or verbatim style.	**Author's themes:** • Search strategies • Pathways for Help-Seeking: Informal online help-seeking • Pathways for Help-Seeking: Formal online help-seeking Easy access to quality information via familiar search engines such as Google was a preferred avenue for accessing the information on health. This ensured their tough identity was protected via a gender-free zone. **Findings** Participants raised concerns about the relationship between ease of access and anonymity. Online personal support networks increased ease of access and a sense of control. However, this sense of control can be false and concerns regarding digital footprints were raised.	**Limitations <u>(assessed using the CASP checklist for qualitative studies)</u>.** *Q1: Was there a clear statement of the aims of the research?* Yes *Q2: Was a qualitative methodology appropriate?* Yes *Q3: Was the research design appropriate to address the aims of the research?* Yes. Qualitative design using focus groups allow for in-depth exploration(s) of various sensitivities and idiosyncrasies. Photo elicitation technique and discussion vignettes were also used to stimulate discussion. *Q4: Was the recruitment strategy appropriate to the aims of the research?* Yes. Purposive sampling of 7 schools using teachers and school staff to ensure a wide variety of characteristics

Study details	Participants	Methods	Themes and findings	Limitations
To explore how adolescent males locate and access support online. **Study dates** 2014 **Source of funding** This study received support from a Department of Education and Learning PhD studentship.		**Data analysis** Iterative thematic analysis. Themes were developed in an iterative manner, incorporating contrary ideas and input from a research team to ensure rigour and meanings of data captured at face value. These were then analysed using thematic analysis conducted within an ontological framework of critical realism and with an epistemological framework of contextualism.	Young people raised concerns over the undefined legal implications of informal help-seeking. Professional services gave an impression of safe disclosure, more control over their image and reduced embarrassment. Continuity of care, reliability of information and continued monitoring were also benefits of formal help-seeking.	and abilities are represented in the sample. *Q5: Were the data collected in a way that addressed the research issue?* Yes, data collection and analysis were performed in parallel; All focus groups were recorded and then transcribed to ensure accurate records. A topic guide was developed that included the following: (a) online versus offline help-seeking, (b) use of social networking sites to seek help, (c) role of online and offline friends, and (d) positive and negative aspects of online help-seeking. The study used novel techniques to explore online help-seeking among a hard-to-reach population of adolescent males. The sample covered a wide range of educational levels and socio-demographic backgrounds and thus is broadly representative. *Q6: Has the relationship between the researcher and participants been adequately considered?* Can’t tell. Descriptions of potential bias/influence or reflexivity between researcher and participants was not described in detail but was considered/mentioned. 3 members of the research team from three different institutions. A fourth

Study details	Participants	Methods	Themes and findings	Limitations
				member of the research team supervised this. *Q7: Have ethical issues been taken into consideration?* Yes. Ethical approval was granted by Ulster University's Research Ethics Committee. A teacher was present during each of the focus groups as a safeguarding measure. *Q8: Was the data analysis sufficiently rigorous?* Yes. The findings were supported by evidence derived from interviews. *Q9: Is there a clear statement of findings?* Yes. Detailed recommendations based on findings for accessing quality information, informal and formal pathways for help-seeking was supported by literature on broader online UK mental health services and how they can be used to inform best practice. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* Yes. Details on recommendations for improving access, confidentiality, online quality filters to promote health literacy are suitable to the UK and future policy making. 2. Yes. Findings and recommendations may be

Study details	Participants	Methods	Themes and findings	Limitations
				generalised to other hard-to-reach settings or adolescent males, but details on the sample age ranges and ethnic groups were not reported, perhaps still representative of the wider geographical area within the UK. However, only focuses on male help seeking. *Overall judgement of quality:* Minor concerns **Other information** None.
Full citation Dickson, C. M., Every child has the right to smile!--A qualitative study exploring barriers to dental registration in a SureStart area in Northern Ireland, Community practitioner: the journal of the Community Practitioners' & Health Visitors' Association, 88, 36-39, 2015 **Ref Id** 988388	**Sample size** N=8 parental proxies (8 mothers) of children under 5 **Characteristics** Age of child: 1-month-3 years Gender of children: not reported Ethnicity of children: not reported **Inclusion criteria** Participants had to be a parent of a child that was:	**Setting** Dental registrants in a Sure-Start area in Northern Ireland **Sample selection** Participants with children who were not registered with a dentist were identified from data stored on the 'Sure-Start Play' database by their electoral ward postcode and contacted by a Sure-Start health visitor to take part in the research. A follow-up letter was issued, and consent obtained. **Data collection** Face-to-face, semi-structured interviews were conducted	**Author's themes:** • Inconsistencies in advice or information given across professions • Childhood experiences, behaviour and attitudes • Barriers/reasons for non-attendance **Findings** Contradictory advice by health professionals was reported as a barrier to accessing services early. The lived experience of parents influenced future behaviours. So also, wrong health beliefs, perceptions, emotions and practicalities relating to the individual or some external factors	**Limitations** **<u>(assessed using the 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. Using interviews with set schedules allowed participants to respond to the privacy of their homes. *Q4: Was the recruitment strategy appropriate to the aims of the research?* Yes. A purposive

Study details	Participants	Methods	Themes and findings	Limitations
Country/ies where the study was carried out Northern Ireland, UK **Study type** Semi-structured interview **Aim of the study** To explore parents' perceptions of factors influencing the dental registrations of their children. **Study dates** Not reported. **Source of funding** This study received funding from the Sure-Start project.	• Aged 0-4 years old • Not registered with a dentist • Eligible for Sure-Start Programme (from 1 of 25 most deprived wards in Northern Ireland) **Exclusion criteria** None applied	using an interview schedule containing thirteen questions. 7 interviews took place on a one-to-one basis within the home setting, and one was facilitated by telephone at the mother's request. All interviews were recorded and then transcribed as soon as possible after the event to ensure that data available for analysis was an accurate record of the interview. To capture any additional information, notes were made during the interview process. **Data analysis** Phenomenological analysis and systematic thematic analysis.	about service provision were barriers to improving oral health.	sample of families with unregistered wards living in disadvantaged areas selected from the SureStart database. But 12 were contacted, 8 participated suggesting the possibility of non-responder bias in the sample and no attempts were made to recruit other families. *Q5: Were the data collected in a way that addressed the research issue?* Yes, data collection and analysis were performed in parallel; All interviews were recorded and then transcribed to ensure accurate records. But the interview schedule was not discussed in detail *Q6: Has the relationship between the researcher and participants been adequately considered?* Can’t tell. The researcher did not address potential bias or researcher-to-participant influence, limitations of the participants sampling frame, and how that may impact findings. *Q7: Have ethical issues been taken into consideration?* Yes. Informed consent received before interviews and ethical approval received from the National Research Ethics Committee..

Study details	Participants	Methods	Themes and findings	Limitations
				Q8: Was the data analysis sufficiently rigorous? Yes. The findings were supported by evidence derived from interviews. *Q9: Is there a clear statement of findings?* Yes. Details on recommendations of dental care in Ireland were itemised, which fits with current literature and the UK population, and how they can be used to inform best practice. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* Yes. Details on recommendations of dental care in Ireland were itemised, which fits with current research and the UK population, and how they can be used to inform best practice. 2. Can't tell. Data saturation was not considered by the Author, although the small sample size may not affect transferability to the rest of the disadvantaged Irish population. *Overall judgement of quality:* Minor concerns **Other information** None.

Study details	Participants	Methods	Themes and findings	Limitations
Full citation Diwakar, L., Cummins, C., Hackett, S., Rees, M., Charles, L., Kerrigan, C., Creed, H., Roberts, T., Parent experiences with paediatric allergy pathways in the West Midlands: A qualitative study, Clinical & Experimental Allergy, 4, 4, 2019 **Ref Id** 988400 **Country/ies where the study was carried out** West Midlands, UK **Study type** Semi-structured interview **Aim of the study** To explore the experiences of babies, children and young people in accessing regional allergy services. **Study dates**	**Sample size** N=18 parental proxies ○ Only the views of parents of children under the age of 5 years old are included in this review. **Characteristics** Age of children: • <1 year, n=3 • 1-5 years, n=9 • 5-10 years, n=1 • 10-15 years, n=4 • >15 years, n=1 Gender of children: not reported Ethnicity of children: not reported Age of parents (range): 26-55 years Gender of parents: not reported **Inclusion criteria** Participants had to be parents of children: ○ Aged 0-16 years-old	**Setting** 2 specialist paediatric allergy clinics **Sample selection** Purposive sampling. Participants were recruited by clinicians at participating allergy clinics. No further details reported. **Data collection** Individual semi-structured interviews. 12 were conducted over the telephone and 6 conducted at the home of the participants. The interview schedule was designed according to prior literature on the experiences of people with allergies and modified as the study progressed based on views expressed by previous interviewees. No further details reported. **Data analysis** Framework method. 2 interim analyses were carried out during December 2014 and April 2016 to identify emerging themes and inform further recruitment. Interviews were audio-recorded and transcribed verbatim by an external company into Nvivo 11	**Author's themes:** • Access to appropriate health care **Findings** Previous and ongoing parent-to-Doctor relationships affected children and young people ability to access appropriate care. Delays in the referral system, long waiting times and unhelpful face-to-face consultations were identified as structural hindrances.	**Limitations <u>(assessed using the CASP checklist for qualitative studies)</u>.** *Q1: Was there a clear statement of the aims of the research?* Yes *Q2: Was a qualitative methodology appropriate?* Yes *Q3: Was the research design appropriate to address the aims of the research?* Yes. Qualitative design justified as exploring the paediatric allergy pathway within the West Midlands to increase the understanding of the needs of the local population. Parents were targeted as they usually are the ones who access care for children. No information on why semi-structured interviews were used over other qualitative methods. *Q4: Was the recruitment strategy appropriate to the aims of the research?* Can't tell. Parents of children with allergies attending specialist clinics recruited by clinicians. No further information given regarding sampling, clinics or demographic data of participants. No information given about non-responders or parents who refused to participate.

Study details	Participants	Methods	Themes and findings	Limitations
Not reported. **Source of funding** This study received funding from the Wellcome Trust.	○ Who had allergies or related conditions ○ Attending 1 of 2 participating specialist paediatric allergy clinics **Exclusion criteria** • Parents aged under 18 years-old • Parents unable to converse in English	software. Codes were developed using both the interviews themselves and adapted from previous literature.		*Q5: Were the data collected in a way that addressed the research issue?* Yes. Interviews were conducted via telephone or face-to-face at the participant's home, depending on their preference. Qualitative data collected via audio-recorded semi-structured interview. A brief version of the interview guide is included in the article, which appears to cover all areas relevant to topic. Interviews continued until thematic saturation was reached. There was a pause in data collection between Dec 2014 and Jan 2016 (reason given) but no mention about how/if service, and therefore experiences, changed during this time. *Q6: Has the relationship between the researcher and participants been adequately considered?* Can't tell. No description of potential bias/influence between researcher and participants. *Q7: Have ethical issues been taken into consideration?* Yes. Informed consent obtained for all participants and ethical approval received from National Research Ethics Committee (and the Research & Development departments of each hospital).

Study details	Participants	Methods	Themes and findings	Limitations
				Q8: Was the data analysis sufficiently rigorous? Yes. Although there was a lack of detailed data analysis description, there were a number of techniques employed to ensure rigour. 50% of the transcripts were coded by 2 independent researchers who were experienced in qualitative coding in order to ensure consistency throughout the analysis. The final study report was sent to participants who wanted to see it before publication in order to report any inconsistencies or disagreements with the findings. Contradictory data is presented and discussed where appropriate. A good amount of data is shown to support the reported findings. *Q9: Is there a clear statement of findings?* Yes. A concise explanation of outcomes in the discussion, with good description within the results section and regular referral back to the original research question. Analysis around the credibility of findings, particularly respondent validation, However, there is no discussion surrounding evidence both for and against the study's findings. *Q10: Is the research valuable for the UK? (1. Contribution to*

Study details	Participants	Methods	Themes and findings	Limitations
				literature and 2. Transferability) Can't tell. 1. Can't tell. Details how the study findings can be used to inform best practice as well as ideas and directions for future research presented. However, it does not describe how the evidence fits in with current literature and the UK population 2. Can't tell. Allergy pathway users in the West Midlands is a very specific population. Small sample size and lack of demographic data limits transferability. *Overall judgement of quality:* Moderate concerns **Other information** Parents of children over 5 were also included in this study. As these parents are outside of the protocol data was not extracted for these parents where possible.
Full citation Fargas-Malet, Montserrat, McSherry, Dominic, The mental health and help-seeking behavior of children and young people in care in Northern Ireland: Making services accessible and	**Sample size** N=25 young people **Characteristics** Age: not reported but all interview participants were over 12 years-old Gender (M/F): not reported	**Setting** Mental health services in Northern Ireland **Sample selection** Purposive sampling. Social Services Client and Administration and Retrieval Environment register was used to identify all 2,500 children &	**Author's themes:** • Help seeking • Barriers to help-seeking **Findings** Putting effort into making culturally sensitive services available, e.g. therapeutic services for children under the age of eleven, young people with autism spectrum	**Limitations <u>(assessed using the 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*

Study details	Participants	Methods	Themes and findings	Limitations
engaging, British Journal of Social Work, 48, 578-595, 2018 **Ref Id** 1055604 **Country/ies where the study was carried out** Northern Ireland, UK **Study type** Mixed-method including semi-structured interview **Aim of the study** To explore the barriers to help-seeking for looked after children and young people, as well as their carers and social work practitioners, in order to improve their engagement with mental health services. **Study dates** Not reported **Source of funding**	*Characteristics of young people were only reported using the initial sample of 233 carers* Age (%): • < 1 year-old: 3 • 1-4 years-old: 12 • 5-11 years-old: 31 • 12-15 years-old: 32 • ≥16 years-old: 22 Gender (M/F): 112/121 Ethnicity: not reported **Inclusion criteria** Participants had to: • Be aged 12 years or above • Be registered with Social Services • Have a parent/carer who had participated in their own interview **Exclusion criteria** None reported.	young people in care in Northern Ireland. 10% of carers and parents were contacted to take part in the study. If their wards/children were over the age of 12, they were also invited to interview. **Data collection** Face-to-face interviews were conducted with young people in their homes, who provided consent. They asked the young people about their understanding of their health and their experience of help-seeking and supports. All interviews were digitally recorded and transcribed. **Data analysis** Using content analysis. No further details reported.	disorder, high risk-taking behaviour and severe mental health issues, services with multidisciplinary teams, providing a timely response (local drop-in centres or outreach programmes) and building healthy relationships with professionals would make more engaging, overcoming feelings of shame and stigma.	*the research?* Yes. Using a mixed-methods approach of semi-structured interviews which allowed for the exploration of underlying reasons driving current access to mental health services *Q4: Was the recruitment strategy appropriate to the aims of the research?* Yes. The recruitment approach was adequate. Demographic data suggest a good spread of participants, but Stakeholders and children and young people participation was possibly informed by the level of interest. *Q5: Were the data collected in a way that addressed the research issue?* Yes. Focus groups were conducted with practitioners and carers, which would facilitate in-depth content. While children and young people had one-to-one interview session due to the sensitive nature of the topic and to maintain confidentiality *Q6: Has the relationship between the researcher and participants been adequately considered?* No. The authors did not discuss the impact of implicit bias or reflexivity during data collection and analysis.

Study details	Participants	Methods	Themes and findings	Limitations
This study received support from the Office of the First Minister and Deputy First Minister in Northern Ireland.				*Q7: Have ethical issues been taken into consideration?* Yes. All participants in the study gave informed consent and ethical approval was received from each participating HSC Trust and the Office of Research Ethics Committee in Northern Ireland. *Q8: Was the data analysis sufficiently rigorous?* Can't tell. Although content analysis framework was used, the authors to not provide details of the number of coders and coding process. No contrary quotes were reported. *Q9: Is there a clear statement of findings?* Yes. The authors provide a clear discussion of findings on structural barriers, poor communication and collaboration; supported by literature on broader UK mental health services. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* Yes. Details on recommendations for improving access fits with current literature and the UK population, and how they can be used to inform best practice and future policymaking. 2. Can't tell. An adequate and representative sample was used,

Study details	Participants	Methods	Themes and findings	Limitations
				but different contextual factors may affect the applicability of findings. *Overall judgement of quality:* Moderate concerns **Other information** None.
Full citation Haig-Ferguson, A., Loades, M., Whittle, C., Read, R., Higson-Sweeney, N., Beasant, L., Starbuck, J., Crawley, E., "It's not one size fits all"; the use of videoconferencing for delivering therapy in a Specialist Paediatric Chronic Fatigue Service, Internet Interventions, 15, 43-51, 2019 **Ref Id** 989339 **Country/ies where the study was carried out** South-west England, UK	**Sample size** N=27 - n=12 children and young people - n=6 mothers - n=9 healthcare professionals **Characteristics** Age of children and young people (range): 9-18 years Gender of children and young people (M/F): 3/9 Ethnicity: not reported **Inclusion criteria** Participants had to be: - ≤18 years-old - Receiving treatment within the specialist CFS/ME team	**Setting** Specialist chronic fatigue syndrome clinics **Sample selection** Purposive sampling of children and young people within specialist chronic fatigue syndrome clinics who agreed to use of videoconferencing for delivering therapy and some young people who had opted not to use videoconferencing. All parents of children and clinical staff at the specialist centre were invited to take part. Participants were recruited until no new themes emerged from the interviews. **Data collection** Semi-structured interviews. The majority of interviews were conducted on an individual basis with either the parent or the child/young person.	**Author's themes:** - Convenient and flexible - Privacy concerns - Access to service - Feeling anxious **Findings** Challenges with lack of engagement, confidentiality, privacy and security issues were considered as a barrier to using remote consultation options. This was considered exacerbate the anxieties or problems in interaction that result from a young person's (CFS/ME) symptoms. Some positive experiences of using technology for consultation were easier access to services which overcame issues with travel/ affordability/time.	**Limitations <u>(assessed using the CASP checklist for qualitative studies)</u>.** *Q1: Was there a clear statement of the aims of the research?* Yes. *Q2: Was a qualitative methodology appropriate?* Yes. *Q3: Was the research design appropriate to address the aims of the research?* Yes. Qualitative design; semi-structured interviews to address sensitive topics with children and mothers; and focus groups with health professionals to uncover barriers/difficulties were both justified. *Q4: Was the recruitment strategy appropriate to the aims of the research?* Can't tell. Recruitment was carried out in 2 Chronic Fatigue Syndrome clinics; purposive sampling was used to select child/young person

Study details	Participants	Methods	Themes and findings	Limitations
Study type Semi-structured interview **Aim of the study** To explore the views of children and young people, their parents, and healthcare professionals of treatment delivered by video-conferencing in a specialist paediatric chronic fatigue syndrome clinic. **Study dates** Phase 1: May to October 2016; Service evaluation with children and young people Phase 2: September to December 2017; expansion of interviews to include parents and health professionals **Source of funding** This study received support from the Royal United Hospital Research Charity.	• Well enough to complete an interview **Exclusion criteria** None reported	However, one parent and children and young people were interviewed together as a dyad. **Data analysis** Inductive thematic analysis.		accessing the service using videoconferencing or not. Families of children were invited to participate in interviews as well as all clinical staff at the specialist centre. *Q5: Were the data collected in a way that addressed the research issue?* Yes. Data collection and analysis were iterative and performed in parallel until data saturation was achieved; All interviews were recorded and then transcribed to ensure accurate records. The interview schedule was provided and adapted to suit study participants. *Q6: Has the relationship between researcher and participants been adequately considered?* Yes. Details were provided on descriptive accounts of the major themes were developed. Constant comparison was used to identify important similarities and differences. Items that contradicted emergent findings (deviant cases) were sought, examined, and used to further refine themes. *Q7: Have ethical issues been taken into consideration?* Yes. Ethical approval was granted by the East Midlands Derby Research Ethics Committee with informed

Study details	Participants	Methods	Themes and findings	Limitations
				consent and assent (where possible) obtained before commencing interviews with participants *Q8: Was the data analysis sufficiently rigorous?* Yes. Details on the coding and development themes and sub-themes were provided. Topics were developed iteratively to in cooperate contrary ideas and facilitate input from a research team to ensure rigour. Transcripts of the 18 interviews and one focus group were analysed using inductive thematic analysis, which allowed for the exploration of new concepts. Peer debriefing, purposive sampling of knowledgeable participants, triangulation and data triangulation, as well as reflexivity, was employed. *Q9: Is there a clear statement of findings?* Yes. The study findings were adequately described; multiple views were considered from the interviews and focus groups. The results were well situated within the study aims and current literature. Credibility trustworthiness and triangulation were discussed, although how this informed data collection, analysis and presentation of findings were

Study details	Participants	Methods	Themes and findings	Limitations
				not described in detail; but limitations were acknowledged. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* Yes. 1. The study findings were well placed within the current literature on improving access within UK clinical settings and implications for practice. Ideas and directions for future research were presented. 2. Yes. Adequate population size for qualitative study and well-represented samples for each sub-group interviewed *Overall judgement of quality:* Minor concerns **Other information** Six parents and 9 healthcare professionals were also included in this study. However, both these groups are outside of the protocol (parents due to the age of the children participants) and data was not extracted for these populations where possible.
Full citation Heath, G., Greenfield, S., Redwood, S., The meaning of 'place' in families' lived experiences of	**Sample size** N=14 children and young people **Characteristics**	**Setting** Paediatric outpatient clinic • Hospital outpatient: n = 8 • Community clinic outpatient: n = 6	**Author's themes:** • Time wasted, time saved • My community, not the community	**Limitations (assessed using the CASP checklist for qualitative studies).** *Q1: Was there a clear statement of the aims of the research?* Yes.

Study details	Participants	Methods	Themes and findings	Limitations
paediatric outpatient care in different settings: A descriptive phenomenological study, Health and Place, 31, 46-53, 2015 **Ref Id** 989549 **Country/ies where the study was carried out** Birmingham, UK **Study type** Semi-structured interview **Aim of the study** To explore paediatric outpatient care as experienced by patients and parents, focusing on the impact of healthcare setting. **Study dates** Not reported. **Source of funding** This study received support from National Institute for Health Research via	Not reported. **Inclusion criteria** Not reported **Exclusion criteria** Not reported (although a lower age limit of 'approximately 8 years' was noted)	**Sample selection** Purposive sampling. Families were approached in person while in the waiting area for general paediatric clinic, and via a letter for families who had received an appointment at general paediatric clinic. Participants were selected through their experience with attending appointments in 1 of 3 settings (hospital, health centre, children's centre). **Data collection** Semi-structured interviews. Each interview began with an overarching question about the decision to attend the clinic, followed by a description of their last visit. After this, responses were tailored to participant's stories and care experiences. Interviews were audio-recorded and transcribed. No further details reported. **Data analysis** Descriptive phenomenology. Researchers familiarised themselves with the data, dividing them into units of meaning before developing codes and themes. These themes were organised into experiences found in hospital	**Findings** Community-based clinics save time by allowing families to access specialist care during times that are more suitable to them. Community-based clinics allowed children and young people to become familiar with the service, and build relationships with healthcare professionals. Community-based clinics were seen as a symbol of healthcare professionals investing in connecting with families in their own environment, which made them seem more empathetic towards patients.	*Q2: Was a qualitative methodology appropriate?* Yes. *Q3: Was the research design appropriate to address the aims of the research?* Yes. Semi-structured interviews justified. *Q4: Was the recruitment strategy appropriate to the aims of the research?* Can’t tell. Purposive sampling used to ensure each setting was covered, with a range of demographic characteristics ensured (including age, sex, ethnicity and geographical distance from hospital). However, lack of reported demographics, inclusion criteria and exclusion criteria mean that it is not possible to see whether the final sample was representative. *Q5: Were the data collected in a way that addressed the research issue?* Can’t tell. Interviews justified but poorly described. Interviews were driven by interviewee so no use of topic guides, and no mention of much the methods deviated between participants. Interviews were conducted at a time and place of participants choosing, with discussion on how place of interview might affect the answers. Interviews were audio-recorded

Study details	Participants	Methods	Themes and findings	Limitations
Collaborations for Leadership in Applied Health Research and Care for Birmingham and Black Country programme.		settings and those found in community settings. Variations between these 2 settings were compared and highlighted.		and transcribed. No mention of data saturation. *Q6: Has the relationship between researcher and participants been adequately considered?* Can't tell. Researcher's reflected answers back to participants and asked to explain their use of descriptive words in order to confirm understanding of their experience. However, lack of information on other aspects of the interview limits certainty. *Q7: Have ethical issues been taken into consideration?* Yes. Informed consent received from all parents (and assent from young people) and ethical approval received from West Midlands NHS Research Ethics Committee. *Q8: Was the data analysis sufficiently rigorous?* Yes. Confusing description of analysis process and how themes were derived, but accurate. Good presentation of data to support findings. No mention of multiple or independent analysis. Discussion of contradictory data. Researcher bias was discussed and limited by acknowledging existing views and preventing attributing false importance to certain aspects by

Study details	Participants	Methods	Themes and findings	Limitations
				treating all areas of an experience as equally important. *Q9: Is there a clear statement of findings?* Yes. Good discussion on the findings, with relation back to the original question. Adequate discussion concerning evidence surrounding the findings (both for and against) and the credibility of findings. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* Yes. Nature of review question in highlighting other areas important to babies, children and young people experience not previous identified means all are important. *Overall judgement of quality:* Moderate concerns **Other information** 13 parents were also interviewed during this study. However, as children participants were over 5 years old, these parents are outside of the protocol and data was not extracted for this population where possible.
Full citation Leavey, Gerard, Rothi, Despina, Paul, Rini,	**Sample size** N=48 young people	**Setting** School	**Author's themes:** - Information	**Limitations (assessed using the CASP checklist for qualitative studies).**

Study details	Participants	Methods	Themes and findings	Limitations
Trust, autonomy and relationships: The help-seeking preferences of young people in secondary level schools in London (UK), Journal of Adolescence, 34, 685-693, 2011 **Ref Id** 1058433 **Country/ies where the study was carried out** London, UK **Study type** Mixed method including focus group **Aim of the study** To explore young people's attitudes to their family doctors, in the context of seeking help for mental and physical health concerns. A secondary aim was to understand the more general help-seeking concerns and beliefs of secondary school pupils.	**Characteristics** Age (range): 14-15 years Gender (M/F): not reported **Inclusion criteria** Participants had to: • Be attending 1 of 6 London schools participating in previous survey phase of survey **Exclusion criteria** Not reported	**Sample selection** Purposive sampling of 20 schools in North London who were invited by letter to participate. Six schools, broadly representative of the socioeconomically and ethnically diverse population. An inclusive strategy was used to enrol voluntary participants after an incentivised seminar on help-seeking help for stress was delivered. Focus groups were conducted after informed consent, and parental approval was provided. **Data collection** Six (3 male, 3 female) focus group interviews were conducted in order to explore help-seeking attitudes of girls and boys towards their family doctor. All focus groups were digitally recorded and transcribed. **Data analysis** Using content analysis.	• Access • Trust **Findings** Children and young people were unsure of or anxious about their ability or right to consult their GP in the absence of a parent or guardian. This was exacerbated by a lack of knowledge regarding the legal requirements of GPs surrounding privacy and confidentiality. Additionally, children and young people commonly reported being unaware of the range of healthcare services offered by GP surgeries. Increasing awareness using effective and efficient methods were suggestions provided to improve knowledge and understanding, especially for mental health services.	*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 and focus groups both justified informed by survey results on YP health-seeking preferences. However, due to the sensitive nature of the topic area, semi-structured interviews would have been more suitable for time-consuming concepts. *Q4: Was the recruitment strategy appropriate to the aims of the research?* Yes. A sample of voluntary pupils willing to participate after receiving a lecture on mental health and coping strategies were enrolled *Q5: Were the data collected in a way that addressed the research issue?* Yes. Focus groups were conducted with young people, which would facilitate in-depth content. Due to the sensitive nature of the topic and to maintain confidentiality, focus groups were single-gendered and facilitated by gender-matched researchers

Study details	Participants	Methods	Themes and findings	Limitations
Study dates Not reported **Source of funding** Not reported				*Q6: Has the relationship between researcher and participants been adequately considered?* Can't tell. Field notes were incorporated into the analysis, but details of the interview guide were not provided and not necessarily indicating reflexivity. *Q7: Have ethical issues been taken into consideration?* Yes. Ethics approval received from Local Research Ethics Committee of Barnet, Enfield and Haringey Health Authority. *Q8: Was the data analysis sufficiently rigorous?* Yes. Independent researchers developed themes and categories using a funnelling approach. Consensus meetings were held to ensure rigour and identification of unanticipated concepts. contrary statements were incorporated in the findings *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,

Study details	Participants	Methods	Themes and findings	Limitations
				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. The study findings were well placed within current literature on improving access for young people seeking help for mental health issues within UK schools and generated implications for practice. Ideas and directions for future research were presented. 2. Can't tell. The findings may not be generalizable to other regions within the UK with different ethnic and economic profile *Overall judgement of quality:* Moderate concerns **Other information** Phase 1 of this study involved a survey of 298 young people which was analysed quantitatively.
Full citation Neill, Jones, Lakhanpaul, Roland and Thompson, Parents' help-seeking behaviours during acute childhood illness	**Sample size** N=27 parental proxies (3 fathers and 24 mothers) of children under 5 years old **Characteristics**	**Setting** Sure-Start centre **Sample selection** Sampling targeted parents in communities with differing	**Author's themes:** • Experience and knowledge and their influence on help seeking • Social support and its impact on help-seeking behaviours • Access to health services	**Limitations (assessed using the CASP checklist for qualitative studies).** *Q1: Was there a clear statement of the aims of the research?* Yes.

Study details	Participants	Methods	Themes and findings	Limitations
at home: A contribution to explanatory theory, Journal of Child Health Care, 20, 77-86, 2016 **Ref Id** 991707 **Country/ies where the study was carried out** East Midlands, UK **Study type** Focus group and semi-structured interview **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** Not reported **Source of funding** This study received support from a Programme Grants	Age of children: not reported but inclusion criteria states at least 1 child aged 1-<5 years per parent Gender of children: not reported Ethnicity of children: not reported Age of parents: • <20 years-old, n=1 • 20-29 years-old, n=5 • 30-39 years-old, n=16 • 40-49 years-old, n=5 Gender of parents: not reported Ethnic group of parents: • Travelling community, n= 6 • South Asian community, n=11 • White British community, n=10 **Inclusion criteria** • Parent of at least 1 child less than 5 years-old	social, economic and ethnic profiles. • Focus groups: n = 24 • Interviews: n = 3 **Data collection** Two researchers (a children's nurse lecturer and a social scientist) conducted 24 focus groups (together) and 3 interviews (separately), which lasted between one and two hours. Focus groups/semi-structured interviews were audio-recorded and transcribed verbatim. **Data analysis** Constant comparative analysis. Data were initially coded substantively, with emerging themes informing future data collection. As data collection and analysis progressed, codes were refined, added, and relationships between codes were explored, enabling theoretical code development, explaining relationships between themes. The analysis was conducted by a children's nurse lecturer and a non-clinical researcher with discussions with the wider research team (including healthcare professionals and parents from the Acutely Sick Kids – Safety	• 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. 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	*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 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

Study details	Participants	Methods	Themes and findings	Limitations
from Applied Research and a Career Development Fellowship from the National Institute for Health Research.	**Exclusion criteria** Not reported	Netting Interventions for Families (ASK SNIFF) parent panel).	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 obtain healthcare information.	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 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,

Study details	Participants	Methods	Themes and findings	Limitations
				but limitations were acknowledged. Yes. *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 general, minority or deprived populations. *Overall judgement of quality:* Serious concerns **Other information** None.
Full citation Robards, F., Kang, M., Usherwood, T., Sanci, L., How Marginalized Young People Access, Engage With, and Navigate Health-Care Systems in the Digital Age: Systematic Review, Journal of Adolescent Health, 365-381, 2018	**Sample size** K=68 studies **Characteristics** Type of study: • Qualitative k=44 • Quantitative k=16 • Mixed-methods k=8 ○ This study incorporated all their results (qualitative and	**Data collection** A systematic literature search of 5 online databases (Medline, CINAHL, PyscInfo, The University of Sydney Library database and Google Scholar) for qualitative, quantitative and mixed-methods studies (published between Jan 2006 and Feb 2017) identified 1758 articles. Hand searching of reference lists and evidence	**Author's themes:** • Young people's ability to recognize and understand health issues underpins help-seeking • Professionals' knowledge, skills, and attitudes affect engagement • Service environments and structures need to be welcoming and respectful of all groups of young people	**Limitations <u>(assessed using the CASP checklist for Systematic reviews)</u>.** *Q1: Did the review address a clearly focused question?* Yes. *Q2: Did the authors look for the right type of papers?* Yes. *Q3: Do you think all the important, relevant studies were included?*

Study details	Participants	Methods	Themes and findings	Limitations
Ref Id 958204 **Country/ies where the study was carried out** Australia, Canada, New Zealand, Portugal, UK, USA **Study type** Systematic review **Aim of the study** To explore the current literature and determine the factors affecting access to, engagement with, and navigation through healthcare systems for marginalised young people in the digital age. **Study dates** Search dates: January 2006 - February 2017 **Source of funding** None.	quantitative) into a narrative summary, which was then used in the findings of this review. Range of sample size: N= 3 – 1388 Participants: • Young people k=61 • Professionals k=11 • Parents k=7 ○ Although the study notes that their themes were identified by all the participants in their population (marginalised young people up to age 24 years old, parents and healthcare professionals), views of people > 18 years old, parents and health professionals will also have been included in their results. Our findings have been downgraded for relevance where applicable. Area of healthcare: • General k=37	from national surveys of children’s experience search identified 38 more articles. The search was conducted in 2 phases. The first phase involved a generalised search of the literature for terms relating to access, barriers or navigation of healthcare. The second phase specifically searched for 5 marginalised groups of young people (those who are homeless, living in remote areas, refugees and migrants, LGBTQ and part of the indigenous population). While reviewing the literature, 3 more populations were identified (young offenders, low income, and living with a disability). These terms were subsequently included but were not included in the original systematic search terms. Abstracts were screened, with 2 researchers performing an initial 200 paper pilot and achieving more than 95% inter-rater agreement. Any disagreements were discussed, and an agreement reached. Out of 1241 abstracts screen, 235 full texts were read, and 68 were included for the final review. **Data analysis**	**Findings** Marginalised young people were mostly unaware of the services available to them. Culturally appropriate services, cultural sensitivity of staff, use of interpreters, and cultural concepts of health, including traditional indigenous therapeutic practices, should be provided. Trust was a central theme, building trusting relationships with both providers and services.	Yes. A wide variety of online databases were used, and the search strategy was devised in collaboration with a librarian from the University of Sydney. Reference lists of included studies were checked for relevant studies, and a search from national surveys of children’s experience was conducted. No restrictions were placed on full-text or language of publication. No mention of personal contact with experts. However, only 5 of the 8 marginalised groups of young people were pre-defined before searching and included in the systematic search terms. Young offenders, low income and young people living with a disability were only included after reviewing the identified studies. Authors decided to include studies encompassing these populations but did not re-do the systematic search to with these terms included. This means that all available papers for these 3 populations may not have been identified and they may be under-represented in the findings. *Q4: Did the review's authors do enough to assess the quality of the included studies?* Yes. Quality appraisal of studies was done using both quantitative and qualitative appraisal tools. Qualitative studies received an

Study details	Participants	Methods	Themes and findings	Limitations
	- Mental health services k=13 - Sexual health services k=7 - Substance use services k=2 - Emergency departments k=2 - Pregnancy-related services k=2 - Primary care k=2 - Youth services k=1 - School health services k=1 - Social services k=1 Marginalised groups: - Homeless k=20 - Living in remote areas k=14 - Refugees and migrants k=11 - LGBTQ k=11 - Indigenous populations k=4 - Low income k=4 - Young offenders k=2 - Living with a disability k=2 Study country: - United States k=24 - Australia k=24	Study characteristics and outcomes were extracted into Microsoft Excel. Data extraction included year, language of publication, country, marginalised group, sample size, age definition, gender distribution, healthcare setting, the focus of the study, and key limitations in the study protocol. Key findings for access to, engagement with and/or navigation through healthcare systems were recorded through each study. Qualitative thematic synthesis was conducted with all included studies, beginning with free-coding of the extracted themes. These were input into an Excel spreadsheet alongside the other extracted data, forming a matrix. This matrix was then transferred through to NVivo, allowing grouping of codes and the organisation of higher-level thematic analysis. The method of synthesis involved integrating multiple data components (i.e. qualitative and quantitative) into the analysis, to allow comparisons within and across categories. **Quality appraisal of included papers**		average CASP checklist score of 7.96/10 (range 3-10). Each criterion was met by 67% of studies, excepting considering the relationship between interviewer and participants (only 25% of studies addressed this). Quantitative studies received an average Glasziou criteria score of 2.88/5 (range 1-5). Participant demographics and ethical review was well scoring among the studies. However, drop-out rates, sampling, use of validate questionnaires and description of outcome measurements were each addressed by 50% of studies or less. *Q5: If the results of the review have been combined, was it reasonable to do so?* Yes. Thematic analysis applied to the data, with a good description of the process of combining quantitative and qualitative data. *Q6: What are the overall results of the review?* Table presenting the characteristics of included studies is very informative, including details on the country, health issue focus, study design, participant characteristics and summary of findings. However, I would have liked to see the marginalised group listed in there as well. Very good

Study details	Participants	Methods	Themes and findings	Limitations
	- Canada k=11 - UK k=7 - New Zealand k=1 - Portugal k=1 **Inclusion criteria** Studies had to: - Be focused on marginalised groups (defined as refugees and migrants, homeless, LGBTQ, living in remote areas, part of the indigenous population; young offenders, low income, living with a disability) - Have at least 75% of study participants aged 12-24, their parents or healthcare professionals - Have a study question involved access and barriers to access to, engagement with, and/or navigation through healthcare services - Be conducted in a high-income country - Report original research - Be published from Jan 2006 onwards **Exclusion criteria** Not reported.	- Quantitative studies: Glasziou criteria - Qualitative studies: CASP checklist - Mixed-methods: both as appropriate.		qualitative description of the 8 general themes identified across the literature, presented in chronological order, i.e. help-seeking, access to healthcare services, engagement with healthcare services, navigation through healthcare services, and future directions for increasing access to healthcare (technology). Further discussion surrounding the variation in the themes between marginalised groups of young people, as well as parental and professional views. *Q7: How precise are the results?* Not applicable. *Q8: Can the results be applied to the local population?* Can't tell. The review incorporates data from a wide range of setting and participants. However, only 7 studies were conducted in the UK. 24 were done in the USA, which has a very different healthcare system here, in which cost plays a huge part to access. Convenience sampling used by single services were prevalent within the studies, which also affects generalisability. *Q9: Were all important outcomes considered?* Not applicable. Themes are driven by data.

Study details	Participants	Methods	Themes and findings	Limitations
				Q10: Are the benefits worth the harms and costs? Not applicable. Literature review. *Overall judgement of quality:* Minor concerns **Other information** None.
Full citation Sime, D., 'I think that Polish doctors are better': Newly arrived migrant children and their parents' experiences and views of health services in Scotland, Health and Place, 30, 86-93, 2014 **Ref Id** 993043 **Country/ies where the study was carried out** Scotland, UK **Study type** Mixed method including focus group and family case studies	N=105 children, young people, parents and healthcare professionals • n=86 children and young people • n=19 parents and healthcare professionals ○ Only the views of children and young people were included in this review. *Focus group* n=57 children and young people *Family case studies* n=29 children and young people **Characteristics** *Focus group (n=57)* Age (range): 7-16 years	**Setting** Urban and rural locations in Scotland **Sample selection** Service providers from a range of health, education and voluntary sectors in urban and rural locations in Scotland were used to recruit potential participants for focus groups. The children were informed of the study through translated leaflets. No further details reported. **Data collection** *Focus groups* Conducted in either in Polish or Romanian or using an interpreter if the children's first language was another one. Children were encouraged to discuss the experiences of a typical migrant family in	**Author's themes:** • Barriers to service use • Lack of adequate information • The language barrier **Findings** Issues with eligibility, legitimacy or status affected participants the confidence to access health systems. Perceived social, cultural, and religious differences made participants to seek care through familiar formal or informal social networks. Participants were unaware of different routes for accessing health but considered services as adequate about access, practitioners' perceived levels of competence and quality. Individuals with language barrier experienced difficulty accessing health services or following instructions; this resulted in differences in the provision of	**Limitations <u>(assessed using the CASP checklist for qualitative studies)</u>.** *Q1: Was there a clear statement of the aims of the research?* Yes *Q2: Was a qualitative methodology appropriate?* Yes *Q3: Was the research design appropriate to address the aims of the research?* Yes. Qualitative design justified. Focus groups used to allow children to encourage each other's views as well as allowing the researcher to gauge the level of shared experiences within the sample. *Q4: Was the recruitment strategy appropriate to the aims of the research?* Yes. Researchers wanted to recruit recently arrived children of Eastern European workers, which is a very select

Study details	Participants	Methods	Themes and findings	Limitations
Aim of the study To explore the experiences of recently migrated Eastern-European children when accessing UK healthcare services. **Study dates** May 2008 - June 2010 **Source of funding** This study received support from the Economic and Social Research Council.	Gender (M/F): 26/31 Country of origin: • Poland: n=48 • Other: n=9 *Family case studies* (n=29) Age (mean; range): 11 years; 8-16 years Gender (M/F): 14/15 Country of origin (n): • Poland: n=13 • Lithuania: n=5 • Slovakia: 4 • Bulgaria: 2 • Romania: 2 • Hungary: 1 • Russia: 1 • Czech Republic: 1 **Inclusion criteria** None applied. **Exclusion criteria** Not reported.	Scotland, along with hands-on activities and images of services children were likely to use. This format was designed to reduce the pressure on sharing personal stories while still encouraging participants to share their experiences. *Family case studies* Depending on the family's preference, interviews could be conducted in Romanian/Polish/English, or with an interpreter present. Each family was visited at least twice, with children being encouraged to keep an activity diary or take photographs to use as prompts within the interviews. **Data analysis** Grid analysis and thematic coding. Interviews focus groups and case study visits were tape recorded before being translated (if necessary) and transcribed. Descriptive summaries of emerging issues were organised using an overview thematic grid, developing common key themes across the data. NVivo7 was used to assign appropriate thematic codes to data sections and refining sub-themes which were allocated to relevant	healthcare and approaches to treatment.	group. Initially started with interviewing education, health and voluntary service providers throughout Scotland, who then acted recruiters for participants. No information on why some children did not take part. *Q5: Were the data collected in a way that addressed the research issue?* Yes. Qualitative data collected via audio-recorded interviews with professional's focus groups and family case studies. Interactions were conducted in either English, Polish, Romanian or with a translator depending on preference. Although no reason was provided for 2 visits made to families, questions were asked each visit or if there were discrepancies between each visit. This process could have ensured triangulation. No description of the interview guide development or content. *Q6: Has the relationship between the researcher and participants been adequately considered?* No. No description of potential bias/influence between researcher and participants. No mention of the type of translation or how this might affect qualitative data collection. No mention of data saturation.

Study details	Participants	Methods	Themes and findings	Limitations
		transcript texts. 2 researchers coded each transcript for increased reliability.		*Q7: Have ethical issues been taken into consideration?* Can't tell. Children were informed of the study through translated leaflets and signed a consent form but no description of the ethical approval procedure. *Q8: Was the data analysis sufficiently rigorous?* Can't tell. Adequate description of data analysis process including how codes, themes and sub-themes were developed. Discusses the need to increase rigour during qualitative reporting but no critical examination of the researcher's own role in the process or description of any techniques used to mitigate potential bias and influence during analysis, e.g. Number of analysts. However, contradictory data is presented and discussed where appropriate. A good amount of information is shown to support the reported findings. *Q9: Is there a clear statement of findings?* Yes. Good, detailed explanation of findings within the identified themes, with regular referral back to the original research question. Adequate discussion surrounding evidence both for and against the study's

Study details	Participants	Methods	Themes and findings	Limitations
				findings. Discussion around the credibility of findings. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* Yes. 1. 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 sampled from a variety of services in a wide geographical area. *Overall judgement of quality:* Serious concerns **Other information** 6 parents and 19 healthcare professionals were also included in this study. However, both these groups are outside of the protocol (parents due to the age of the children participants) and data was not extracted for these populations where possible.
Full citation Turnbull, J., Pope, C., Martin, D., Lattimer, V., Do telephones overcome	**Sample size** N=8 parental proxies of children under 5 years old	**Setting** GP out-of-hours co-operative telephone services	**Author's themes:** • Reasons for geographical variation: familiarity with, and making trade-offs between, available services	**Limitations (assessed using the CASP checklist for qualitative studies).** *Q1: Was there a clear statement of the aims of the research?* Yes

Study details	Participants	Methods	Themes and findings	Limitations
geographical barriers to general practice out-of-hours services? Mixed-methods study of parents with young children, Journal of Health Services & Research Policy, 15, 21-27, 2010 **Ref Id** 993700 **Country/ies where the study was carried out** Devon, UK **Study type** Mixed method including semi-structured interview **Aim of the study** To explore the experiences of parents and young children when using an out-of-hours telephone-based healthcare delivery service. **Study dates** Phase 1: June and December 2003-	**Characteristics** Age of children (range): 0-4 years Gender of children: not reported Ethnicity of children: not reported Age of parents: not reported Gender of parents: not reported Ethnicity of parents: not reported **Inclusion criteria** • Resident in Devon • Parent of child aged 0-4 years who phoned the general practice out-of-hours telephone service for clinical problems including: fever; rashes; coughing; breathlessness; vomiting and/or diarrhoea **Exclusion criteria** None applied	**Sample selection** For the semi-structured interviews (20-60 minutes), purposive sampling was used to select participants. The co-operative identified 100 individuals to be invited to take part in the study. Eight agreed to participate. To avoid increasing the burden on the co-operative, non-respondents were not sent a second invitation. 6 interviews were recorded and subsequently transcribed verbatim; one participant did not wish to be recorded; the recording equipment failed to record during the telephone interview. In both these cases, detailed notes were taken during and immediately after the interview. **Data collection** Interviews lasted 20-60 minutes and took place in the participant's house or by phone. **Data analysis** A mixed-methods approach was adopted, comprising a quantitative geographical analysis based on routine data on calls to the out-of-hours services and a qualitative study to build up a picture of patients' out-of-hours service	**Findings** Some parents were unfamiliar with out-of-hours services. Participants living in rural areas were unfamiliar with out-of-hours service limited by distance or travel time to be a barrier, as rural services tend to be under-staffed.	*Q2: Was a qualitative methodology appropriate?* Yes *Q3: Was the research design appropriate to address the aims of the research?* Yes. Semi-structured interviews with topic guides were used to discuss experiences of recent use with parents and allowed for non-participant observation. *Q4: Was the recruitment strategy appropriate to the aims of the research?* Yes. The setting of the 6 recorded interviews were purposively selected to cover a range (3 in primary care centres, 1 in an urban PCT and 2 in predominantly rural PCTs). *Q5: Were the data collected in a way that addressed the research issue?* Yes. 8 semi-structured interviews were conducted with parents of children who had used the service and a retrospective review of a sample of out-of-hours telephone call recordings about children 0–4 years. Seven periods of observation (totalling 30 hours) were chosen in consultation with operational staff at the co-operative to ensure different activity; shift patterns and time of week were covered. Detailed notes

Study details	Participants	Methods	Themes and findings	Limitations
Quantitative data collection; Phase 2: 2007- Qualitative data collection **Source of funding** This study received support from a PhD studentship funded by the University of Southampton.		experiences and decision-making. The studies were undertaken sequentially, and the findings from the quantitative analyses generated hypotheses for investigation in the qualitative study. They were analysed using a thematic and framework approach in ATLAS.ti to explore potential access barriers for parents and examine how decisions were reached.		describing calls, observations about the centre, the roles of staff and their interactions with other staff and patients were taken contemporaneously and transcribed soon afterwards. Interviews took place in participants' homes (one conducted by telephone) and lasted between 20–60 minutes. Six interviews were recorded and subsequently transcribed verbatim; 2 interviews were not recorded (1 due to due to equipment failure, 1 because the participant did not wish to be recorded). In both these cases, detailed notes were taken during and immediately after the interview. *Q6: Has the relationship between the researcher and participants been adequately considered?* Yes. Detailed descriptive accounts of the major themes were developed. Constant comparison was used to identify significant similarities and differences. Items that contradicted new findings (deviant cases) were sought, examined, and used to refine the analysis as it proceeded. Patterns were explored and mapped to reduce the data into a smaller number of concepts and to look for inter-relationships.

Study details	Participants	Methods	Themes and findings	Limitations
				Q7: Have ethical issues been taken into consideration? Yes. The two parts of the study was approved by North and East Devon Research Ethics Committee. *Q8: Was the data analysis sufficiently rigorous?* Yes. Independent researchers developed themes and categories using an iterative approach; disagreements were resolved with consensus, and contrary statements were incorporated in the findings *Q9: Is there a clear statement of findings?* Yes. A good, detailed explanation of results and adequate discussion of the literature. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* Yes. 1. Yes. Details on how the study findings fit within the UK population, and how they can be used to inform best practice as well as limitations. Ideas and directions for future research presented and constraints of the extrapolating telephone and out-of-hours access to health access. 2. Cant' tell. Small population size,

Study details	Participants	Methods	Themes and findings	Limitations
				though perhaps adequate for qualitative study. *Overall judgement of quality:* No/very minor concerns **Other information** None.
Full citation Walsh, J., Scaife, V., Notley, C., Dodsworth, J., Schofield, G., Perception of need and barriers to access: The mental health needs of young people attending a Youth Offending Team in the UK, Health and Social Care in the Community, 19, 420-428, 2011 **Ref Id** 910269 **Country/ies where the study was carried out** Suffolk, UK **Study type**	**Sample size** N=6 young people **Characteristics** Age (range): 13-17 years Gender (M/F): 4/2 Ethnicity: not reported **Inclusion criteria** Participants had to: • Be a case load member of participating Youth Offending Service • Be aged 10-18 years old • Be residing in Suffolk • Answered the initial quantitative survey **Exclusion criteria** None applied.	**Setting** Community **Recruitment** Target sample size of 66 participants with wide age-range was targeted to maximise the sample size for questionnaire phase of study and to gain a representative distribution of views. Employees of commissioning Youth Offending Service contacted caseload members who met the criteria, and were deemed to not be at risk from participation, to take part in the research. Participants for questionnaire were recruited from the whole of the Suffolk geographical area (a county in the East of England), whilst interview participants were subset of original sample. **Data collection**	**Author's themes:** • Understanding concepts of mental health and stigma **Findings** Young people lacked adequate information of mental illness. Popular media where extreme symptoms were described, or the internet informed their understanding. Participants were not able to coordinate these descriptions with their own experiences. This highlight the need for accurate and consistent information provided by a health professional	**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 were used to explore who young people sought help from in the past in relation to any mental health or emotional difficulties, which they would be most likely to seek advice from if problems were experienced in the future, what the barriers might be, and what they understood about mental health problems. *Q4: Was the recruitment strategy appropriate to the aims of the*

Study details	Participants	Methods	Themes and findings	Limitations
Mixed method including semi-structured interview **Aim of the study** To explore young offenders' views on their mental health needs and support when accessing mental health services. **Study dates** May – September 2008 **Source of funding** This study received support from the Suffolk Youth Offending Service.		Interviews lasted 30–45 minutes and were structured around the responses the young people had given to their questionnaires. Interviews were tape-recorded. **Analysis** Data were qualitatively analysed using a practical thematic analysis method		*research?* No. Details on recruitment strategy was not provided, suitable volunteers (6) were identified and approached by caseworkers, suggesting selection bias. Caseload members targeted were screened by workers and considered not to be at risk of harm by participation. Forty-four young people completed and returned questionnaires, and six young people agreed to participate in a follow-up interview. *Q5: Were the data collected in a way that addressed the research issue?* Yes. Semi-structured interviews were used, but no detailed information on interview guides. *Q6: Has the relationship between the researcher and participants been adequately considered?* No. Descriptions of potential bias/influence between researcher and participants were not described. *Q7: Have ethical issues been taken into consideration?* Yes. A Local University Ethics Committee granted ethical approval for the study. Legal guardian consent was obtained for each participant below 18 years.

Study details	Participants	Methods	Themes and findings	Limitations
				Q8: Was the data analysis sufficiently rigorous? Yes. Independent researchers developed themes and categories using an iterative approach; disagreements were resolved with consensus, and contrary statements were incorporated in the findings. *Q9: Is there a clear statement of findings?* Yes. The authors provide a clear discussion of results on structural barriers, poor communication and collaboration; supported by literature on broader UK mental health services. *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. *Overall judgement of quality:* Serious concerns **Other information**

Study details	Participants	Methods	Themes and findings	Limitations
				Forty-four participants completed and returned questionnaire phase of study. Interviewees received a shopping voucher in recognition of their participation.
Full citation Whittle, N., Macdonald, W., Bailey, S., A Study of Young Offenders' Perceptions of Health and Health Care Services in Custody and in the Community, Journal of Correctional Health Care, 2, 2, 2012 **Ref Id** 994059 **Country/ies where the study was carried out** Northern and Southern England, UK **Study type** Semi-structured interview **Aim of the study**	**Sample size** N=28 young people **Characteristics** Age (range): 16-18 years Gender (M/F): 23/5 Ethnicity: not reported **Inclusion criteria** Attending 1 of 4 young offender institutions (YOIs) in the North and South of England **Exclusion criteria** Not reported	**Setting** Young offender institutions **Sample selection** Unclear. Authors do not provide a detailed description of the recruitment process **Data collection** The interviews covered knowledge of physical health, mental health, sexual health, and drugs and alcohol, as well as facilitators and barriers to good health and health services in secure settings and in the community. Interviews were 30-45 minutes and were audiotaped and transcribed. **Data analysis** Early interviews were analysed by one researcher (W.M.), who devised an initial coding framework using the constant comparison method. Data were then compared and contrasted both within single interviews and against other transcripts.	**Author's themes:** • Health Care **Findings** Participants had overly simplistic views of health and GP scope of practice. They reported substandard access to adequate service within YOI was highlighted as an issue. However, in other cases, it meant shorter waiting times to see a GP or nurse.	**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 were used to explore experiences among young people in custody and develop an appropriate programme to meet such needs. *Q4: Was the recruitment strategy appropriate to the aims of the research?* Can't tell. No details on recruitment strategy was provided *Q5: Were the data collected in a way that addressed the research issue?* Unclear. Authors do not provide a detailed description of the ethical approval. A reference to

Study details	Participants	Methods	Themes and findings	Limitations
To inform the development of a DVD capturing views of young people in custody about health issues and their experiences of coping while in custody. **Study dates** Not reported. **Source of funding** This study received support from the Youth Justice Board.		Following discussions with the research team, the coding framework was altered, and the transcripts checked against the revised framework to avoid significant omissions. All transcripts were analysed line by line to allocate data to the framework by W.M. and N.W. The units of analysis were chunks of text that reflect a theme		"participants' permission" was mention in the methods. *Q6: Has the relationship between researcher and participants been adequately considered?* No. Descriptions of potential bias/influence between researcher and participants were not described, neither was reflexivity considered. *Q7: Have ethical issues been taken into consideration?* Can't tell. No information presented on informed consent of ethical approval process. *Q8: Was the data analysis sufficiently rigorous?* Yes. Themes were developed iteratively to in cooperate contrary ideas and input from a research team to ensure rigour. *Q9: Is there a clear statement of findings?* Yes. The authors discuss findings on structural barriers, poor communication and collaboration; supported by literature on broader UK mental health services. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* Yes. Details on recommendations

Study details	Participants	Methods	Themes and findings	Limitations
				for improving access are suitable to the UK and future policymaking. 2. Can’t tell. Findings may not be generalisable to other settings. Still, the sample had a variety of age ranges and ethnic groups, and perhaps more representative of a wider geographical area within the UK. *Overall judgement of quality:* Serious concerns **Other information** None.

CASP: Critical Skills Appraisal Programme; CFS: Chronic fatigue syndrome; F: Female; GP: General practitioner; K: Number of studies; M: Male; ME: Myalgic encephalomyelitis; NHS: National Health Service; N: Number of participants, SD: Standard deviation

Appendix E – Forest plots

Forest plots for review question: What are the facilitators of, and barriers to, accessing healthcare services for babies, children and young people?

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: What are the facilitators of, and barriers to, accessing healthcare services for babies, children and young people?

Table 7: Evidence summary for theme 1: Individual factors

Study information			**CERQual Quality assessment**				
No of studies	**Design**	**Description of review finding**	**Methodological limitations**	**Coherence of findings**	**Adequacy of data**	**Relevance of evidence**	**Overall confidence**
Sub-theme 1.1: Personal perceptions							
5 (Ali 2017, Best 2016, Fargas-Malat 2018, Haig-Ferguson 2019, Robards 2018)	Semi-structured interview, focus group, systematic review	Data from 5 studies shows that children and young people often internalise public perceptions of certain illnesses (particularly mental health disorders) and how they should behave if they do seek help for them. Religion, culture and stigma appeared to be at the root of the perceived judgement and left young people feeling unable to access healthcare services, for fear of being blamed or permanently labelled. Young men felt as though stereotypical gender roles prevented them from talking about their feelings and conditions. These factors caused embarrassment, shame and anxiety for young people which further distressed them. This could be alleviated by increasing the amount of information or peer support available to young people in an anonymous setting. Additionally, children and young people felt that healthcare services should ensure that education is not just for individuals, but has a community engagement	Minor concerns[1]	No/very minor concerns	No/very minor concerns	Minor concerns[2]	HIGH

Study information			CERQual Quality assessment				
No of studies	Design	Description of review finding	Methodological limitations	Coherence of findings	Adequacy of data	Relevance of evidence	Overall confidence
		component so that healthcare discussions and help-seeking behaviour is normalised. *'I wouldn't be able to open up to someone that I don't even know and they could go and tell their friends'. (Ali 2017, page 39)*					
Sub-theme 1.2: Health education							
2 (Ali 2017, Walsh 2011)	Semi-structured interview, focus group	Data from 2 studies shows that the level of health education among children and young people affected their ability to recognise symptoms of healthcare issues, especially concerning complex mental health disorders. This is compounded when they do not understand the risk factors for medical disorders, as they are can't tell what they are experiencing, what it might mean and to whom they should turn for help. *'like voices in the head and stuff, and like people telling you to do things that … you don't want to do and things'. (Walsh 2011, page 426)*	Serious concerns[3]	No/very minor concerns	Minor concerns[4]	Minor concerns[5]	LOW
Sub-theme 1.3: Parental influences							
3 (Dickson 2015, Neill 2016, Sime 2014)	Face-to-face interview, family case study interview, focus group	Data from 3 studies shows that the parental experiences with healthcare services, and their health education, impacts babies, children and young people when they are accessing healthcare services. This ranges from practical matters such as scheduling	Moderate concerns[6]	No/very minor concerns	Minor concerns[4]	Moderate concerns[7]	MODERATE

Study information			CERQual Quality assessment				
No of studies	Design	Description of review finding	Methodological limitations	Coherence of findings	Adequacy of data	Relevance of evidence	Overall confidence
		appointments or perceptions on who is entitled to services (in the example of recently-arrived immigrants), to more emotional factors such as previous poor experiences with healthcare services. Parent’s reported that they have felt judged by healthcare professionals in the past, which affects their confidence in the present. This can affect access to healthcare in 2 ways. If parents have been advised that they are needlessly worried, then they report being less likely to seek help. If parents have been advised that they should have contacted healthcare services sooner, they report being more likely to seek help. *‘if she’s [a mother] had bad experience, or negative experiences . . . she’s like given up and that’s why . . . she mightn’t go again’. (Neill 2016, page 81, parental proxy)*					

1 Evidence downgraded for methodological limitations as per CASP qualitative and CASP systematic review checklists

2 Evidence downgraded for relevance because it contains 1 systematic review which includes views of children and young people (up to the age of 24 years old), parents and health professionals and 1 study which includes participants up to 19 years old

3 Evidence downgraded methodological limitations as per CASP qualitative checklist

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

5 Evidence downgraded for relevance because studies only reported the experiences of young people and 1 study included participants up to the age of 19

6 Evidence downgraded for methodological limitations as per CASP qualitative checklist

7 Evidence downgraded for relevance because 2 studies only reported the views and experiences of parents when accessing healthcare on behalf of their children. While this has an impact on their children’s healthcare access, it is not necessarily a primary consideration for babies, children and young people.

Table 8: Evidence summary for theme 2: Healthcare professionals

Study information			CERQual Quality assessment				
No of studies	Design	Description of review finding	Methodological limitations	Coherence of findings	Adequacy of data	Relevance of evidence	Overall confidence

Study information			**CERQual Quality assessment**				
Sub-theme 2.1: Lack of trust in healthcare professionals							
5 (Ali 2017, Best 2016, Dickson 2015, Neill 2016, Robards 2018)	Semi-structured interview, focus group, systematic review	Data from 5 studies shows that lack of trust in healthcare professionals is a barrier to babies, children and young people accessing healthcare services. Inconsistent information from a variety of professionals meant that parents and young people became less confident in their ability to provide care. Young people report concerns with confidentiality within consultations, especially when using electronic means of communication. *'The doctors don't really bother, they send you back saying that there is nothing really wrong with you'. (Ali 2017, page 81)*	Minor concerns[1]	Moderate concerns[2]	No/very minor concerns	Minor concerns[3]	MODERATE
Sub-theme 2.2: Explaining limits of confidentiality							
4 (Best 2016, Haig-Ferguson 2019, Leavey 2011, Robards 2018)	Semi-structured interview, focus group, systematic review	Data from 4 studies shows that young people were confused about the rules for accessing care independently, without their parents or carers. Even if they are able to attend consultations without an adult present, there is confusion about what patient confidentiality means for people under 18 years old and if healthcare professionals have a legal duty to inform parents of consultation discussions. While this might not impact accessing primary care services for common illnesses such as colds, it does impact their willingness to access care for more personal healthcare such as mental or sexual health. Children and young people felt that healthcare professionals	No/very minor concerns	Minor concerns[4]	No/very minor concerns	Minor concerns[5]	HIGH

Study information			CERQual Quality assessment				
		and services should make their legal and professional responsibilities clear in order to set expectations of confidentiality safeguarding. *Participant 1: 'If there were rules that, you know, that you [GPs] have to keep certain things confidential'.* *Participant 2: 'There are, but they [GPs] don't always stick to them'. (Leavey 2011, page 690)*					
Sub-theme 2.3: Relationships with healthcare professionals							
3 (Heath 2015, Neill 2016, Robards 2018)	Semi-structured interview, focus group, systematic review	Data from 3 studies shows that relationships with healthcare professionals are an important facilitator to accessing healthcare for babies, children and young people. Healthcare professionals can help build relationships with their under 18 patients by ensuring that they treat them as individuals, that they are respectful, and that they do not discriminate. Similarly, forging connections with communities is an important tool for healthcare services as it shows investment in the community and an effort to engage with babies, children and young people outside of formal healthcare structures. *'It's part of my community. It's just around the corner and like when you go to school or something you go past it, you see it and I'm used to it being there'. (Heath 2015, page 50)*	Moderate concerns[6]	Moderate concerns[7]	No/very minor concerns	Minor concerns[8]	LOW

1 Evidence downgraded for methodological limitations as per CASP qualitative and CASP systematic review checklists

2 Evidence downgraded for coherence because there is an overlap in the evidence between lack of trust in and building relationships with healthcare professionals

3 Evidence downgraded for relevance because it contains 1 systematic review which includes views of children and young people (up to the age of 24 years old), parents and health professionals and 1 study which includes participants up to 19 years old

4 Evidence downgraded for coherence because some evidence was regarding the importance of confidentiality for young people rather than the importance of managing their expectations

5 Evidence downgraded for relevance because it contains a systematic review which includes views of children and young people (up to the age of 24 years old), parents and health professionals

6 Evidence downgraded for methodological limitations as per CASP qualitative and CASP systematic review checklists

7 Evidence downgraded for coherence because there is an overlap in the evidence between lack of trust in and building relationships with healthcare professionals

8 Evidence downgraded for relevance because it contains a systematic review which includes views of children and young people (up to the age of 24 years old), parents and health professionals

Table 7: Evidence summary for theme 3: Healthcare services

Study information			**CERQual Quality assessment**				
No of studies	**Design**	**Description of review finding**	**Methodological limitations**	**Coherence of findings**	**Adequacy of data**	**Relevance of evidence**	**Overall confidence**
Sub-theme 3.1: Accessible language							
2 (Sime 2014, Whittle 2012)	Semi-structured interview, focus group, family case study interview	Data from 2 studies shows that healthcare services should ensure that they provide information in an accessible language. This includes both the language itself (for example, providing translators or written information in a variety of languages) and the complexity of the information (for example, keeping explanations and consultations free of medical jargon). *'You get little booklets when you first come in 'cos you have to be in your cell a lot of the time and you can read them and they're not all written in like more adult language right, whereas you can't understand them. It's all written in words that I would be able to read easily and understand easily'. (Whittle 2012, page 10)*	Serious concerns[1]	Moderate concerns[2]	Serious concerns[3]	Moderate concerns[4]	VERY LOW
Sub-theme 3.2: Alternatives to physical appointments							
2 (Haig-Ferguson 2019,	Semi-structured interview,	Data from 2 studies shows that providing alternatives to physical appointments helps babies, children and	Minor concerns[5]	Moderate concerns[6]	Minor concerns[7]	Minor concerns[8]	MODERATE

Study information			CERQual Quality assessment				
Neill 2016)	family case study and interviews, focus groups	young people to overcome both practical barriers (for example, parents having to arrange childcare for other children), physical barriers (for example, distance to travel to appointments) or individual barriers (for example, decreasing perceived stigma towards sensitive health issues) when accessing healthcare services. Examples include videoconferencing, telephone consultations and NHS111 services. However, none of the evidence shows that these alternatives should replace face-to-face consultations, but instead they can augment potential difficulties for families regarding out of hours care, or regular travelling to specialist clinics. *'I don't think that we would've been able to use the service coming out every month; we wouldn't be able to afford it to be able to travel that much, no I wouldn't be able to go to school and everything it would've been a lot more limiting. It would've had to have been every couple of months if that, whereas now I feel totally supported I mean even like my actual ME has improved so much since I've been actually using the service that if I wouldn't have been able to access it and still be where I was say a year ago. The service has just helped so much and we wouldn't have been able to do that without Skype'. (Haig-Ferguson 2019, page 47)*					
Sub-theme 3.3: Availability of appointments and services							
6 (Diwakar	Semi-structured	Data from 6 studies showed that availability of appointment and services	Moderate concerns[9]	Moderate concerns[10]	No/very minor concerns	Moderate concerns[11]	VERY LOW

Study information			**CERQual Quality assessment**				
2019, Fargas-Malat 2018, Heath 2015, Neill 2016, Turnbull 2010, Whittle 2012)	interview, focus group	offered to babies, children and young people is often a barrier to accessing specialist healthcare services. Parents report that appointments are regularly scheduled during school hours. The availability of specialist services is often different for different populations. For example, some young offenders felt that their access to mental health services had decreased while in custody. Parents in rural communities reported a lack of general practitioners in their local centres. Community-based clinics and walk-in centres were recommended as a means of decreasing these barriers. *'There's no paediatric doctors there [rural primary care centre] . . . . it's just basically . . . a cottage hospital that's got a minor injuries unit attached to it [. . .] I think it's nearly 20 miles [to the emergency department] . . . to my mind, he was in the right place'. (Turnbull 2010, page 24)*					
Sub-theme 3.4: Promotion of primary healthcare services							
5 (Ali 2017, Fargas-Malat 2018, Leavey 2011, Robards 2010, Sime 2014)	Semi-structured interview, family case study and interview, focus group, systematic review	Data from 5 studies shows that babies, children and young people were often unaware of the services available to them. As primary healthcare services commonly act as gatekeepers to specialist services, this lack of awareness severely impacts help-seeking behaviour. By actively promoting themselves, healthcare services can help to inform under 18s of the variety of ways primary healthcare can be used.	Moderate concerns[12]	Moderate concerns[13]	No/very minor concerns	Minor concerns[14]	LOW

Study information			CERQual Quality assessment				
		'May be if you got letters through the post and stuff that said like how, what they [general practitioners] can do to help you and told you a bit more about it, because I don't think many people know much about the doctor so they don't use it as much as they could'. (Leavey 2011, page 688)					

1 Evidence downgraded for methodological limitations as per CASP qualitative checklist

2 Evidence downgraded for coherence because there was discrepancy in the meaning of accessible language in the evidence

3 Evidence downgraded for adequacy because studies together did not offer rich data

4 Evidence downgraded for relevance because contributing studies are investigating very specific populations (recent migrants from Eastern-Europe and young offenders in custody)

5 Evidence downgraded for methodological limitations as per CASP qualitative checklist

6 Evidence downgraded for coherence because there were differences in the meaning of accessible language in the evidence

7 Evidence downgraded for adequacy because studies together offered moderately rich data

8 Evidence downgraded for relevance because it contains 1 study reported the views and experiences of parents when accessing healthcare on behalf of their children. While this has impact on their children's healthcare access, not necessarily a primary consideration for babies, children and young people.

9 Evidence downgraded for methodological limitations as per CASP qualitative checklist

10 Evidence downgraded for coherence because data included evidence for availability of primary healthcare and specialist appointments within studies

11 Evidence downgraded for relevance because it contains 3 studies using the views of and experiences of parents when accessing healthcare on behalf of their children. While this has impact on their children's healthcare access, not necessarily a primary consideration for babies, children and young people.

12 Evidence downgraded for methodological limitations as per CASP qualitative and CASP systematic review checklists

13 Evidence downgraded for coherence because data included evidence for knowledge regarding when and how to access primary healthcare services

14 Evidence downgraded for relevance because it contains 1 systematic review which includes views of children and young people (up to the age of 24 years old), parents and health professionals and 1 study which includes participants up to the age of 19 years

Appendix G – Economic evidence study selection

Economic evidence study selection for review question: What are the facilitators of, and barriers to, accessing healthcare services for babies, children and young people?

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

Appendix H – Economic evidence tables

Economic evidence tables for review question: What are the facilitators of, and barriers to, accessing healthcare services for babies, children and young people?

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

Appendix I – Economic evidence profiles

Economic evidence profiles for review question: What are the facilitators of, and barriers to, accessing healthcare services for babies, children and young people?

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

Appendix J – Economic analysis

Economic evidence analysis for review question: What are the facilitators of, and barriers to, accessing healthcare services for babies, children and young people?

No economic analysis was conducted for this review question.

Appendix K – Excluded studies

Excluded studies for review question: What are the facilitators of, and barriers to, accessing healthcare services for babies, children and young people?

Clinical studies:

Table 9: Excluded studies and reasons for their exclusion

Study	Reason for Exclusion
Aagaard, H., Hall, E. O. C., Ludvigsen, M. S., Uhrenfeldt, L., Fegran, L., Parents' experiences of neonatal transfer. A meta-study of qualitative research 2000-2017, Nursing InquiryNurs Inq, 15, 15, 2018	Population not in protocol - parent-centred views on neonatal transfer, not a suitable proxy for neonates
Abbott, David, Carpenter, John, "The things that are inside of you are horrible": Children and young men with Duchenne muscular dystrophy talk about the impact of living with a long-term condition, Child Care in Practice, 21, 67-77, 2015	Phenomenon of interest not in protocol - no themes relating to access or continuity of healthcare
Abraham, J., Kannampallil, T., Caskey, R. N., Kitsiou, S., Emergency department-based care transitions for pediatric patients: A systematic review, Pediatrics, 138 (2) (no pagination), 2016	No qualitative data extracted or analysed. Included studies checked for inclusion.
Adams, N., Churchill, R., Eve, E., Chronic widespread pain in adolescents: A primary care based study, European Journal of Pain Supplements, 5 (1), 146, 2011	Conference abstract
Agnew, T., Shared experience, Nursing Standard, 26, 22-4, 2012	Narrative review
Ahmed, M., Boyd, C., Vavilikolanu, R., Rafique, B., Visual symptoms and childhood migraine: Qualitative analysis of duration, location, spread, mobility, colour and pattern, Cephalalgia, 38, 2017-2025, 2018	Study design not in protocol - no qualitative analysis
Ahmed, S., Ihe, C., Findings from a pre-clinic questionnaire given prior consultation at an NHS paediatric diabetes outpatient service in England-the patient's perspective: A survey of patient/carer experience of a paediatric diabetes outpatient service, Pediatric Diabetes, 17 (Supplement 24), 127-128, 2016	Conference abstract
Ahuja, Alka S., Williams, Richard, Telling stories: Learning from patients' and families' experiences of specialist child and adolescent mental health services, International Journal of Consumer Studies, 34, 603-609, 2010	Population not in protocol - 15 families with children between 5-15 years old. Only 2 children participated in interviews. No way of identifying which themes used data from these participants.
Ainslie, Susan, Foster, Rob, Groves, Jean, Grime, Kate, Straker, Katherine, Woolhouse, Clare, 'Making children count': An exploration of the implementation of the Every Child Matters agenda, Education 3-13, 38, 23-38, 2010	Population not in protocol - parents of children >3 years but no way of matching data origin with age of child
Aiyer, S., Issit, R., Rogers, Y., Sebire, N. J., Research and design for cardiac perfusion-visualisation of data 'quality markers', Archives of disease in childhood, 103 (Supplement 2), A54, 2018	Conference poster
Al Maghaireh, Dua'a Fayiz, Abdullah, Khatijah Lim, Chan, Chong Mei, Piaw, Chua Yan, Al Kawafha, Mariam Mofleh, Systematic review of qualitative studies exploring parental experiences in the Neonatal Intensive Care Unit, Journal of Clinical Nursing, 25, 2745-2756, 2016	Phenomenon of interest not in protocol - no themes relating to access or continuity of healthcare
Al-bedaery, R., Brown, H., Common adolescent and paediatric gynaecological referrals and the development of a targeted patient	Conference poster

Study	Reason for Exclusion
information leaflet, BJOG: An International Journal of Obstetrics and Gynaecology, 1), 346, 2013	
Albutt, A. K., O'Hara, J. K., Conner, M. T., Fletcher, S. J., Lawton, R. J., Is there a role for patients and their relatives in escalating clinical deterioration in hospital? A systematic review, Health ExpectationsHealth Expect, 20, 818-825, 2017	No qualitative data extracted or analysed. Included studies checked for inclusion.
Al-Harthy, Z. S., Cowling, J. P., Mann, G. K., Salama, M., Medical intervention for children with medical complexity (MICMAC), Archives of disease in childhood, 3), A127-A128, 2015	Conference abstract
Alins Sahun, Y., Camara, K., Gething, K., Gane, J., Schenck, D., Tse, Y., School-based diabetes clinics: QI to engage frequent non-attenders and improve teenager's self-management, Archives of disease in childhood, 103 (Supplement 1), A158, 2018	Conference abstract
Alins Sahun, Y., Camara, K., Gething, K., Shenck, D., Gane, J., Tse, Y., Setting up school-based diabetes clinics to engage adolescents who frequently 'were not brought to clinic' and improve self-management, Archives of Disease in Childhood., 2019	Study design not in protocol - no qualitative analysis
Allcock, D., Smith, K., Exploring parent views of community matrons, Nursing Times, 110, 21-23, 2014	Study design not in protocol - no qualitative analysis
Allen, D., Gillen, E., Rixson, L., The Effectiveness of Integrated Care Pathways for Adults and Children in Health Care Settings: A Systematic Review, JBI Library of Systematic Reviewis, 7, 80-129, 2009	No qualitative data extracted or analysed. Included studies checked for inclusion.
Allen, N., McFarlane, L., Shanahan, R., Bassett, E. Z. A., Wellcome home: The work of shelter, a charitable organisation in facilitating the discharge of children with medical complexities (CMIC) at birmingham children's hospital, Developmental medicine and child neurology, 59 (Supplement 4), 76, 2017	Conference abstract
Allerton, L., Emerson, E., British adults with chronic health conditions or impairments face significant barriers to accessing health services, Public Health, 126, 920-927, 2012	Study design not in protocol - no qualitative data reported
Almunef, M., Mason, J., Curtis, C., Jalal, Z., Management of chronic illness in young people aged 10-24 years: A systematic review to explore the role of primary care pharmacists, Archives of Disease in Childhood, 104, 2019	Conference abstract
Almunef, M., Mason, J., Curtis, C., Jalal, Z., The role of primary care pharmacist in the management of chronic illnesses in young people aged 10-24 years: A systematic review, International Journal of Pharmacy Practice, 27, 48-49, 2019	Poster Abstract
Alonso, J., Liu, Z., Evans-Lacko, S., Sadikova, E., Sampson, N., Chatterji, S., Abdulmalik, J., Aguilar-Gaxiola, S., Al-Hamzawi, A., Andrade, L. H., Bruffaerts, R., Cardoso, G., Cia, A., Florescu, S., de Girolamo, G., Gureje, O., Haro, J. M., He, Y., de Jonge, P., Karam, E. G., Kawakami, N., Kovess-Masfety, V., Lee, S., Levinson, D., Medina-Mora, M. E., Navarro-Mateu, F., Pennell, B. E., Piazza, M., Posada-Villa, J., Ten Have, M., Zarkov, Z., Kessler, R. C., Thornicroft, G., W. H. O. World Mental Health Survey Collaborators, Treatment gap for anxiety disorders is global: Results of the World Mental Health Surveys in 21 countries, Depression & Anxiety, 35, 195-208, 2018	Population not in protocol - UK not among countries sampled
Amin, A., Oragui, E., Khan, W., Puri, A., Psychosocial considerations of perioperative care in children, with a focus on effective management strategies, Journal of perioperative practice, 20, 198-202, 2010	Narrative review

Study	Reason for Exclusion
Amsalem, D., Hasson-Ohayon, I., Gothelf, D., Roe, D., Subtle ways of stigmatization among professionals: The subjective experience of consumers and their family members, Psychiatric rehabilitation journal, 41, 163-168, 2018	Population not in protocol - mean age 26.5 years old with no way of identifying which themes used data from <18 years
Anderson, C., Lupfer, A., Shattuck, P. T., Barriers to receipt of services for young adults with autism, Pediatrics, 141, S300-S305, 2018	Country not in protocol - America
Anderson, C., Roy, T., Patient experiences of taking antidepressants for depression: A secondary qualitative analysis, Research in Social and Administrative Pharmacy, 9, 884-902, 2013	Population not in protocol - age 17-75 with no way of identifying which themes used data from <18 years
Anderson, Joanna K., Howarth, Emma, Vainre, Maris, Jones, Peter B., Humphrey, Ayla, A scoping literature review of service-level barriers for access and engagement with mental health services for children and young people, Children and Youth Services Review, 77, 164-176, 2017	Literature review
Andrade, L. H., Alonso, J., Mneimneh, Z., Wells, J. E., Al-Hamzawi, A., Borges, G., Bromet, E., Bruffaerts, R., de Girolamo, G., de Graaf, R., Florescu, S., Gureje, O., Hinkov, H. R., Hu, C., Huang, Y., Hwang, I., Jin, R., Karam, E. G., Kovess-Masfety, V., Levinson, D., Matschinger, H., O'Neill, S., Posada-Villa, J., Sagar, R., Sampson, N. A., Sasu, C., Stein, D. J., Takeshima, T., Viana, M. C., Xavier, M., Kessler, R. C., Barriers to mental health treatment: results from the WHO World Mental Health surveys, Psychological medicine, 44, 1303-1317, 2014	Population not in protocol - UK not among countries sampled
Andrews, H., A divisive set-up: The problems caused by the separation of medical and surgical neonatal services, Archives of Disease in Childhood: Fetal and Neonatal Edition, 99, A26, 2014	Conference poster
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
Arai, L., Stapley, S., Roberts, H., 'Did not attends' in children 0-10: a scoping review, Child: care, health and development, 40, 797-805, 2014	Scoping review. Included studies checked for inclusion.
Arain, M., Nicholl, J., Campbell, M., Patients' experience and satisfaction with GP led walk-in centres in the UK; a cross sectional study, BMC health services research, 13, 142, 2013	Population not in protocol - mean age 31.5 with no way of identifying data from <18 years
Arenson, M., Hudson, P. J., Lee, N., Lai, B., The Evidence on School-Based Health Centers: A Review, Lobal Pediatric HealthGlob, 6, 2333794X19828745, 2019	Duplicate
Arenson, Michael, Hudson, Philip J., Lee, NaeHyung, Lai, Betty, The Evidence on School-Based Health Centers: A Review, Global pediatric health, 6, 2333794X19828745, 2019	Setting not in protocol: School-based health centres in the USA
Arheiam, A., Albadri, S., Laverty, L., Harris, R., Reasons for low adherence to diet-diaries issued to pediatric dental patients: A collective case study, Patient Preference and Adherence, 12, 1401-1411, 2018	Phenomenon of interest not in protocol - no themes relating to access or continuity of healthcare
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 - no themes relating to access or continuity of healthcare

Study	Reason for Exclusion
Aston, J., Huynh, C., Sinclair, A., Wilson, K., Terry, D., Medication Review of Children on Long Term Medications: A Review of the Literature, Archives of disease in childhood, 101, e2, 2016	Conference abstract
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 - 1 adolescent and 23 parents with no information on the ages of their children
Aston, J., Wilson, K., Terry, D., Starting a new medicine study, Archives of disease in childhood, 101 (9), A28, 2016	Conference abstract
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	Population not in protocol – aged ≥16 years. Sub-group of 16-24 with no way of identifying which themes used data from under 18s
Atkins, E., Colville, G., John, M., A 'biopsychosocial' model for recovery: A grounded theory study of families' journeys after a Paediatric Intensive Care Admission, Intensive and Critical Care Nursing, 28, 133-140, 2012	Phenomenon of interest not in protocol - no themes relating to access or continuity of healthcare
Atkins, E., Colville, G., John, M., Finding the way to a 'new normal': Families' recovery in the year after a paediatric intensive care admission, Pediatric critical care medicine, 1), A3-A4, 2011	Conference abstract
Babakinejad, P., Arujuna, N. R., Caruana, D. M., Venables, Z. C., Tan, S. P., Atkar, R., George, S. M. C., Chalmers, J. R., Batchelor, J. M., Order and timing of applying emollients and topical corticosteroids in atopic eczema: A survey of U.K. patients and healthcare professionals, British Journal of Dermatology, 175 (Supplement 1), 77, 2016	Conference poster
Babbage, C., Jackson, G. M., Nixon, E., Desired Features of a Digital Technology Tool for Self-Management of Well-Being in a Nonclinical Sample of Young People: Qualitative Study, JMIR Mental Health, 5, e10067, 2018	Phenomenon of interest not in protocol - no themes relating to access of healthcare
Badri, P., Saltaji, H., Flores-Mir, C., Amin, M., Factors affecting children's adherence to regular dental attendance: a systematic review, Journal of the American Dental Association (1939), 145, 817-828, 2014	No qualitative data extracted or analysed. Included studies checked for inclusion.
Bailey,S., Taylor,A., Kent,A., More space, Better quality care?Parents' perception of quality of care prior to and after neonatal unit relocation, Intensive Care Medicine, 37, S428-S429, 2011	Conference abstract
Bains, R. M., African American adolescents and mental health care: a metasynthesis, Journal of child and adolescent psychiatric nursing : official publication of the Association of Child and Adolescent Psychiatric Nurses, Inc, 27, 83-92, 2014	Country not in protocol - USA
Balato, N., Megna, M., Di Costanzo, L., Balato, A., Ayala, F., Educational and motivational support service: a pilot study for mobile-phone-based interventions in patients with psoriasis, British journal of dermatology, 168, 201â€• 205, 2013	Population not in protocol – Adults aged 18-65 years
Ball, S. L., Newbould, J., Corbett, J., Exley, J., Pitchforth, E., Roland, M., Qualitative study of patient views on a 'telephone-first' approach in general practice in England: Speaking to the GP by telephone before making face-to-face appointments, BMJ open, 8 (12) (no pagination), 2018	Population not in protocol - adult population with ages not reported
Bancroft, V., Ganesan, V., Pistrang, N., Murphy, T., How adolescents and their parents understand and manage paediatric stroke, Developmental Medicine and Child Neurology, 3), 14-15, 2010	Conference abstract

Study	Reason for Exclusion
BaniHani, A., Deery, C., Toumba, J., Munyombwe, T., Duggal, M., The impact of dental caries and its treatment by conventional or biological approaches on the oral health-related quality of life of children and carers, International journal of paediatric dentistry, 28, 266-276, 2018	Study design not in protocol - no qualitative analysis
Banks, J., Cramer, H., Sharp, D. J., Shield, J. P., Turner, K. M., Identifying families' reasons for engaging or not engaging with childhood obesity services: a qualitative study, Journal of child health care, 18, 101â€• 110, 2014	Population not in protocol - parental views of children >5 years old. Children present in some interviews but no way of identifying which themes used data from them
Barber, S., Bekker, H., Marti, J., Pavitt, S., Khambay, B., Meads, D., Development of a Discrete-Choice Experiment (DCE) to Elicit Adolescent and Parent Preferences for Hypodontia Treatment, Patient, 12, 137-148, 2019	Phenomenon of interest not in protocol - no themes relating to access or continuity of healthcare
Barber, S., Pavitt, S., Meads, D., Khambay, B., Bekker, H., Can the current hypodontia care pathway promote shared decision-making?, Journal of orthodontics, 46, 126-136, 2019	Phenomenon of interest not in protocol - no themes relating to access or continuity of healthcare
Bloom, Kathleen, Tam, Jane A., Walk-in services for child and family mental health, Journal of Systemic Therapies, 34, 61-77, 2015	No qualitative data extracted or analysed. Included studies checked for inclusion.
Branson, C. E., Clemmey, P., Mukherjee, P., Text message reminders to improve outpatient therapy attendance among adolescents: a pilot study, Psychological services, 10, 298-303, 2013	Country: USA
Brown, A., Rice, S. M., Rickwood, D. J., Parker, A. G., Systematic review of barriers and facilitators to accessing and engaging with mental health care among at-risk young people, Asia-Pacific psychiatry : Official Journal of the Pacific Rim College of PsychiatristsAsia Pac Psychiatry, 8, 3-22, 2016	Later version of systematic review using similar population included (Robards 2018). Excluded this systematic review to prevent double counting of studies.
Chandra-Mouli, V., Lenz, C., Adebayo, E., Lang Lundgren, I., Gomez Garbero, L., Chatteriee, S., A systematic review of the use of adolescent mystery clients in assessing the adolescent friendliness of health services in high, middle, and low-income countries, Global health action, 11, 1536412, 2018	No qualitative data extracted or analysed. Included studies checked for inclusion.
Colucci, Erminia, Szwarc, Josef, Minas, Harry, Paxton, Georgia, Guerra, Carmel, The utilisation of mental health services by children and young people from a refugee background: A systematic literature review, International Journal of Culture and Mental Health, 7, 86-108, 2014	No qualitative data extracted or analysed. Included studies checked for inclusion.
Connolly, M., Fortuna, R. J., Snyder, E. D., Weppner, W. G., Impacts of improved continuity of care in resident primary care clinics on patient outcomes: A systematic review, Journal of General Internal Medicine, 34 (2 Supplement), S254, 2019	Conference abstract
Corcoran, P. M., Catling, C., Homer, C. S. E., Models of midwifery care for Indigenous women and babies: A meta-synthesis, Women and Birth, 30, 77-86, 2017	Phenomenon of interest not in protocol - continuity of care relating to maternal care only
Dale, H., Watson, L., Adair, P., Moy, M., Humphris, G., The perceived sexual health needs of looked after young people: findings from a qualitative study led through a partnership between public health and health psychology, Journal of Public Health, 33, 86-92, 2011	Health promotion excluded as per protocol

Study	Reason for Exclusion
Davey, A., Asprey, A., Carter, M., Campbell, J. L., Trust, negotiation, and communication: young adults' experiences of primary care services, BMC family practice, 14, 202, 2013	Population not in protocol - participants ≥18 years
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 - no themes relating to access of healthcare
De La Cruz, L. F., Jassi, A., Kolvenbach, S., Vidal-Ribas, P., Llorens, M., Mataix-Cols, D., Children from ethnic minorities with obsessive-compulsive disorder: Service use inequalities, reasons behind these inequalities, and treatment outcomes, European Child and Adolescent Psychiatry, 1), S94, 2015	Conference abstract
De Vito, E., De Waure, C., Specchia, M. L., Parente, P., Azzolini, E., Frisicale, E. M., Favale, M., Teleman, A. A., Ricciardi, W., Are undocumented migrants' entitlements and barriers to healthcare a public health challenge for the European Union?, Public Health Reviews, 37, 13, 2016	Narrative review. Included studies checked for inclusion.
Desai, A. D., Popalisky, J., Simon, T. D., Mangione-Smith, R. M., The effectiveness of family-centered transition processes from hospital settings to home: A review of the literature, Hospital Pediatrics, 5, 219-231, 2015	Narrative review. Included studies checked for inclusion.
Dhaliwal, Jasmine, Nosworthy, Nicole M., Holt, Nicholas L., Zwaigenbaum, Lonnie, Avis, Jillian L., Rasquinha, Allison, Ball, Geoff D., Attrition and the management of pediatric obesity: An integrative review, Childhood Obesity, 10, 461-473, 2014	No qualitative data extracted or analysed. Included studies checked for inclusion.
Dhital, R., Whittlesea, C. M., Norman, I. J., Milligan, P., Community pharmacy service users' views and perceptions of alcohol screening and brief intervention, Drug and Alcohol Review, 29, 596-602, 2010	Population not in protocol - Adults aged >18 years
Dickinson, K., Parr, M., Robinson, L., Bennett, E., Hancox, T., White, P., Spencer, R., Webb, N., Walker, D., Neuro-oncology survivorship project (NOSP) to support transition to home, rehabilitation, education and vocational development, Pediatric Blood and Cancer, 62 (Supplement 4), S197-S198, 2015	Conference abstract
Dickinson, K., Parr, M., Walker, D., Robinson, L., Bennett, E., Webb, N., Hancox, T., White, P., Spencer, R., Moving on, Neuro-Oncology, 8), viii18, 2015	Conference abstract
Diffin, Janet, Byrne, Bronagh, Kerr, Helen, Price, Jayne, Abbott, Aine, McLaughlin, Dorry, O'Halloran, Peter, The usefulness and acceptability of a personal health record to children and young people living with a complex health condition: A realist review of the literature, Child: care, health and development, 45, 313-332, 2019	Phenomenon of interest not in protocol - no themes relating to access of healthcare
Dominguez, M. D. G., Fisher, H. L., Johnson, S., Hodes, M., Differential pathways to care in first episode psychosis: Adolescents versus adults, European Child and Adolescent Psychiatry, 1), S167, 2013	Conference abstract
Donaldson, L., Subramanian, A., Conway, M. L., Eye care in young children: a parent survey exploring access and barriers, Clinical & experimental optometry, 101, 521-526, 2018	Study design not in protocol - quantitative, close-questions questionnaire
Dooris, M., McArt, D., Hurley, M. A., Baybutt, M., Probation as a setting for building well-being through integrated service provision: evaluating an Offender Health Trainer service, Perspectives in Public Health, 133, 199-206, 2013	Population not in protocol - participants ≥18 years
Dotson, J., Bricker, J., Crandall, W., Chisolm, D., Mackner, L., Barriers to pediatric inflammatory bowel disease care at time of diagnosis: Results from a prospective cohort, Journal of Pediatric	Conference abstract

Study	Reason for Exclusion
Gastroenterology and Nutrition, 67 (Supplement 1), S184-S185, 2018	
Dovey-Pearce, Gail, Price, Christine, Wood, Helen, Scott, Tracy, Cookson, Jennifer, Corbett, Sally, Young people (13 to 21) with disabilities in transition from childhood to adulthood: An exploratory, qualitative study of their developmental experiences and health care needs, Educational and Child Psychology, 29, 86-100, 2012	Population not in protocol - 13-21 years with 82% 16-21
Drewett, O., Hann, G., Price, N., Tipper, C., Devereux, E., A qualitative study to explore the use of the RCPCH epilepsy passport, Archives of disease in childhood, 102 (Supplement 1), A150, 2017	Conference abstract
Dror, S., Kohn, Y., Avichezer, M., Sapir, B., Levy, S., Canetti, L., Kianski, E., Zisk-Rony, R. Y., Transitioning home: A four-stage reintegration hospital discharge program for adolescents hospitalized for eating disorders, Journal for Specialists in Pediatric Nursing: JSPN, 20, 271-9, 2015	Country: Israel
Dugdale, E., Gerrard, G., Priestley, L., Mariappan, L., Choong, E. S., Follow up of low risk thyroid cancer patients by specialist nurse phone consultations rather than via clinic visits, European Thyroid Journal, 1), 165-166, 2014	Conference abstract
Duran, C., Curtis-Tyler, K., Exploring children's healthcare experiences of haematopoietic stem cell transplantation (HSCT)-a small scale study for service improvement, Bone Marrow Transplantation, 1), S257, 2016	Poster abstract
Eaton, S., Biggerstaff, D., Petrou, S., Osipenko, L., Gibbs, J., Estcourt, C. S., Sadiq, T., Szczepura, A., Young people's preferences for the use of emerging technologies for asymptomatic regular chlamydia testing and management: A discrete choice experiment in England, BMJ open, 9 (1) (no pagination), 2019	Study design not in protocol - no qualitative analysis
Edmonds, J., Twycross, A., Mothers' experiences of managing their child's pain before and during attendance at the emergency department, Journal of Clinical Nursing, 27, 2003-2013, 2018	Phenomenon of interest not in protocol - no themes relating to access or continuity of healthcare
Edwards, R., Dyoss, M., Hesslewood, J., Improving the use of community pharmacies among 16-24 year olds in the Dudley borough, International journal of pharmacy practice, 2), 31-32, 2011	Conference abstract
Egbunike, J. N., Shaw, C., Porter, A., Button, L. A., Kinnersley, P., Hood, K., Bowden, S., Bale, S., Snooks, H., Edwards, A., Streamline triage and manage user expectations: lessons from a qualitative study of GP out-of-hours services, British Journal of General Practice, 60, e83-97, 2010	Population not in protocol - parents of <10 years old and people >16 years old with no way of identifying which themes used data from which age groups
Ellis, J., Boger, E., Latter, S., Kennedy, A., Jones, F., Foster, C., Demain, S., Conceptualisation of the 'good' self-manager: A qualitative investigation of stakeholder views on the self-management of long-term health conditions, Social Science and Medicine, 176, 25-33, 2017	Population not in protocol - adults ≥18 years
Evans, N., Experiences of a child and adolescent mental health service, Nursing Children and Young People, 29, 41-45, 2017	Phenomenon of interest not in protocol - no themes relating to access or continuity of healthcare
Evans-Lacko, S., Gronholm, P., Roberts, R., Laurens, K., Stigma and other barriers to health and social care services among youth	Conference abstract

Study	Reason for Exclusion
in Greater London, Psychiatrische Praxis. Conference: 9th International Conference of the European Network for Mental Health Service Evaluation, ENMESH, 38, 2011	
Fagerstad, A., Windahl, J., Arnrup, K., Understanding avoidance and non-attendance among adolescents in dental care - an integrative review, Community dental health, 33, 195-207, 2016	No qualitative data extracted or analysed. Included studies checked for inclusion.
Fawcett, R., Porritt, K., Stern, C., Carson-Chahhoud, K., Experiences of parents and carers in managing asthma in children: A qualitative systematic review, JBI Database of Systematic Reviews and Implementation Reports, 17, 793-984, 2019	Population of included studies not in protocol. Included studies checked for inclusion.
Flynn, Rachel, Walton, Sarah, Scott, Shannon D., Engaging children and families in pediatric Health Research: a scoping review, Research involvement and engagement, 5, 32, 2019	Scoping review. Included studies checked for inclusion.
Foster, M. J., Whitehead, L., Maybee, P., Cullens, V., The parents', hospitalized child's, and health care providers' perceptions and experiences of family centered care within a pediatric critical care setting: a metasynthesis of qualitative research, Journal of Family Nursing, 19, 431-468, 2013	Phenomenon of interest not in protocol - themes relating to access or continuity of healthcare but these as heavily parent and professional influenced
Gill, F., Butler, S., Pistrang, N., The experience of adolescent inpatient care and the anticipated transition to the community: Young people's perspectives, Journal of Adolescence, 46, 57-65, 2016	Phenomenon of interest not in protocol - no themes relating to access or continuity of healthcare
Goossens, E., Bovijn, L., Gewillig, M., Budts, W., Moons, P., Predictors of care gaps in adolescents with complex chronic condition transitioning to adulthood, Pediatrics, 137, 2016	No qualitative data extracted or analysed. Included studies checked for inclusion.
Graham, T., Rose, D., Murray, J., Ashworth, M., Tylee, A., User-generated quality standards for youth mental health in primary care: A participatory research design using mixed methods, BMJ Quality and Safety, 23, 857-866, 2014	Outcomes not in protocol - user-generated quality standards
Gurung, G., Richardson, A., Wyeth, E., Edmonds, L., Derrett, S., Child/youth, family and public engagement in paediatric services in high-income countries: A systematic scoping review, Health expectations : an international journal of public participation in health care and health policy, 23, 261-273, 2020	Scoping review. Included studies checked for inclusion.
Harper, B., Dickson, J. M., Bramwell, R., Experiences of young people in a 16-18 Mental Health Service, Child and Adolescent Mental Health, 19, 90-96, 2014	Phenomenon of interest not in protocol - no themes relating to access of healthcare
Hughes, V. C., Phillips, S., Exploring the pre-hospitalisation needs of parents of children with cystic fibrosis, Journal of Cystic Fibrosis, 13, S115, 2014	Poster abstract
Hynes, L., Byrne, M., Casey, D., Dinneen, S. F., O'Hara, M. C., 'It makes a difference, coming here': A qualitative exploration of clinic attendance among young adults with type 1 diabetes, British journal of health psychology, 20, 842-858, 2015	Population not in protocol - age 16-28 years (10% (n=2) under 18 years old)
Hynes, L., Byrne, M., Dinneen, S. F., McGuire, B. E., O'Donnell, M., Mc Sharry, J., Barriers and facilitators associated with attendance at hospital diabetes clinics among young adults (15-30 years) with type 1 diabetes mellitus: a systematic review, Pediatric Diabetes, 17, 509-518, 2016	Population of included studies not in protocol. Included studies checked for inclusion.
Jansen, R., Reid, M., Caregivers of adolescents with mental health issues using communication technology: a systematic review, JMIR mHealth and uHealth, 2020	Population of included studies not in protocol. Included studies checked for inclusion.

Study	Reason for Exclusion
Kew, K. M., Cates, C. J., Home telemonitoring and remote feedback between clinic visits for asthma, Cochrane Database of Systematic Reviews, 2016 (8) (no pagination), 2016	No qualitative data extracted or analysed. Included studies checked for inclusion.
Kinchin, I., Tsey, K., Heyeres, M., Cadet-James, Y., Systematic review of youth mental health service integration research, Australian Journal of Primary Health, 22, 304-315, 2016	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Kirk, S., Milnes, L., An exploration of how young people and parents use online support in the context of living with cystic fibrosis, Health Expectations, 19, 309-21, 2016	Phenomenon of interest not in protocol - no themes relating to access or continuity of healthcare
Kolvenbach, S., Fernandez de la Cruz, L., Mataix-Cols, D., Patel, N., Jassi, A., Perceived treatment barriers and experiences in the use of services for obsessive-compulsive disorder across different ethnic groups: a thematic analysis, Child and Adolescent Mental Health, 23, 99-106, 2018	Population not in protocol - parents of children aged 13-17 years old
Krishna, S., Boren, S. A., Balas, E. A., Healthcare via cell phones: A systematic review, Telemedicine and e-Health, 15, 231-240, 2009	No qualitative data extracted or analysed. Included studies checked for inclusion.
Lamb, J., Bower, P., Rogers, A., Dowrick, C., Gask, L., Access to mental health in primary care: a qualitative meta-synthesis of evidence from the experience of people from 'hard to reach' groups, Health: an Interdisciplinary Journal for the Social Study of Health, Illness & Medicine, 16, 76-104, 2012	Population of included studies not in protocol. Included studies checked for inclusion.
Law, H., Gee, B., Dehmahdi, N., Carney, R., Jackson, C., Wheeler, R., Carroll, B., Tully, S., Clarke, T., What does recovery mean to young people with mental health difficulties?-"It's not this magical unspoken thing, it's just recovery", Journal of Mental Health, 2020	Phenomenon of interest not in protocol - no themes relating to access of healthcare services.
Lester, H., Khan, N., Jones, P., Marshall, M., Fowler, D., Amos, T., Birchwood, M., Service users' views of moving on from early intervention services for psychosis: A longitudinal qualitative study in primary care, British Journal of General Practice, 62, e183-e190, 2012	Population not in protocol - participants ≤18 years
Lion, K. C., Kieran, K., Desai, A., Hencz, P., Ebel, B. E., Adem, A., Forbes, S., Kraus, J., Gutman, C., Horn, I., Audio-Recorded Discharge Instructions for Limited English Proficient Parents: A Pilot Study, Joint Commission Journal on Quality and Patient Safety, 45, 98-107, 2019	Country: USA
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 relating to access or continuity of healthcare
Ly, A., Tremblay, G. A., Beauchamp, S., What is the efficacy of specialised early intervention in mental health targeting simultaneously adolescents and young adults?" An HTA, International Journal of Technology Assessment in Health Care, 35, 134-140, 2019	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
MacDonald, K., Fainman-Adelman, N., Anderson, K. K., Iyer, S. N., Pathways to mental health services for young people: a systematic review, Social psychiatry and psychiatric epidemiology, 53, 1005-1038, 2018	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Manuel, J. I., Munson, M. R., Dino, M., Villodas, M. L., Barba, A., Panzer, P. G., Aging out or continuing on? Exploring strategies to	Population not in protocol - aged 18-75 years

Study	Reason for Exclusion
prepare marginalized youth for a transition to recovery in adulthood, Psychiatric rehabilitation journal, 41, 258-265, 2018	
Markkula, N., Cabieses, B., Lehti, V., Uphoff, E., Astorga, S., Stutzin, F., Use of health services among international migrant children - a systematic review, Global Health, 14, 52, 2018	No qualitative data extracted or analysed. Included studies checked for inclusion.
Masoumi, M., Shahhosseini, Z., Self-care challenges in adolescents: A comprehensive literature review, International Journal of Adolescent Medicine and Health, 31, 0152, 2019	Narrative review. Included studies checked for inclusion.
Mc Manus, V., Savage, E., Cultural perspectives of interventions for managing diabetes and asthma in children and adolescents from ethnic minority groups, Child: Care, Health and Development, 36, 612-622, 2010	No qualitative data extracted or analysed. Included studies checked for inclusion.
McCashin, Darragh, Coyle, David, O'Reilly, Gary, Bandura, Beck Beck Borenstein Boyatzis Braun Carr Cartwright Cavanagh Chapman Cheek Coyle Cromby de Graaf Ebert Finfgeld-Connett Fleming Fleming Gerhards Gilgun Grave Green Grist Hannes Harden Henson Herbert Kaltenthaler Khanna Knowles Kruger Law Lenhard Lovell Lucassen Lucassen Lucassen McCashin McLeod Merry Mohr Nieto Noyes O'Cathain O'Reilly O'Reilly Ouzzani Padgett Pennant Popay Poznanski Richards Salloum Scahill Schilling Scozzari Seidman Shepherd Shepherd Shuster Spek Sucala Terp Thomas Thomas Thomas Thornicroft Torgerson Torous Tunney Waller Wise, Qualitative synthesis of young people's experiences with technology-assisted cognitive behavioral therapy: Systematic review, Journal of Medical Internet Research, 21, 2019	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
McCormack, A., Norrish, S., Parker, L., Frampton, I., Consulting with young people about healthcare. Part 2: Experience of long-term health conditions, Pediatric Health, 4, 167-175, 2010	Phenomenon of interest not in protocol - no themes relating to access or continuity of healthcare
McLauchlan, K., Ramlakhan, S., Irving, A., Why do parents present to the Paediatric Emergency Department with conditions suitable for management in less acute settings? A Qualitative Study, European journal of emergency medicine : official journal of the European Society for Emergency Medicine., 20, 2019	Population not in protocol - parental views on access, not a suitable proxy
McMaster, C., Gow, M., Cohen, J., Neal, R., Alexander, S., Baur, L., Patient and parent satisfaction with hospital-based paediatric weight management services and reasons for attrition: a mixed methods systematic review, Obesity Research and Clinical Practice, 13 (3), 311, 2019	Conference abstract
Mimmo, L., Harrison, R., Taking time to care: Meta narrative review of the experience of parents with a child with intellectual disability in hospital, Journal of Intellectual Disability Research, 63, 812, 2019	Systematic review. References checked for possible included studies - none were identified.
Naert, Jan, Roose, Rudi, Rapp, Richard C., Vanderplasschen, Wouter, Continuity of care in youth services: A systematic review, Children and Youth Services Review, 75, 116-126, 2017	Study design of included studies not in protocol. Included studies checked for inclusion.
Narayan, O., Davies, S., Bakewell, K., Lenney, W., Gilchrist, F., Review of personal hand held record for cystic fibrosis children, Journal of Cystic Fibrosis, 2), S105, 2014	Poster abstract
Neill, S. J., Coyne, I., Felt or enacted criticism: Impact on parents' interactions with health care in differing contexts and communities, Archives of disease in childhood, 1), A181, 2014	Conference poster

Study	Reason for Exclusion
Neill, S. J., Social influences on parents' health service use when their child is sick: Barriers to timely treatment?, Archives of disease in childhood, 3), A11-A12, 2015	Conference abstract
Nelson, P. A., Kirk, S. A., Parents' perspectives of cleft lip and/or palate services: A qualitative interview, Cleft Palate-Craniofacial Journal, 50, 275-285, 2013	Phenomenon of interest not in protocol - no themes relating to access of healthcare
Newby, K. V., Brown, K. E., Bayley, J., Kehal, I., Caley, M., Danahay, A., Hunt, J., Critchley, G., Development of an Intervention to Increase Sexual Health Service Uptake by Young People, Health promotion practice, 18, 391-399, 2017	Description of intervention development. No qualitative data analysed.
Nightingale, R., Hall, A., Gelder, C., Friedl, S., Brennan, E., Swallow, V., Desirable Components for a Customized, Home-Based, Digital Care-Management App for Children and Young People With Long-Term, Chronic Conditions: A Qualitative Exploration, Journal of medical Internet research, 19, e235, 2017	Phenomenon of interest not in protocol - no themes relating to access or continuity of healthcare
Noyes, Jane, Brenner, Maria, Fox, Patricia, Guerin, Ashleigh, Reconceptualizing children's complex discharge with health systems theory: novel integrative review with embedded expert consultation and theory development, Journal of advanced nursing, 70, 975-96, 2014	Population of included studies not in protocol. Included studies checked for inclusion.
Nuti, A., Pryce, R., Assessing service satisfaction levels of adolescents with diabetes in out-patient clinic setting: A patient response outcome measure, Hormone Research in Paediatrics, 1), 291, 2013	Poster abstract
Ochieng, B. M., Black African migrants: the barriers with accessing and utilizing health promotion services in the UK, European Journal of Public Health, 23, 265-269, 2013	Population not in protocol - ≤18 years old
O'Reilly, M., Vostanis, P., Taylor, H., Day, C., Street, C., Wolpert, M., Service user perspectives of multiagency working: A qualitative study with children with educational and mental health difficulties and their parents, Child and Adolescent Mental Health, 18, 202-209, 2013	Phenomenon of interest not in protocol - no themes relating to access of healthcare
Oxley, R., Parents' experiences of their child's admission to paediatric intensive care, Nursing Children and Young People, 27, 16-21, 2015	Population not in protocol - parents experiences and ages of children not reported.
Page, C. J., Dunkley, L., Edgerton, J., Hawley, D., Tattersall, R. S., Don't lose your HEADSS in the adolescent clinic: An evaluation of how an adolescent rheumatology service counsels young people's issues, Rheumatology (United Kingdom), 3), iii6, 2014	Poster abstract
Page, C. J., Using headss in the adolescent clinic: An evaluation of how an adolescent rheumatology service counsels young people's issues with patients, Rheumatology (United Kingdom), 1), i170, 2014	Conference abstract
Parker, R., A small-scale study investigating staff and student perceptions of the barriers to a preventative approach for adolescent self-harm in secondary schools in Wales-a grounded theory model of stigma, Public Health, 159, 8-13, 2018	Phenomenon of interest not in protocol - no themes relating to access or continuity of healthcare
Petrie, K., McArdle, A., Cookson, J., Powell, E., Poblete, X., 'Let us speak'-children's opinions of doctors, Archives of Disease in Childhood, 102 (Supplement 1), A200-A201, 2017	Conference abstract
Planey, Arrianna M., Smith, Sharde McNeil, Moore, Stephanie, Walker, Taylor D., Barriers and facilitators to mental health help-seeking among African American youth and their families: A systematic review study, Children and Youth Services Review, 101, 190-200, 2019	Country not in protocol - USA

Study	Reason for Exclusion
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	No qualitative data extracted or analysed. Included studies checked for inclusion.
Pretorius, N., Rowlands, L., Ringwood, S., Schmidt, U., Young people's perceptions of and reasons for accessing a web-based cognitive behavioural intervention for bulimia nervosa. European Eating Disorders Review: The Professional Journal of the Eating Disorders Association, 18(3):197-206, 2010	Identified in Struthers 2015 systematic review. Population not in protocol - includes young people 16-20 years but does not provide sufficient demographic information to source supporting quotations for themes.
Price, C. S., Corbett, S., Lewis-Barned, N., Morgan, J., Oliver, L. E., Dovey-Pearce, G., Implementing a transition pathway in diabetes: a qualitative study of the experiences and suggestions of young people with diabetes, Child: care, health and development, 37, 852-860, 2011	Phenomenon of interest not in protocol - no themes relating to access of healthcare
Read, N., Lim, E., Tarzi, M. D., Hildick-Smith, P., Burns, S., Fidler, K. J., Paediatric hereditary angioedema: A survey of UK service provision and patient experience, Clinical and Experimental Immunology, 178, 483-488, 2014	Phenomenon of interest not in protocol - no themes relating to access or continuity of healthcare
Reardon, T., Harvey, K., Young, B., O'Brien, D., Creswell, C., Barriers and facilitators to parents seeking and accessing professional support for anxiety disorders in children: qualitative interview study, European Child and Adolescent Psychiatry, 27, 1023-1031, 2018	Population not in protocol - parents of children aged 7-11 years
Richardson, C., Paslakis, G., Men's experiences of eating disorder treatment: A qualitative systematic review of men-only studies, Journal of psychiatric and mental health nursing, 2020	Population of included studies not in protocol. Included studies checked for inclusion.
Robert, Marie, Leblanc, Line, Boyer, Thierry, When satisfaction is not directly related to the support services received: Understanding parents' varied experiences with specialised services for children with developmental disabilities, British Journal of Learning Disabilities, 43, 168-177, 2015	Country not in protocol - Canada
Rucci, P., Latour, J., Zanello, E., Calugi, S., Vandini, S., Faldella, G., Fantini, M. P., Measuring parents' perspective on continuity of care in children with special health care needs, International Journal of Integrated Care [Electronic Resource], 15, e046, 2015	Country not in protocol - Italy
Ryan, Siobhan M., Jorm, Anthony F., Toumbourou, John W., Lubman, Dan I., Parent and family factors associated with service use by young people with mental health problems: A systematic review, Early Intervention in Psychiatry, 9, 433-446, 2015	Study design not in protocol - quantitative data only
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 data only
Schuller L Fau - Thaker, Kelly, Thaker, K., Community, Pract, Instant messaging: The way to improve access for young people to their school nurse	Narrative description of a study. No information presented on data collection (beyond school aged children in Doncaster) or data analysis.
Settipani, C. A., Hawke, L. D., Cleverley, K., Chaim, G., Cheung, A., Mehra, K., Rice, M., Szatmari, P., Henderson, J., Key attributes of integrated community-based youth service hubs for mental health: A scoping review, International Journal of Mental Health Systems, 13, 52, 2019	Scoping review. Included studies checked for inclusion.

Study	Reason for Exclusion
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 - no themes relating to access or continuity of healthcare
Shilling, V., Edwards, V., Rogers, M., Morris, C., The experience of disabled children as inpatients: a structured review and synthesis of qualitative studies reporting the views of children, parents and professionals, Child: care, health and development, 38, 778-88, 2012	Phenomenon of interest not in protocol - no themes relating to access or continuity of healthcare
Simons, D., Pearson, N., Dittu, A., Why are vulnerable children not brought to their dental appointments?, British dental journal, 219, 61-65, 2015	Study design not in protocol - no qualitative analysis
Smith, Kathryn A., Gehricke, Jean- G., Iadarola, Suzannah, Wolfe, Audrey, Kuhlthau, Karen A., Disparities in Service Use Among Children With Autism: A Systematic Review, Pediatrics, 145, S35-S46, 2020	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Spencer, A. E., Platt, R. E., Bettencourt, A. F., Serhal, E., Burkey, M. D., Sikov, J., Vidal, C., Stratton, J., Polk, S., Jain, S., Wissow, L., Implementation of Off-Site Integrated Care for Children: A Scoping Review, Harvard Review of Psychiatry, 27, 342-353, 2019	Scoping review. Included studies checked for inclusion.
Spencer, G., Smith, M., Thompson, J., Fairbrother, H., Hoare, K., Fouche, C., Curtis, P., Health experiences of children and young people who migrate - Opportunities for health education, Health education journal, 78, 96-107, 2019	Narrative review. Included studies checked for inclusion.
Stafford, V., Hutchby, I., Karim, K., O'Reilly, M., "Why are you here?" Seeking children's accounts of their presentation to Child and Adolescent Mental Health Service (CAMHS), Clinical child psychology and psychiatry, 21, 3-18, 2016	Phenomenon of interest not in protocol - no themes relating to access or continuity of healthcare
Starkman, Harold, Fisher, Kathleen, Pilek, Nicole L., Lopez-Henriquez, Gloria, Lynch, Laura, Bilkins-Morgis, Briana L., Listening to adolescents with uncontrolled diabetes, their parents and medical team, Families, systems & health : the journal of collaborative family healthcare, 37, 30-37, 2019	Country not in protocol: USA
Struthers, Ashley, Charette, Catherine, Bapuji, Sunita Bayyavarapu, Winters, Shannon, Ye, Xibiao, Metge, Colleen, Kreindler, Sara, Raynard, Melissa, Lemaire, Jacqueline, Synyshyn, Margaret, Sutherland, Karen, The acceptability of E-mental health services for children, adolescents, and young adults: A systematic search and review, Canadian Journal of Community Mental Health, 34, 1-21, 2015	Study design of included studies not in protocol. Included studies checked for inclusion.
Sunderland, E., Wood, K., Barwick, S., What do looked after young people think about the specialist health services they use?, Archives of disease in childhood, 3), A184, 2015	Conference abstract
Svirydzenka, N., Ronzoni, P., Dogra, N., Meaning and barriers to quality care service provision in Child and Adolescent Mental Health Services: Qualitative study of stakeholder perspectives, BMC health services research, 17, 151, 2017	Phenomenon of interest not in protocol – themes relating to healthcare access but unable to identify which themes used data from <18 years
Taylor, S., Haase-Casanovas, S., Weaver, T., Kidd, J., Garralda, E. M., Child involvement in the paediatric consultation: a qualitative study of children and carers' views, Child: care, health and development, 36, 678-685, 2010	Phenomenon of interest not in protocol - no themes relating to access or continuity of healthcare
Vogel, J. A., Rising, K. L., Jones, J., Bowden, M. L., Ginde, A. A., Havranek, E. P., Reasons Patients Choose the Emergency	Population not in protocol - Adult population only

Study	Reason for Exclusion
Department over Primary Care: a Qualitative Metasynthesis, Journal of General Internal Medicine, 34, 2610-2619, 2019	
Waibel, Sina, Henao, Diana, Aller, Marta-Beatriz, Vargas, Ingrid, Vazquez, Maria-Luisa, What do we know about patients' perceptions of continuity of care? A meta-synthesis of qualitative studies, International Journal for Quality in Health Care, 24, 39-48, 2012	Population of included studies not in protocol. Included studies checked for inclusion.
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	Phenomenon of interest not in protocol - no themes relating to access of healthcare
Waite-Jones, J., Swallow, V., Smith, J., Stones, S., Majeed-Ariss, R., Van Rooyen, V., Developing a mobile-app to aid young people's self-management of chronic rheumatic disease: A qualitative study, Rheumatology (United Kingdom), 56 (Supplement 6), vi8, 2017	Poster presentation
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Watts, R., Zhou, H., Shields, L., Taylor, M., Munns, A., Ngune, I., Family-centered care for hospitalized children aged 0-12 years: A systematic review of qualitative studies, JBI Database of Systematic Reviews and Implementation Reports, 12, 204-283, 2014	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
Watts, Robin, Zhou, Huaqiong, Shields, Linda, Taylor, Marjory, Munns, Ailsa, Ngune, Irene, Family-centered care for hospitalized children aged 0-12 years: a systematic review of qualitative studies, JBI Evidence Synthesis, 12, 2014	Duplicate
Webb, C. M., Collin, S. M., Deave, T., Haig-Ferguson, A., Spatz, A., Crawley, E., What stops children with a chronic illness accessing health care: a mixed methods study in children with Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME), BMC health services research, 11, 308, 2011	Population not in protocol - interviews conducted with parents of children >5 years (mean age 11.9 (4.3))
Whale, K., Cramer, H., Wright, A., Sanders, C., Joinson, C., 'What does that mean?': A qualitative exploration of the primary and secondary clinical care experiences of young people with continence problems in the UK, BMJ open, 7 (10) (no pagination), 2017	Phenomenon of interest not in protocol - no themes relating to access of healthcare

Economic studies

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

Appendix L – Research recommendations

Research recommendation for review question: What are the facilitators of, and barriers to, accessing healthcare services for babies, children and young people?

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: What are the facilitators of, and barriers to, accessing healthcare services for babies, children and young people?

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 10: Evidence from reference groups and focus groups

Age < 7 years	Age 7-11 Years	Age 11-14 years	Overall quality of the evidence
• Who is someone you go to if you are not feeling very well? o ‘A doctor/surgeon’ x15 o ‘A nurse’ x6 o ‘School nurse’ o ‘Policeman’ x3 o ‘Mummy’ x8 o ‘Daddy’ x7 o ‘Brothers/sisters’ x2 o ‘Nanny and grandad’ x2 o ‘A friend’ o ‘Dentist’ x10 o ‘Ambulance’ o ‘A fire engine/firemen’ x2 o ‘Teachers’ x4 o ‘Optician’ x3 o ‘Audiologist’ o ‘Person that does X-rays’ o ‘Mountain rescue’ o ‘Lifeguard’	• What makes it easier to access health services? o ‘Hospital nearby/near my house’ o ‘Short waiting times’ o ‘Doctor is there when you visit; not a waste of time’ o ‘Not missing a lot of school to see the doctor’ o ‘Swift in and out’ o ‘More doctors so you don’t have to wait long’ o ‘Close to home – emergency, it’s important to be close to home, if you’re in a rush, ambulance can get there quickly’ x 2 o ‘If not in an emergency, still important it is close to home so you can easily go there and back’ o ‘If you are close to home, then the hospital will keep having to move to wherever you are and is that really a good idea? If the hospital moves	• What makes it easier to access health services? o ‘In a convenient location’ o ‘Not too much travelling’ o ‘Same gender’ • What are barriers to accessing healthcare? o ‘Hospital is too far away from home’ x2 o ‘Scared of doctors’ o ‘Death!!!’ o ‘Might be afraid of hospitals’ o ‘Might not want to be stuck inside a hospital’ o ‘Being squeamish’ o ‘Being scared of needles’ x2 o ‘When family don’t know where you are’ - ‘When I feel ill I just want my mum but she might be stuck in traffic’ o ‘Scared of loud noises, and so scared of the ambulances’ o ‘Anxiety’ o ‘Covid worries’ o ‘Not having family around’	• Low

Age < 7 years	Age 7-11 Years	Age 11-14 years	Overall quality of the evidence
○ 'Bus driver/taxi driver' ○ 'Waiter' ○ 'Pets' ○ 'Teddies' ○ 'Mainworker / keyworker / careworker' x3 ○ 'Charity' • Where might you go if you are not feeling very well? ○ 'Hospital' x8 ○ 'Dentist for your teeth' x4 ○ 'Chemist/pharmacy/Boots' x3 ○ 'Eye doctor/optician' x5 ○ 'Doctor' x4 ○ 'Sometimes have medicines at home' x2 ○ 'Ear doctor' ○ 'A tummy nurse or a tummy doctor' ○ 'For an X-ray' ○ 'An ambulance' x4 ○ 'The surgery/GP' x2 ○ 'Mountain rescue place' x2 ○ 'Royal college of nursing (mummy works there)' ○ 'NHS' x3 ○ 'A place to get flu vaccine' • Are health services scary? ○ Agree (12/18) - 'Because I don't know what is happening or what is going to happen'	closer to you then other people won't be able to get there quicker' • What is a barrier? ○ 'It can protect you' ○ 'A prison cell' ○ 'It can keep you safe' ○ 'As you get older, you keep things private - that is a barrier to healthcare. You notice that your parents are a bit more like 'have you registered for your SATs' you don't want them to worry about your healthcare as well.' ○ 'Something that separates something from something' ○ 'It is something that can be invisible or visible ○ 'When you are not allowed to go somewhere, it's because there is a barrier there' ○ 'You cannot get across' ○ 'You can break or jump over them' • What are the most significant barriers to accessing healthcare? ○ 'Feeling embarrassed' ○ 'Not telling anyone you feel unwell' ○ 'Gender of doctor' ○ 'Not being able to explain what is wrong' ○ 'Not being taken seriously by healthcare staff' (x2) ○ 'Not knowing how to ask for help'	○ 'Don't know what side-effects of the treatment are' ○ 'Not enough time/too busy/already have plans – if you have a busy schedule you might not have enough time' x3 ○ 'Embarrassed' ○ 'Overwhelmed' ○ 'Might want to go to a friend's house or an after school club/already have plans/ interrupting social life' ○ 'The days and times [for appointments] might be difficult' ○ 'Waiting times' ○ 'Missing out on education' - 'I quite enjoy science, there's no experiments if you have to go to hospital' ○ 'Being a burden' - 'Worrying about being a burden… there could be someone with a lot worse than you and you would take up too much time when they should' ○ 'Not knowing the doctors' - 'Don't know who they [the doctor] are' - 'If they are new you don't know if you can trust them or not' • Case study 1: Alex is 10, has a learning disability and has a hearing impairment. He lives in a single parent family and has 3 siblings who are all between 7 – 14 years old. • He gets nervous when he is around people he does not know very well and does not like going to the doctors. He does not talk to his parents about why he does not like going to the doctors.	

Age < 7 years	Age 7-11 Years	Age 11-14 years	Overall quality of the evidence
- 'I went to the dentist and I was scared because I thought something bad might happen to my teeth' - 'It might hurt' ○ Disagree or not sure (6/18)	○ 'If the staff is not taking my health seriously and I could die and I would get really worried' ○ 'If it was something private I would feel embarrassed' ○ 'What would make me less embarrassed is choosing what I get to talk about' ○ 'Not being taken seriously by health staff would be really dangerous and worrying' ○ 'Too far to travel there - 'I don't like travelling without company. I'd rather they came to me' ○ 'I don't know how to ask for help' ○ 'At home no body actually listens to me. It makes me feel sad when people don't listen to me' ○ 'Coronavirus' ○ 'Scared of the doctor' • How could you overcome these barriers? ○ 'I'm a bit scared.' ○ 'If one of my family died, I would go to their house and stay until the doctor comes there. I'm scared in case I had to get plastic surgery. I am going to be brave.' ○ 'Because I've been before and it wasn't bad, nothing would stop me going before.' ○ 'If I go alone, then I might feel scared and terrified a lot.'	• What barriers do you think Alex might have if he needed to access healthcare? ○ 'Scared' ○ 'Parent is always busy with other children' ○ 'Sounds overwhelm him' ○ 'He doesn't want to worry parent' ○ 'Maybe he has other learning difficulties' ○ 'His hearing impairment might make him nervous around loud noises' ○ 'His parents have other things on their plate' ○ 'He might be worried about what people are saying about him because he can't properly hear' ○ 'He doesn't know how to explain that he doesn't like the doctor' ○ 'Scared' ○ 'Doesn't want to admit that he is scared to his parents' ○ 'His learning disability might make it harder for him' ○ 'Physical barriers' ○ 'Not being able to hear' ○ 'Fear – not wanting to be around doctors' ○ 'Parent may not be supporting him because of time and finances with 4 children and one parent' • What solutions might help Alex access healthcare? ○ 'Bursary for young people to access' services e.g. to get public transport or a taxi ○ 'He needs to speak out to his parents so he can get extra support' ○ 'I would tell him there is nothing to be scared about [about telling his parents] because they are the people who know him the most'	

Age < 7 years	Age 7-11 Years	Age 11-14 years	Overall quality of the evidence
	○ 'If the doctor asked where are your family, where do you live, he might be an imposter and try to rob me' ○ 'Something that might stop me is if I have to go to the doctor and have an operation I might die. But something that stops me more is if my mum goes to the doctor and I went with her and she died and then I had no one to take care of me.' ○ 'The big long injections would stop me' ○ 'If my family are not there I would not have anybody to hold my hand getting a big injection' • Would it matter to you if the doctor was a boy or a girl? ○ Yes - 2 (both girls) - 'I feel like boys are a bit rough and I would rather see a girl doctor because she is nice' - 'I don't want to see a boy doctor because boys are different to girls and they don't know what we like and what we don't like.' ○ No - 2 (both boys) (no quotes) • How would you like to explain something to the doctor? ○ 'I'd like to draw a picture' ○ 'Draw a picture' ○ 'I'd tell my mum and tell her to tell them'	○ ‘He could ask his parents for a quiet word’ ○ ‘Maybe he could bring up something else he was scared of first e.g. something at school’ ○ ‘He could chat to a teacher and ask them if a parent could come in to school to talk, have the teachers help the conversation happen’ ○ ‘Drop in session before he starts accessing a services - doctor coming into school, sit down with him, get to know him - or video call’ ○ ‘Workshops for students to help them understand healthcare options, what it will be like’ ○ ‘Pamphlets for parents so they are more aware and can help’ • Case study 2: Sam is 9 years old and uses a wheelchair because of her disability. She goes to school far away from her home because there are no special schools in her local area that have space. • She is at school when she starts to feel unwell. Her teacher suggests she should go and see the school nurse or meet a doctor. • What barriers might Sam have if she needed to see a school nurse about something? ○ ‘Access and unawareness because she is only 9 years old’ ○ ‘Because she is only 9 she might get lost trying to find the school nurse’ ○ ‘Aren’t often school nurses in primary school’ ○ ‘Feeling sad because she is far away from her house so she would tire easily from the big journey each morning’ ○ ‘Doesn’t have a parent to help’	

Age < 7 years	Age 7-11 Years	Age 11-14 years	Overall quality of the evidence
	• Case study 1: Alex is at primary school and feels unwell during a lesson. What are the barriers to accessing healthcare and how can they be overcome? o Barrier 1: Who can Alex speak to about going to see the nurse? - 'Teacher' (x2) - 'Needs to be one you like - won't always be possible' - 'Teacher you trust that can help' (x3) - 'Could ask your TA' o Barrier 2: Alex is embarrassed asking this person to go to see the nurse - 'See if closest friend can come with them' (x3) - 'Ask if there is a relative' - 'My mum works at school' - 'Ask someone who has experience in something' - 'By having someone else to speak to.' o Barrier 3: Alex is worried about having to take medicine - 'You can tell Alex that the medicine will make him better' - 'Give him a flavour he likes' - 'Say it is a secret potion' - 'Have a distraction - fun activity' - 'Tell him it tastes really nice' - 'Cover his eyes so he can't see it'	o 'Overwhelming and feels a burden, plus no family' o 'Wondering what does a school nurse do' o 'Doctors is too far away' o 'Physical access – harder to move through school to find the nurse, she might end up missing lessons if she's a bit slower' o 'Feeling of vulnerability' o 'Doesn't know her way round the school' o 'Physical access in getting to the nurse and then the nurses room might be too small' o 'Younger so might be more scared, not be in a position to make the whole decision herself - parent support is really important, especially for younger children' o 'Services closer to home' • What solutions might help Sam access healthcare? o 'Could ask a teacher for assistance' o 'Having a helper in school to go with her could help' o 'Physical access e.g. ramp, bigger school office' o 'Making all services accessible' • Case study 3: Ali is 15 and has autism. His mum and dad both work 2 jobs and work until very late in the evening, getting home sometimes around 11pm. • He does not go to see his doctor that much but when he does go, he gets really anxious about seeing his doctor. • What do you think could be a barrier for Ali to see his doctor? o 'Worried about what the doctor will say'	

Age < 7 years	Age 7-11 Years	Age 11-14 years	Overall quality of the evidence
	• Case study 2: Remi is living in a foster home and needs to go to the dentist. What are the barriers to accessing healthcare and how can they be overcome? ○ Barrier 1: who can Remi tell that he needs to go to the dentist? - 'Tell an adult he trusts' - 'He can tell the owner of the foster home he likes and trust' (x2) - 'He could tell a best friend to tell the adults' - Tell a friend (x2) - Tell an adult - Mum or dad 'can you help me' - 'He could tell a doctor' - 'He could walk to the doctors' - 'If he can't find a doctor anywhere he should tell an adult and ask for help' - 'His parents' - 'He could be brave and go on his own' ○ Barrier 2: Remi is worried about how to travel to the dentist as it is too far away - 'He could ask for a lift' (x2) - 'Ask a friend' - 'If he has money he could get the bus' - 'I think he would want someone to go with him' - 'Use the computer'	○ 'Anxiety' ○ 'Worries about getting an anxiety attack' ○ 'Travel and not going often makes him going to the doctor into an unknown' ○ 'If he's 15 he might be expected to do things by himself, but he needs support ' ○ 'He might need a special helper [if his parents aren't around]' ○ 'He might want to have someone beside him' ○ He can't really talk to his parents or go with them if they work long hours' ○ 'Parents don't have time to talk and he doesn't have a person to go with' ○ 'Not having a good understanding of what to do ' ○ 'Not knowing what is wrong with him – thinking it is maybe nothing' • What solutions might help Ali access healthcare? ○ 'Quiet room could help' ○ 'Stress toys' ○ 'Home doctor' ○ 'Could get a guardian or friend to go with him, or a TA if a friend wasn't allowed out of class' ○ 'Have a childminder go with him'	

Age < 7 years	Age 7-11 Years	Age 11-14 years	Overall quality of the evidence
	- Over the road - Boat/ferry/train/drive - 'I would want someone to help me on the train' - 'I would ask people on the bus to help me' - 'I'd ask the bus driver to help me' - 'I would just have to go over the road and it is easy' - 'My mum would know' - 'There is an app called NHS COVID19' ○ Sub-question: Would you rather talk to the dentist on the phone or app or see him in person? - 'Facetime or phone. I'd rather just Facetime' - 'I'd rather see them in person because if they had enough time they could get it done in the same day. So it's over and done with so I don't have to go over these stepping stones again' ○ Barrier 3: Remi is worried the dentist will do something painful to his teeth - 'Ask them if they can give him a toy/teddy' - 'Think happy thoughts' - 'Ask for something to watch/play as a distraction' - 'Get the dentist to explain what they are doing to do' - 'Drink water'		

Age < 7 years	Age 7-11 Years	Age 11-14 years	Overall quality of the evidence
	- 'Going with a friend' - 'Marshmallows to look at instead' - 'Tell him it won't hurt' - 'I would not be worried' - 'I would take him to the doctors' - 'Going with a friend would help me' - 'My idea is basically if you tell him it will not hurt' - 'Something that would look nice that he could look at instead like a toffee apple' - 'Therapy dog!' - 'My Nintendo switch would distract me 100%' - 'A diamond because it is shiny' - 'If you see the same doctor you know they will take care of you' - Tell him he is brave' - 'Tell him he is strong' - 'Have anyone tell him he is brave' - 'Tell him he could get £50 or a sweet afterwards' - 'If an appointment was cancelled I would get worried, I would be worried about paying and worried about having holes in my teeth'		

In addition to the evidence above the 7-11 and 11-14 years reference group identified barriers to accessing healthcare and suggested solutions to some of these barriers. The results of this are summarized in Table 11 and Table 12.

Table 11: Barriers to accessing healthcare and possible solutions identified by the age 7-11 reference group

Potential barrier	Possible solution	Overall quality of the evidence
‘You don’t want parents to worry’		• Low
‘You’re scared and frightened of the doctor’ (x4)	• ‘Explains things better and in an easier way so it doesn’t sound scary’ • ‘Translate’ • ‘Have toys in waiting room’ • ‘Show you what is going to happen to you on a YouTube video’ • ‘Ask us if we want a sticker’ • ‘Be friendly’ • ‘Holding hand’ • ‘Dad/Mum coming with me and holding my hand’ • ‘Being brave’ • ‘Make them happy again’ • ‘Make you laugh’ • ‘Make a funny joke’ • ‘Do something fun for me’ • ‘Distract them’ • ‘Make them focus on something else’ • ‘Make sure you know how to get help’ • ‘Share why we feel scared – ask parents to help’ • ‘Bring a cuddly toy’ • ‘Have a dog or a pet to hug’ • ‘Tell the doctor why you feel scared’ • ‘Tell your parents then they can tell the doctor’ • ‘If you have to stay overnight, the doctors could show you what to press if you need help and they can come’ • ‘If you have a dog, or just any pet, you could maybe give it a hug’ • ‘Think of things you like to do and try and forget’	
‘Doctors use big words that I don’t understand and my mum has to translate it for me’	• 'Make it more informal' • 'Break it down for us'	

Potential barrier	Possible solution	Overall quality of the evidence
	• 'Explain in a way we speak to our friends' • 'If you don't speak English - have a translator'	
'You're embarrassed' (x4); 'worried that my parents might be embarrassed too'	• 'Choosing what to talk about, not talking about private parts' • 'Not going to the doctors - talking to mum' • 'Make people laugh' • 'Have a funny doctor' • 'Have separate areas for children' • 'Say why you are embarrassed' • 'Maybe telling them why are you feeling embarrassed, they could help you'	
'Don't have internet to make an appointment'		
'Don't know what will happen – if you go to the dentist you don't know if they will drill your teeth out		
'Don't want to miss your school club that you really like'		
'Don't have time'		
'GP closes too early and you can't make any medical appointments'		
'Might think people will make fun of you – if you tell someone you have a health condition and they tell everyone, they all make fun of you; people might laugh at me'	• 'Make the doctor's more private'	
'Live too far from the one they want to get to because maybe their friends goes there a lot and they rate it really good'	• 'Find another one near you' • 'Ask one you like for a recommendation for a different doctor'	
'Can't see the same doctor every time (makes a big difference)' 'Sometimes when you go to new doctors it's a bit weird'	• 'Ask for recommendations' • 'If they knew all doctors were friendly, they would go every time' • 'Ask for the same doctor'	

Potential barrier	Possible solution	Overall quality of the evidence
'Worried you'll get told off'		
'Appointment is too late'	• 'Make 12pm [appointments]or children and young people so you can leave school - go and come back to school' • 'Dr asks what time is best' • 'Adults are more flexible than children'	
'If you have a friend who has had the same treatment that you're getting and they tell you all about it and it sounds scary to you, you might not go because it seems scary'		
'Too far to travel'	• '[Doctor/service should] come to me' • 'If I was in a lot of pain, it would be really bad going to a different doctor that was too far away' • 'If it's something that is not serious, I would be fine going further' • 'If it was serious I would go to a different doctor or to accident and emergency'	
'Not being taken seriously by health staff' (x4)	• 'Doctors and nurses not acting silly, acting serious and really focusing' • 'Make sure I am put in the right place to make me better and to tell me the truth' • 'Right place - make sure I get the right treatment and they aren't doing something on the wrong part of the body'	
'Gender of the doctor/rather see a girl doctor'		
'If it was a scary different hospital'		
'Not being able to explain what is wrong'	• 'Doctor not just saying 'ok' but actually listening and telling you what will actually help'	
'Not knowing how to ask for help'	• 'Ask Mum'	
'Not knowing'		
'Alone'		
'Scared about doctor being an imposter – fake doctor'	• 'Seeing the same doctor' • 'Knowing they will take care of you'	
'Nobody to hold your hand'		

Potential barrier	Possible solution	Overall quality of the evidence
‘If it was something that might hurt me, I won’t like it’	• 'Put me under anaesthetic' • 'Explain what was going to happen, would help because it might be serious, so I want to know what's going on'	
‘Not sure what will happen with the information’ ‘Sometimes you don’t know where your information is going to. If you didn’t want anyone else to know you didn’t know where that information is going. Don’t want it to go somewhere not appropriate for you like going on the internet’	• 'Ask doctors not to tell before we share'	
‘Catching germs in hospital’ ‘Might be worried you went there and the germs spread from someone who is poorly’	• ‘Make doctors and nurses aware and ask them how to stay safe; say to the person who is looking after you, how do I not catch the germs?’	
‘Friendships’	• 'Make new friends - finding things in common' • 'If someone is being mean you could go and find someone else' • 'You could find someone you don't know at all and ask them to play with you. You could make friends with someone who is unwell like you and you had the same illness'	
‘Our emotions – feeling sad or nervous’ ‘If you feel really sad and if you feel really nervous’	• ‘Tell doctor how we feel, and friends and parents’	
‘Worried if it is your 1st time – not sure what will happen’ ‘Worried it’s your first what they will do and think’	• 'Let everyone know it is your first time and they can reassure you' • 'Tell the doctor it is your first time and you are worried then they can tell you all about hospitals and it will be ok'	
‘Wanting to be a turtle’ ‘When you need space, it shows you have a barrier around you and people can’t enter and it’s a place you feel safe’	• 'Ask questions to healthcare workers to feel less upset' • 'Instead of going into turtle, you could ask questions about why this is happening'	
‘Being worried – not sure what is happening’	• 'Doctor meeting at the door - introduce themselves 'say a bit about yourself''	

Potential barrier	Possible solution	Overall quality of the evidence
‘Worried if you don’t know what’s happening’	• 'Sharing what will happen'	
‘Nervous about things going wrong’	• 'Ask for an explanation of what will happen' • 'You could ask the person what is going to happen and what will happen if something went wrong so they could answer you' • 'The doctor now knows you are worried about if something went wrong'	
‘Worried we wouldn’t see our friends for a while’	• 'Play team with games' • 'Have games to play with other children' • 'Go with friends' • 'When you met the doctor they said the play team could come in with games and if you did not have a virus you could walk around' • 'If you had a virus they could bring games to you and if you didn't you could go and find games to play with other children and make friends there' • 'Maybe you could go on Zoom with your friends'	

Table 12: Barriers to accessing healthcare and possible solutions identified by the age 11-14 reference group

Potential barrier	Possible solution	Overall quality of the evidence
‘Just want to be at home and in bed’	• 'If hospitals were more comfortable it would help' • 'If there was a bookshelf - being able to read books to escape' • 'Access to phone and wifi' • 'Around people you actually like 'rather than being left alone in the children's ward'' • 'Not having it look as professional, having it look more normal'	• Low
‘Long waiting times’	• ‘More services’	
‘CAMHS threshold, depends on severity so you might not be able to get help’	• 'More funding for MH services' • 'Not basing on it severity, more funding, more services'	
‘Lack of support from teachers, parents and the general environment around you’	• ‘Services need to reach parents/teachers/schools to give them info about how to support children to access services’	

Potential barrier	Possible solution	Overall quality of the evidence
‘Ability to physically get to services’	• 'Travel bursary' • 'Services should be in each area'	
‘Not having enough information and knowledge’	• ‘Services should communicate more, go to secondary schools, give workshops etc. and deliver support in schools’	
‘Fear and being scared’	• 'Having a teddy to hold onto' • 'Knowing the risks, knowing it's not going to kill you' • 'Worried about fertility with treatment - having information about the risks' • 'Having parents there/right there beside me'	

Appendix N – Evidence from national surveys

Evidence from national surveys for review question: What are the facilitators of, and barriers to, accessing healthcare services for babies, children and young people?

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	USE OF DIFFERENT HEALTH SERVICES: • Over 80% of young people had used General practice, pharmacies and hospital health services, and were positive about how all these services met their needs • 70% had used accident and emergency, but this was ranked lowest of 7 services for meeting needs. • Specialist services for long-term conditions, counselling services, and sexual health services were each used by less than 40% of young people	• Low
Care Quality Commission. Children and young people's inpatient and day case survey 2018	• No relevant findings were identified for this question	• N/A
Child Outcomes Research Consortium. Child- and Parent-reported Outcomes and Experience from Child and Young People's Mental Health Services 2011-2015	APPOINTMENTS: • 62% of children and young people said the timing of their appointment was convenient • 66.4% of children and young people said the location of the appointment was easy to get to	• Moderate
Health and Social Care Information Centre. Children's Dental Health Survey 2013. (Country specific report for England, published 2015)	ACCESS TO NHS DENTAL SERVICES: • 83% of parents (of children of all ages) said they did not have problems finding an NHS dentist, although a breakdown by free school meal eligibility found that this was 78% where children were eligible for free school meals • 76% of parents of 5 year olds were satisfied with the wait for an urgent appointment, and 82% were satisfied with the wait for a routine appointment	• Moderate

Survey	Findings	Overall quality of the evidence
HM Inspectorate of Prisons. Children in Custody 2016-2017	ACCESS TO HEALTHCARE IN CUSTODY: • Secure training centres: ○ 82% of children and young people said that they were able to see a doctor or nurse if they felt unwell ○ 64% said the health services were 'good' ○ 24% said they had health needs which were not being met • Young offender institutions: ○ 71% of children and young people said it was easy to see a nurse ○ 57% said it was easy to see a doctor ○ 35% said it was easy to see a dentist ○ 53% said health services were good ○ 27% reported having an emotional or mental health problem, and of these 54% were being helped by someone.	• Moderate
National Children's Bureau. Listening to children's views on health provision 2012	ACCESS TO HEALTHCARE FOR CARE-LEAVERS: • Care leavers (age not specified) reported that they needed increased levels of support to access health services such as regular check-ups every six months, more money for dental and NHS doctor care, someone to make sure that all care leavers have a doctor, dentist and health visitor, and help to ensure they are able to cope managing their own care. • Care leavers (age not specified) also said they need more information such as advice and support on health issues, particularly sex education, making health services better known and easier to get involved with, including sexual health clinics. They also needed more information on how to register with doctors and dentists (the social workers need to take them and show them), and an education pack, newsletter or video on leaving care, so care leavers know how to use different health services. • Another consultation with young people in care and care leavers (age not specified) led to recommendation that they needed a guide to local health services. This should include: ○ Where and how to find local health services, and how often young people should go to them (e.g. dentist) ○ Information on health services needs to be clear about young people's entitlements (e.g. free prescriptions and dental care)	• Moderate

Survey	Findings	Overall quality of the evidence
	○ How to get help if you have emotional problems ○ Information on different types of contraception and where you can access them ○ Information and services on giving up smoking, drugs and alcohol ○ Information on how to eat healthily (e.g. what is a healthy 'five a day' diet and what is a bad diet and why) ○ Information on free leisure passes, leisure facilities for children in care	
Opinion Matters. Declare your care survey 2018	APPOINTMENTS: • Of young people who had raised a concern or made a complaint, in 63% the subject had been delays in getting an appointment or the appointment being cancelled	• 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	• No relevant findings were identified for this question	• N/A
Picker Institute/NHS England/Bliss. Neonatal Survey 2014 *Results for individual questions were converted into scores on a scale of 1 to 100, with 100 representing the best possible outcome (the scores are not percentages).*	• No relevant findings were identified for this question	• N/A
Word of Mouth Research and Point of Care Foundation. An options appraisal for obtaining feedback on the experiences of children and young people with cancer 2018	CHOICE OF HOSPITAL: • 1 teenager reported not being treated at a hospital of her (and her parents') choice, resulting in a more difficult journey. Quotes: 'We asked to stay at (hospital 1) because it was more convenient, but they just refused and said, 'no, because it's closer to you, you have to go there' (to hospital 2). But it was difficult for us to get there and it's along country roads and things. They just really	• Low

Survey	Findings	Overall quality of the evidence
	refused. I would have liked them to have listened to me and let me stay at (hospital 1), not (hospital 2). But they said ‘no’. (F15)	

N/A: not applicable