National Institute for Health and Care Excellence

FINAL

Babies, children and young people's experience of healthcare

[P] Continuity of care

NICE guideline NG204

Evidence reviews underpinning recommendations 1.10.12 to 1.10.17 in the NICE guideline

August 2021

Final

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

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Review question

What factors promote, or present barriers to, continuity of care for babies, children and young people?

Introduction

Delivering continuity of care means providing healthcare that is as seamless as possible. It helps babies, children and young people receive care that is focused around their clinical needs, preferences and ideally that allows them to build a therapeutic relationship with their healthcare professionals This, in turn, can improve their overall healthcare experience. Continuity of care is important for all babies, children and young people but may be particularly important for those with ongoing medical conditions or complex needs, who may receive healthcare in a variety of settings and from a number of different healthcare professionals.

The aim of this review is to identify barriers which may hamper continuity, and identify the best ways to promote continuity of care.

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 o The baby or child of the parent or carer is under-5 years-old, or o There is a clear rationale provided as to why the study is using parents' or carers' views on and experiences of healthcare as proxies for their child.
Phenomenon of interest	Experience of healthcare, in particular continuity and co-ordination of healthcare
Primary outcome	Themes will be identified from the literature. The committee identified the following potential themes (however, not all of these themes may be found in the literature, and additional themes may be identified): • Building trusting relationships with healthcare professionals (e.g. with named professional) • Choice regarding who one sees (e.g. seeing the same healthcare staff) • Coordination of healthcare (e.g. scheduling appointments with different healthcare professionals or services on same day) • Distrust of healthcare services • Fear or stigma related to using services • Ease of referral or discharge (e.g. from primary to secondary care, or vice-versa) • Lack of knowledge about NHS structure and related pathways • Lack of communication between services (e.g. the health, education or social care services) • Need for single or universal healthcare records

	• 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) • Timely sharing of information between healthcare professionals or services • Use of electronic technology to ensure accurate and relevant communication/care (e.g. GP patient records for ambulance services)

NHS: National Health Service

For further details see the review protocol in appendix A.

Methods and process

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

Clinical evidence

Included studies

This was a qualitative review with the aim of:

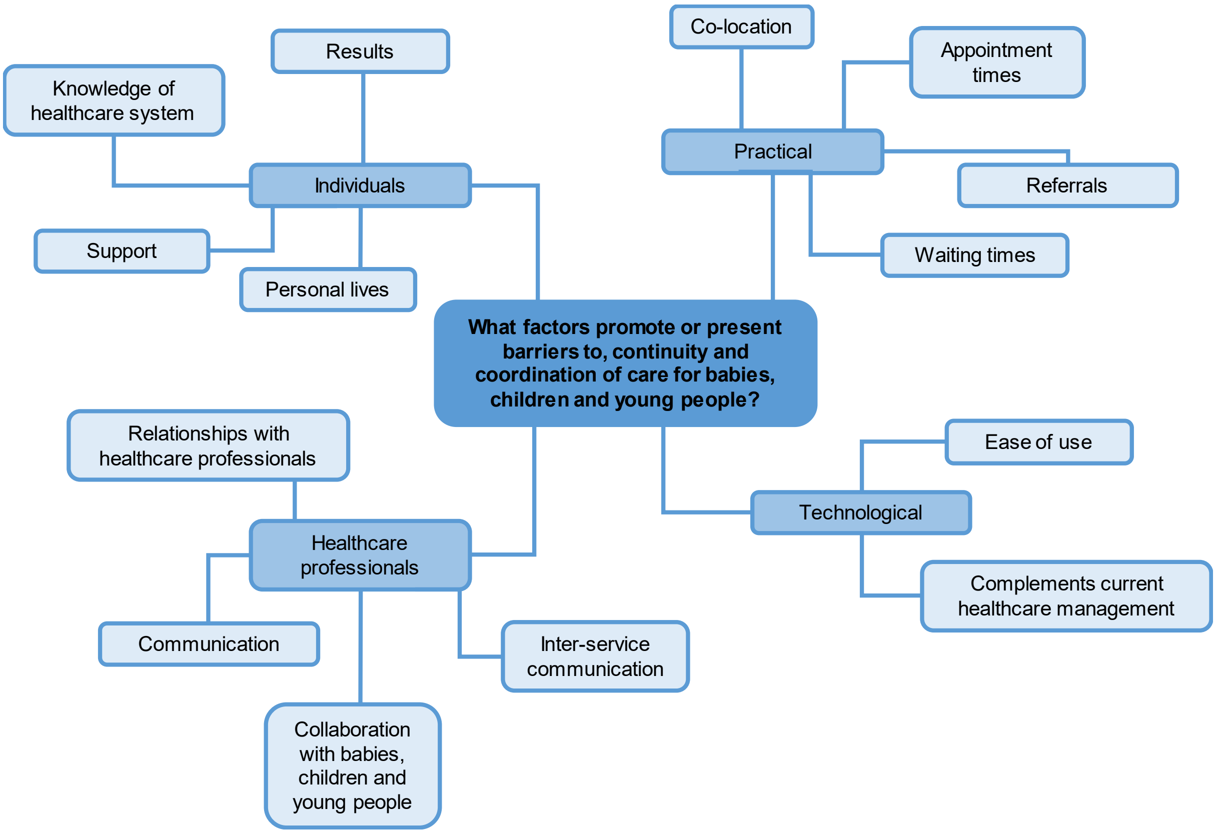
- Understanding how babies, children and young people prefer services to provide continuity and coordination of their healthcare.

A systematic review of the literature was conducted using a combined search. Eleven studies were included for this review: 4 studies used semi-structured interviews (Diwakar 2019, Harper 2014, Law 2020, Price 2011); 3 used participatory-based approaches combined with either semi-structured interviews (O'Reilly 2013, Whale 2017) or family case studies (Sime 2014); 1 used focus groups and semi-structured interviews (Waite-Jones 2018); 1 mixed-methods study included questionnaire and semi-structured interviews (Davison 2017) and 2 systematic reviews which included qualitative, quantitative and mixed-methods studies were included (Diffin 2019 and Robards 2018). With the exception of Diffin 2019 and Robards 2018, which included studies from the US, Australia, Canada, New Zealand, Italy and Portugal, the remaining 10 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

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

Table 2: Summary of included studies.

Study	Population	Methods	Themes
Davison 2017 **Study design** Mixed methods including questionnaire and semi-structured interview **Aim of the study** To explore young people's experience	N=34 young people • n=34 completed a questionnaire • n=17 completed an interview in addition to the questionnaire **Characteristics** Age (mean [SD]): 15 (0.93) years	**Recruitment** Purposive sampling from a secondary school within a multi-site Foundation Special School which teaches 11-16 year-olds referred from CAMHS **Data collection** CHI ESQ Questionnaire, which includes 3 open-ended questions, followed	• Healthcare professionals: Communication • Practical: Appointment time • Practical: Waiting times

Study	Population	Methods	Themes
of using local CAMHS North-East England, UK	Gender (M/F): 9/25	by semi-structured interviews with subset of participants **Analysis** Thematic analysis	
Diffin 2019 **Study design** Systematic review **Aim of the study** To identify factors that help or hinder use of personal care records by children and young people with a complex health condition Multiple countries	K=9 studies **Characteristics** Type of study (k): • Qualitative=3 • Quantitative=1 • Mixed methods=5 o This study incorporated all their results (qualitative and quantitative) into a narrative summary, which was then used in the findings of this review. Participants (k): • Children and young people=3 • Parents/caregivers=6 o The population of this review included young people up to 24 years old and parents, and views of people >18 years old and parents will have been included in the results. The 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	• Healthcare professionals: Collaboration with babies, children and young people • Healthcare professionals: Communication • Technological: Ease of use • Technological: Complements current healthcare management
Diwakar 2019 **Study design** Semi-structured interview **Aim of the study** To understand how parents of children with allergies experience paediatric pathway West Midlands, UK	N=18 parental proxies o Only the views of parents of children under the age of 5 years old are included in this review. **Characteristics** Age of child (years, n): • <1=3 • 1-5=9 • 5-10=1 • 10-15=4 • >15=1	**Recruitment** Purposive sampling by clinicians of parents of children attending 1 of 2 specialist paediatric allergy clinics **Data collection** Telephone or face-to-face semi-structured interviews as preferred by participants **Analysis** Thematic framework analysis	• Individuals: Support • Healthcare professionals: Inter-service communication • Practical: Appointment times • Practical: Referrals • Practical: Waiting times

Study	Population	Methods	Themes
	Gender of child: not reported		
Harper 2014 **Study design** Semi-structured interview **Aim of the study** To explore young people's experiences of 16-18 mental health services. North-West England, UK	N=10 young people **Characteristics** Age (years, n): • 16=1 • 17=5 • 18=4 Gender (M/F): 3/7	**Recruitment** Purposive sampling identified by key workers at 16-18 mental health services **Data collection** Semi-structured interviews **Analysis** Interpretative phenomenological analysis	• Healthcare professionals: Collaboration with babies, children and young people • Healthcare professionals: Relationships with healthcare professionals
Law 2020 **Study design** Semi-structured interviews **Aim of the study** To understand young people's concept of mental health recovery. East Anglia and Greater Manchester, UK	N=23 young people • n=15 <18 years old • n=8 >18 years old ○ Only the views of the young people under 18 years old are included in this review. **Characteristics** Age (years, n): • 14-17=15 • 18-21=5 • 22-25=3 Gender (M/F/non-binary): 4/18/1	**Recruitment** Convenience sampling of 2 regional mental health services. **Data collection** Semi-structured interviews **Analysis** Thematic analysis	• Individuals: Support • Healthcare professionals: Inter-service communication • Healthcare professionals: Relationships with healthcare professionals • Practical: Referrals
O'Reilly 2013 **Study design** Participatory-based activities and semi-structured interview **Aim of the study** To examine the views and experience of children and young people, and their parents, regarding multi-agency working between school and CAMHS	N= 2 families • n=11 children and young people • n=12 mothers • n=2 fathers ○ Only the views of children and young people are included in this review. **Characteristics** Age of child (years, n): • 8=3 • 9=2 • 10=2 • 11=2 • 12=2	**Recruitment** Families recruited from children attending 1 of 3 English CAMHS as part of a larger study into parent's and children's experience of CAMHS **Data collection** Semi-structured home-based interviews with or without other members of family, with those with children involving participatory art techniques (e.g. emoticons, drawing)	• Healthcare professionals: Inter-service communication • Healthcare professionals: Communication

Study	Population	Methods	Themes
England, UK	Gender of child (M/F): 9/2	**Analysis** Thematic analysis	
Price 2011 **Study design** Semi-structured interviews **Aim of study** To evaluate the experience of the diabetes 'Transition Pathway' by young people with Type 1 diabetes. North-West England, UK	N=11 young people • n=9 for 1 interview • n=2 for 2 interviews **Characteristics** Age (range): 16-18 years Gender: not reported.	**Recruitment** Healthcare professionals in each diabetes transition pathway team recruited participants by letter. **Data collection** Semi-structured interviews 3 months after initial clinic appointment. **Analysis** Thematic framework analysis	• Healthcare professionals: Relationships with healthcare professionals • Healthcare professionals: Collaboration with babies, children and young people
Robards 2018 **Study design** Systematic review **Aim of study** To examine how young people who are marginalized access and engage with health services and navigate health-care systems in high-income countries Multiple countries	**Sample size** K=68 studies Range of sample size: N=3 to 1388 **Characteristics** Type of study (k): • Qualitative=44 • Quantitative=16 • Mixed-methods=8 ○ This study incorporated all the results (qualitative and quantitative) into a narrative summary, which was then used in the findings of this review. Participants (k): • Young people=61 • Healthcare professionals=11 • Parents=7 ○ Although the study notes that their themes were identified by all the participants in their population (marginalised young people up to age 24 years old, parents and healthcare	**Recruitment** Not applicable **Data collection** Systematic literature search **Analysis** Data extraction, quality appraisal of studies, and thematic analysis	• Individuals: Knowledge of healthcare systems • Individuals: Support • Individuals: Personal lives • Healthcare professionals: Collaboration with babies, children and young people • Healthcare professionals: Relationships with healthcare professionals • Practical: Co-location

Study	Population	Methods	Themes
	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.		
Sime 2014 **Study design** Participatory-based focus group and family case study **Aim of the study** To examine the experience of recently-arrived Eastern European migrant children, and their parents, accessing healthcare services. Scotland, UK	N=86 children • n=57 focus groups • n=29 family case studies ○ Parents did participate in family case studies but only the views of children are included in this review. **Characteristics** *Focus groups* Age (range): 7-16 years Gender (M/F): 26/31 *Family case studies* Age (range): 8-16 years Gender (M/F): 14/15	**Recruitment** Service providers from a range of health, education and voluntary sectors in Scotland were used to contact potential Eastern European migrant families recently arrived **Data collection** Focus groups using images of health services and hands-on activities to stimulate children's contributions, followed by family case studies comprising at least 2 interviews activity and participant's diaries and/or photograph **Analysis** Thematic analysis	• Individuals: Knowledge of healthcare systems • Individual: Results • Healthcare professionals: Relationships with healthcare professionals • Practical: Waiting times
Waite-Jones 2018 **Study design** Focus groups and semi-structured interviews **Aim of the study** To explore the views of young people with juvenile arthritis (and their parents, carers and healthcare professionals) on essential features of a self-management mobile app. North England, UK	N=25 young people, parents and healthcare professionals • n=9 young people • n=8 parents/carers • n=8 healthcare professionals ○ Only the views of the young people are included in this review. **Characteristics** Age of young people (years, n): • 10=1 • 11=1 • 13=2 • 14=2 • 15=2 • 17=1	**Recruitment** Purposeful sampling of paediatric rheumatology clinic database. **Data collection** Semi-structured interviews using participatory approach, either with or without parents/carers. **Analysis** Thematic framework analysis	• Healthcare professionals: Communication • Technological: Ease of use

Study	Population	Methods	Themes
	Gender of young people (M/F): 2/7		
Whale 2017 **Study design** Participatory-based semi-structured interview **Aim of the study** To explore young people's experience of continence care England and Scotland, UK	N=20 children and young people **Characteristics** Age (years, n): • 11-13=9 • 14-16=8 • 17-19=3 Gender (M/F): 11/9	**Recruitment** Clinicians recruited participants at 1 of 5 paediatric continence clinics and through advertising on paediatric continence website **Data collection** Online or telephone semi-structured interviews as preferred by participant using topic guide and arts-based activity packs **Analysis** Inductive thematic analysis	• Individual: Results

CAMHS: Child and Adolescent Mental Health Service; F: Female; M: Male; N: Number; SD: Standard deviation

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: Individuals

- Sub-theme 1.1: Knowledge of healthcare system. The overall confidence in this sub-theme was judged to be high.
- Sub-theme 1.2: Support. The overall confidence in this sub-theme was judged to be high.
- Sub-theme 1.3: Personal lives. The overall confidence in this sub-theme was judged to be moderate.
- Sub-theme 1.4: Results. The overall confidence in this sub-theme was judged to be very low.

Main theme 2: Healthcare professionals

- Sub-theme 2.1: Inter-service communication. The overall confidence in this sub-theme was judged to be moderate.
- Sub-theme 2.2: Collaboration with babies, children and young people. The overall confidence in this sub-theme was judged to be moderate.
- Sub-theme 2.3: Communication. The overall confidence in this sub-theme was judged to be moderate.
- Sub-theme 2.4: Relationships with healthcare professionals. The overall confidence in this sub-theme was judged to be high.

Main theme 3: Practical

- Sub-theme 3.1: Co-location. The overall confidence in this sub-theme was judged to be very low.
- Sub-theme 3.2: Appointment times. The overall confidence in this sub-theme was judged to be very low.
- Sub-theme 3.3: Referrals. The overall confidence in this sub-theme was judged to be very low.
- Sub-theme 3.4: Waiting times. The overall confidence in this sub-theme was judged to be moderate.

Main theme 4: Technological

- Sub-theme 4.1: Ease of use. The overall confidence in this sub-theme was judged to be very low.
- Sub-theme 4.2: Complements current healthcare management. The overall confidence in this sub-theme was judged to be very low.

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

Evidence from reference groups and focus groups

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

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

Age groups	• <7 years • 7-11 years • 11-14 years
Areas covered	• Continuity of care
Illustrative quotes	• 'I want to see the same doctor every time because if there was a new doctor they might be not nice. Makes you less nervous and scared' • 'Don't lose details for an appointment – avoid repetition' • 'Need to know they are going to help you every time - what if they don't respect me?' • 'If I did see a doctor and they were rude to me I wouldn't want to see them again. If I saw a different doctor every time but they were kind to me, I would be fine to see a different one every time'

See the full evidence summary in appendix M.

Evidence from national surveys

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

Table 4: Summary of the evidence from national surveys

National surveys	• Care Quality Commission. Children and young people's inpatient and day case survey 2018 • National Children's Bureau. Listening to children's views on health provision 2012 • Opinion Matters. Declare your care survey 2018

	• Picker Institute. Children and Young People's Patient Experience Survey 2018 • Picker Institute. Paediatric Emergency Department Survey 2015 and Children and Young People's Outpatient Survey 2015 • Picker Institute/NHS England/Bliss. Neonatal Survey 2014
Areas covered	• Knowledge of medical history • Discharge from hospital • Continuity for care leavers • Admission/ discharge/ transfer
Key findings	• More than half of parents and carers of children and young people confirmed that staff were aware of their child's medical history • Parents and carers of babies in the neonatal unit confirmed that important information was passed from one member of staff to another, although some mentioned that staff had gave them conflicting information about their baby's condition or care • Most children, young people and parents and carers of babies confirmed that they were satisfied with the information provided at discharge. • Some young people with disabilities recommended that, at discharge, they should be provided with a care package with relevant information about impact of their condition in their day to day life

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 views of children and young people in relation to barriers that prevent good continuity of care and how these barriers can be overcome. 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:

- Building trusting relationships with healthcare professionals (e.g. with named professional)
- Choice regarding who one sees (e.g. seeing the same healthcare staff)
- Coordination of healthcare (e.g. scheduling appointments with different healthcare professionals or services on same day)
- Distrust of healthcare services
- Fear or stigma related to using services
- Ease of referral or discharge (e.g. from primary to secondary care, or vice-versa)
- Lack of knowledge about NHS structure and related pathways
- Lack of communication between services (e.g. the health, education or social care services)
- Need for single or universal healthcare records

The evidence review provided data relating to most of these themes, and related to practical issues, such as the time taken to get appointments or when they were scheduled, technology, individual factors (for example having knowledge about the healthcare system), and factors which relate to the healthcare professionals, including communication between healthcare staff and communication between healthcare staff and the children, young people, parents or carers. Additional themes which emerged from the data related to the personal lives of children and young people, and waiting times.

The quality of the evidence

The evidence was assessed using GRADE-CERQual methodology, and the overall confidence in the findings ranged from very low to high. The 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, poor reporting of how interviews were conducted and lack of reflexivity in data analysis. 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. The evidence was also downgraded due to relevance, where some themes used evidence from the included systematic reviews (Diffin 2019 and Robards 2018), both of which included young people up to the age of 24 years as well as the views of parents and healthcare professionals.

There was evidence available for all ages of babies, children and young people.

Benefits and harms

The evidence from the sub-theme of relationships with healthcare professionals showed that it was important for children and young people to build a trusting relationship with their healthcare professional, and therefore the committee discussed that seeing the same healthcare professional every time would help with continuity of care. The evidence showed that children and young people who had experienced good continuity of care (and good communication) reported improved engagement and they were more inclined to go back and continue their care if they could see the same person. The committee were not confident that continuous contact with the same health care professional was always possible in reality, and it may be important to discuss the role of a “healthcare team” to ensure trust is developed and continuity of care encouraged.

The evidence also showed that children and young people did not want to have to repeat their healthcare story many times to multiple people, and again the committee agreed that this could be facilitated by seeing the same healthcare professional every time. If that was not possible, then it would be preferable if they could be seen by a member of the same healthcare team who had access to up to date information about the last contact. The committee also discussed, based on their knowledge and experience, that there were other ways to ensure that children and young people did not have to repeat information. These included ‘health passports’ that parents, children and young people could carry with them, or by using digital health records that could be accessed by all healthcare professionals involved in their care. The committee made a recommendation about access to health records as an important tool which could improve continuity of care. There was evidence that children and young people wanted to be able to update their electronic records in between regular appointments so healthcare professionals could stay up to date with their progress, although the committee were aware that many health records systems may not currently allow this, so they did not include this in a recommendation. There was also evidence from the theme on technology that children and young people would monitor their own symptoms if given an electronic method to do this, and that they liked electronic ways of keeping in touch with their healthcare professionals (for example, via messages created from health record apps), but only as a supplement to personal contact. The committee agreed that as these apps may not be widely available they were unable to include this in a specific recommendation.

There was evidence that children and young people who had positive outcomes (for example, a medication working) were more likely to continue to engage in their care, and that unsuccessful treatments (for example, a medication not having the results they had expected) was likely to lead to them disconnecting from the treatment programme altogether. However, the committee did not make a specific recommendation on this as this was based on individual’s clinical situation.

The committee discussed, based on their experience, that robust communication between healthcare professionals should always be in place so that the children, young people, and the parents or carers of babies and young children receive continuity of care. The evidence also showed that good communication was important across different teams and services. The committee agreed that this was particularly important at key points in care such as when a baby, child or young person moves from primary to secondary care, is discharged from hospital, or is transferred from one healthcare setting to another, and they want to be assured that the new team has been fully informed. As well as communication between healthcare professionals, there was evidence that healthcare professionals needed to work collaboratively with children and young people, listen to their concerns and take them seriously. The committee agreed that this meant keeping the children and young people and the parents or carers of babies and young children fully informed. The committee also discussed the fact that, based on their experience, communication should not just be with other healthcare professionals, but that communication to ensure continuity of care may need to include social services and education services.

There was some evidence on the barriers to continuity of healthcare. This included some practical issues such as long waiting times for treatment, or difficulty in getting referrals, which could lead to fragmented care as people may seek other ways of obtaining healthcare (for example by using a different provider or doctor). There was also evidence that factors that contribute towards reduced engagement in an ongoing programme of care include chaotic personal or family lives, lack of family support, feeling discriminated against, and healthcare professionals not using inclusive language or being culturally aware. The committee agreed that the recommendations they had made under the topic on communication by healthcare professionals and information provision already provided guidance on this and so did not make separate recommendations.

There was some evidence that co-location of services may improve access to care, especially for hard-to-reach groups (for example, those who are homeless, live in remote areas, are refugees), and that other practical issues such as not scheduling appointments in school time could help with continuity of care. There was some evidence about knowing how the healthcare system works, knowing what services were available, and needing ongoing support from parents or help from teachers, healthcare professionals or youth workers to navigate the system, but the committee thought this was more relevant to their recommendations on access to care and therefore used it to support their discussion for that topic.

In addition to the systematic review evidence there was evidence from the reference groups and focus groups on continuity of care. This reinforced the evidence from the systematic review with children and young people preferring to see the same people every time, and saying that a kind and caring approach would encourage them to return in the future. There was also feedback that children and young people wanted to avoid repeating their healthcare story by better transfer of information, and also about not repeating healthcare interventions (for example blood tests) due to lack of coordination between healthcare professionals or services.

The evidence from the national surveys also backed up the systematic review evidence. Approximately a third of children and young people, and parents or carers of babies and young children, raised concerns over information provision on discharge from hospital, for example how to look after themselves at home, who to contact if there was a problem, or what would happen to them next, and this affected continuity of care. Similarly, in a cohort of young people who had raised a concern or made a complaint, a third of these related to admission, discharge, transfer, or lack of communication between services. Young people with disabilities and care leavers reported that they needed special consideration on discharge or on leaving care to ensure continuity of their healthcare provision, and the committee agreed that this may apply to children with complex medical conditions as well.

For the parents of babies on a neonatal unit there was mixed evidence: communication of information between members of staff was reported as good, although some parents reported that conflicting information was given to parents. Parents reported a good discharge process with positive views on preparation for discharge, but lower scores for information on what to expect in terms of their baby’s recovery and progress. The committee agreed that this evidence reinforced the importance of their recommendations on ensuring adequate communication at key points in care, such as on discharge.

The only potential harm the committee identified from the evidence or from their recommendations on continuity of care, was that over-reliance on digital tools (such as digital health records or passports) may disadvantage children and young people who do not have access to digital technology, and in these cases an alternative would have to be available.

Cost effectiveness and resource use

There was no existing economic evidence for this review. The committee explained that implementing more integrated and ideally digital systems to share information with and between healthcare professionals, other services and children and young people or the parents and carers of babies and young children may have resource implications for the health service. Also, there may be a need for improved administration support to facilitate the sharing of information which may also have resource implications. The committee noted potential benefits that include the improved experience of care and outcomes. For example, timely information being available to professionals may reduce delays in care etc. More efficient coordination of care may potentially have an impact on service use outcomes including frequency of primary and secondary care visits with less duplication of work. Overall the committee was of a view that practices implied by the recommendations in this area would represent a more efficient running of services and would represent a value for money to the health service.

Recommendations supported by this evidence review

This evidence review supports recommendations 1.10.12 to 1.10.17 in the NICE guideline.

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Appendices

Appendix A – Review protocol

Review protocol for review question: What factors promote, or present barriers to, continuity of care for babies, children and young people?

Table 5: Review protocol

Field	Content
PROSPERO registration number	CRD42019145566
Review title	Continuity of care
Review question	8.2 What factors promote, or present barriers to, continuity of care for babies, children and young people?
Objective	To determine the factors which promote or present barriers to continuity of healthcare for 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 risk of bias • Standard exclusions filter (animal studies/low level publication types) will be applied • For each search (including economic searches), the principal database search strategy is quality assured by a second information specialist using an adaption of the PRESS 2015 Guideline Evidence-Based Checklist
Condition or domain being studied	• Babies, children and young people’s experience of healthcare
Population	• People <18 years-old who have experience of healthcare Studies that use the 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 involving continuity and coordination of care. 'Continuity of care' will be defined either as having a continuous or sustained caring relationship with a healthcare professional (‘relationship continuity’) or there being continuity of healthcare management (‘management continuity’). Management continuity includes producing and sharing information (e.g. GP knowing about hospital results), care planning, and coordination of care. ‘Coordination of care’ includes referral to specialist services (e.g. secondary or tertiary care), transport between healthcare settings (e.g. from school to hospital). Note: Views on, and experiences of, accessing specific healthcare services will not be included in this review.
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	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. • Child abuse and maltreatment: o Child abuse and neglect (NG76) o Child maltreatment: when to suspect maltreatment in under 18s (CG89) • Community engagement (NG44) • Drug misuse in children and young people: o Alcohol: school-based interventions (PH7) o Alcohol-use disorders: diagnosis, assessment and management of harmful drinking and alcohol dependence (CG115) o Alcohol-use disorders: prevention (PH24) o Drug misuse prevention: targeted interventions (NG64) • End of life care for infants, children and young people with life-limiting conditions: planning and management (NG61) • Immunisations: reducing differences in uptake in under 19s (PH21) • Oral health promotion: general dental practice (NG30) • Physical activity and weight management: o Maternal and child nutrition (PH11) o Obesity prevention (CG43) o Physical activity for children and young people (PH17) o Weight management: lifestyle services for overweight or obese children and young people (PH47) • Pregnancy, including routine antenatal, intrapartum or postnatal care: o Antenatal and postnatal mental health: clinical management and service guidance (CG192) o Antenatal care for uncomplicated pregnancies (CG62) o Intrapartum care for healthy women and babies (CG190) o Intrapartum care for women with existing medical conditions or obstetric complications and their babies (NG121) o Multiple pregnancy: antenatal care for twin and triplet pregnancies (CG129) o Postnatal care up to 8 weeks after birth (CG37) o Pregnancy and complex social factors: a model for service provision for pregnant women with complex social factors (CG110) • Self-harm: o Self-harm in over 8s: long-term management (CG133) o Self-harm in over 8s: short-term management and prevention of recurrence (CG16)

Field	Content
	• Sexual health and contraception o Contraceptive services for under 25s (PH51) o Sexually transmitted infections and under-18 conceptions: prevention (PH3) o Harmful sexual behaviour among children and young people (NG55) • Smoking prevention: o Smoking: preventing uptake in children and young people (PH14) o Smoking prevention in schools (PH23) o Stop smoking interventions and services (NG92) • Transition from children's to adults services for young people using health or social care services (NG43)
Context	Studies should ideally be conducted in the UK and be on the views on and experiences of babies, children or young people of healthcare. 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. Systematic reviews on the views on and experiences of babies, children or young people of healthcare in other high-income countries (as defined by the World Bank) will be included but will, in consultation with the committee, be assessed for their applicability to the UK context using the GRADE-CERQual domain of relevance. Recommendations will apply to those receiving care in all settings where NHS- or local authority commissioned healthcare is provided (including home, school, community, hospital, specialist and transport settings). Specific recommendations for groups listed in the Equality Considerations section of the scope may be also be made as appropriate.
Primary outcomes (critical outcomes)	Themes will be identified from the literature. The committee identified the following potential themes (however, not all of these themes may be found in the literature, and additional themes may be identified): • Building trusting relationships with healthcare professionals (e.g. with named professional) • Choice regarding who one sees (e.g. seeing the same healthcare staff) • Coordination of healthcare (e.g. scheduling appointments with different healthcare professionals or services on same day) • Distrust of healthcare services • Fear or stigma related to using services • Ease of referral or discharge (e.g. from primary to secondary care, or vice-versa) • Lack of knowledge about NHS structure and related pathways • Lack of communication between services (e.g. the health, education or social care services) • Need for single or universal healthcare records • 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) • Timely sharing of information between healthcare professionals or services

Field	Content
	• Use of electronic technology to ensure accurate and relevant communication/care (e.g. GP patient records for ambulance services) The following topics relating to factors that promote continuity and coordination of care will not be covered by this review: • Architectural, physical and design features of the environment (reviewed in RQ6.1) • Barriers to, and facilitators of, accessing specific healthcare services (reviewed in RQ 8.1) • Care and coordination of educational or social activities outside the healthcare environment (remit of social care and education). • Communication between children and young people and staff (reviewed in RQ 1.2)
Secondary outcomes (important outcomes)	Not applicable
Data extraction (selection and coding)	• All references identified by the searches and from other sources will be uploaded into STAR and de-duplicated. Titles and abstracts of the retrieved citations will be screened to identify studies that potentially meet the inclusion criteria outlined in the review protocol. • Duplicate screening will not be undertaken for this question. • Full versions of the selected studies will be obtained for assessment. Studies that fail to meet the inclusion criteria once the full version has been checked will be excluded at this stage. Each study excluded after checking the full version will be listed, along with the reason for its exclusion. A standardised form will be used to extract data from studies, including study reference, research question, theoretical approach, data collection and analysis methods used, participant characteristics, second-order themes, and relevant first-order themes (i.e. supporting quotes). One reviewer will extract relevant data into a standardised form, and this will be quality assessed by a senior reviewer.
Risk of bias (quality) assessment	Risk of bias of individual qualitative studies will be assessed using the CASP Qualitative checklist. Risk of bias of systematic reviews of qualitative studies will be assessed using the CASP (Critical Skills Appraisal Programme) Systematic Review checklist. See Appendix H in Developing NICE guidelines: the manual for further details. The quality assessment will be performed by one reviewer and this will be quality assessed by a senior reviewer.
Strategy for data synthesis	• Extracted second-order study themes and related first-order quotes will be synthesised by the reviewer into third-order themes and related sub-themes. • The GRADE-CERQual (Confidence in the Evidence from Reviews of Qualitative research; Lewin 2015) approach will be used to summarise the confidence in the third-order themes or sub-themes synthesised 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

Field	Content		
	appropriate. Coherence of findings will be assessed by examining the clarity of the data. Adequacy of data will be assessed by looking at the degree of richness and quantity of findings. Relevance of evidence will be assessed by determining the extent to which the body of evidence from the primary studies are applicable to the context of the review question with respect to the characteristics of the study population, setting, place and time, healthcare system, intervention, and broader social, policy, or political issues.		
Analysis of sub-groups	If there is sufficient data, views and experiences will be analysed separately by the following age ranges: • <1 year-old (i.e. 364 days-old or less) • ≥1 to <12 years-old (i.e. 365 days-old to 11 years and 364 days-old • ≥12 to <18 years-old (i.e. 12 years and 0 days-old to 17 years and 364 days-old) The committee are aware that children can experience substantial cognitive and developmental change during the ages of 1 and 12, and that there may be (though not necessarily) substantive differences between children in this group depending on the topic about which they are being asked. The committee will therefore be consulted regarding whether data regarding further subgroups within this age range (e.g. 1-5, 6-11) should be used. Subgroup analysis according to any of the groups listed in the Equality Considerations section of the scope will be conducted if there is sufficient data.		
Type and method of review	☐	Intervention	
	☐	Diagnostic	
	☐	Prognostic	
	☒	Qualitative	
	☐	Epidemiologic	
	☐	Service Delivery	
	☐	Other (please specify)	
Language	English		
Country	England		
Anticipated or actual start date	13 January 2020		
Anticipated completion date	07 April 2021		
Stage of review at time of this submission	Review stage	Started	Completed
	Preliminary searches		☑
	Piloting of the study selection process		☑

Field	Content		
	Formal screening of search results against eligibility criteria		☑
	Data extraction		☑
	Risk of bias (quality) assessment		☑
	Data analysis		☑
Named contact	**5a. Named contact** National Guideline Alliance **5b. Named contact e-mail** Infant&younghealth@nice.org.uk **5c. Organisational affiliation of the review** National Institute for Health and Care Excellence (NICE) and National Guideline Alliance		
Review team members	National Guideline Alliance Technical Team		
Funding sources/sponsor	This systematic review is being completed by the National Guideline Alliance, which receives funding from NICE.		
Conflicts of interest	All guideline committee members and anyone who has direct input into NICE guidelines (including the evidence review team and expert witnesses) must declare any potential conflicts of interest in line with NICE's code of practice for declaring and dealing with conflicts of interest. Any relevant interests, or changes to interests, will also be declared publicly at the start of each guideline committee meeting. Before each meeting, any potential conflicts of interest will be considered by the guideline committee Chair and a senior member of the development team. Any decisions to exclude a person from all or part of a meeting will be documented. Any changes to a member's declaration of interests will be recorded in the minutes of the meeting. Declarations of interests will be published with the final guideline.		
Collaborators	Development of this systematic review will be overseen by an advisory committee who will use the review to inform the development of evidence-based recommendations in line with section 3 of Developing NICE guidelines: the manual. Members of the guideline committee are available on the NICE website: https://www.nice.org.uk/guidance/indevelopment/gid-ng10119/documents		
Other registration details	-		
Reference/URL for published protocol	https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42019145566		
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		

Field	Content	
	• 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	Babies; children; continuity; coordination; experience; healthcare; infants; 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
	☐	Completed, published and being updated
	☐	Discontinued
Additional information		
Details of final publication	www.nice.org.uk	

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

Appendix B – Literature search strategies

Literature search strategies for review question: What factors promote, or present barriers to, continuity of care 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
14	(hospital patient/ or hospitalized adolescent/ or hospitalized child/ or hospitalized infant/ or hospitalization/ or hospital patient/ or outpatient/) use emez

#	Searches
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
46	Qualitative Research/
47	exp interview/ use emez

#	Searches
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 "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

#	Searches
	"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
112	102 not 111
113	animals/ not humans/ use ppez
114	animal/ not human/ use emez
115	nonhuman/ use emez

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

Database: Cochrane Library

Date searched: 29/07/2020

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

#	Search
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
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

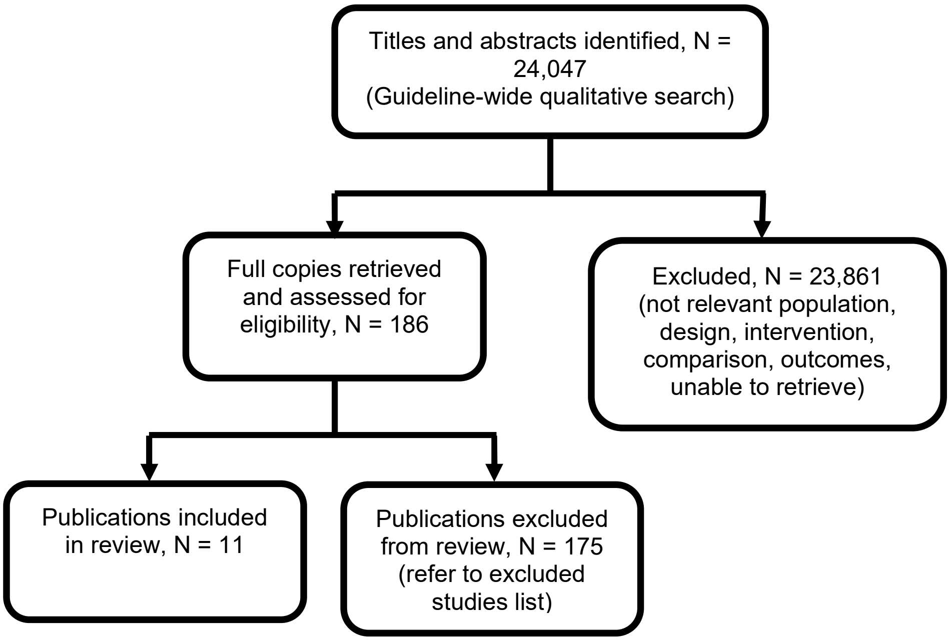
#	Search
83	MeSH descriptor: [Focus Groups] this term only
84	MeSH descriptor: [Professional-Patient Relations] explode all trees
85	(attitude* or choice* or dissatisf* or expectation* or experienc* or inform* or opinion* or perceive* or perception* or perspective* or preferen* or priorit* or satisf* 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
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

#	Search
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
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 factors promote, or present barriers to, continuity of care for babies, children and young people?

Figure 2: Study selection flow chart



Appendix D – Clinical evidence tables

Evidence tables for review question: What factors promote, or present barriers to, continuity of care for babies, children and young people?

Table 6: Evidence tables

Study details	Participants	Methods	Themes and findings	Limitations
Full citation 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 **Ref Id** 1054883 **Country/ies where the study was carried out** North-East England, UK **Study type** Mixed-methods study **Aim of the study** To explore the experiences of a group	**Sample size** N=34 young people • n=34 completed questionnaire • n=17 completed semi-structured interview **Characteristics** Age [Mean (SD)]: 15 (0.93) years Gender (M/F): • Questionnaire: 9/25 • Semi-structured interviews: 6/11 **Inclusion criteria** Participants had to: • Be aged 12-18 years old • Currently attending the study school • Current or prior experience of CAMHS • Able to consent	**Setting** Secondary school in North-East England **Sample selection** Purposive sampling from a secondary school which teaches 11-16 year olds referred from CAMHS. Students have a history of school refusal because of poor attendance at mainstream schools, particularly during transition from primary to secondary education. **Data collection** 3 free-text questions were included in the in the CHI-ESQ. A subset of participants undertook 10-25 minute individual semi-structured interviews, conducted on-site at the study school. The interview guide was designed using a selective literature search and available study	**Author's themes:** • Access and continuity **Findings** Young people discussed the need for quick access and frequent contact when developing a good relationship with CAMHS. 8 (out of 17) participants reported waiting long periods either for an appointment or to hear back from the service. Another participant described how their friend was able to receive a quick appointment only after a suicide attempt.	**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. Mixed-methods design used to answer the dual research aims of this study - exploring the experiences of vulnerable patients accessing CAMHS and to measure the acceptability of a routine service measurement (CHI-ESQ). *Q4: Was the recruitment strategy appropriate to the aims of the research?* Can't tell. Purposive sampling used to ensure recruitment of vulnerable young people. However, study school is a very specific population (multi-site Foundation Special School in

Study details	Participants	Methods	Themes and findings	Limitations
of vulnerable young people using CAMHS in North-East England in order to produce guidance for services wanting to improve user experience. A secondary aim was to validate a new experience measure (Commission for Health Improvement Experience of Service Questionnaire [CHI-ESQ]) for future use in this population. **Study dates** Not reported. **Source of funding** This study was conducted by the Child Outcome Research Consortium and received no external funding.	**Exclusion criteria** Not reported.	data from previous CHI-ESQ answers. The interview schedule explores what young people value in their CAMHS care, and the service in general. The questions were piloted with a sample of 2 young people to ensure relevance and ease of understanding. This resulted in only minor amendments to question wording, and so data was included in the final sample. **Data analysis** Thematic analysis. Interviews were digitally recorded and transcribed verbatim before transcripts were re-read, highlighting key concepts and quotations to form initial descriptive codes. Data with similar codes were collated together into themes and sub-themes. Themes were independently reviewed by another researcher and differences were solved through consensus, before finalising themes.		North-East England providing education for adolescents referred from CAMHS). There is a statement saying there is no difference between responders and non-responders but unsure whether this is referring to students who did not want to be tested or those who did not wish to be interviewed. *Q5: Were the data collected in a way that addressed the research issue?* Yes. Data collected via semi-structured interviews. Topic guide developed using previous literature and available CHI-ESQ data, reported in the article and was piloted with 2 initial participants. The guide was applied flexibly to allow participants to introduce novel views and experiences. However, no mention of data saturation. *Q6: Has the relationship between researcher and participants been adequately considered?* Can't tell. Mentions that some of the longer interviews showed much more negative comments, but that this appears to be also due to participant's anxiety in not being able to communicate their views. No further discussion surrounding potential influence from researcher and participants.

Study details	Participants	Methods	Themes and findings	Limitations
				Q7: Have ethical issues been taken into consideration? Yes. Study received ethical approval from Durham University and the study school. Informed consent obtained from students before interviews. *Q8: Was the data analysis sufficiently rigorous?* Can't tell Very brief description of analysis process and how themes very developed from transcripts. No explanation of how raw data presented was selected from the original sample although adequate data is presented for each theme. Contradictory data not presented. 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. No independent coding. *Q9: Is there a clear statement of findings?* No. Qualitative findings are very poorly explained with little discussion surrounding themes. Brief discussion surrounding credibility of findings. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2.*

Study details	Participants	Methods	Themes and findings	Limitations
				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. Unsure. Lack of demographic data provided combined with the specific population participants were sampled from limits transferability. *Overall judgement of quality:* Moderate concerns. **Other information** None.
Full citation 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 **Ref Id**	**Sample size** K=9 studies **Characteristics** Type of study (k): • Qualitative=3 • Quantitative=1 • Mixed-methods=5 ○ This study incorporated all their results (qualitative and quantitative) into a narrative summary, which was then used in the findings of this review.	**Setting** Not reported. **Methodological details** A systematic literature search of 6 online databases (Medline, Embase, CINAHL, PyscInfo, Cochrane Library, Science Direct) for qualitative, quantitative and mixed-methods studies (published between 1948 and Aug 2018) identified 785 articles. Hand searching of reference lists and a grey literature search identified 4 more articles. 2 reviewers screened all titles and abstracts and read full text of 36 studies. Of these,	**Author's themes:** • Factors that may help or hinder implementations of the PHR: Characteristics of the intervention • Factors that may help or hinder implementations of the PHR: Individual characteristics • Factors that may help or hinder implementations of the PHR: CMO configurations **Findings** Decreasing communication barriers between children and young people and healthcare professionals helps to increase access to credible information and enable collaboration in	**Limitations (assessed using the CASP checklist for systematic reviews).** *Q1: Did the review address a clearly focused question?* Yes. *Q2: Did the authors look for the right type of papers?* Yes. *Q3: Do you think all the important, relevant studies were included?* Yes. A wide variety of online databases were used. Reference lists of included studies were checked for relevant studies and a search of the grey literature was conducted. Restriction to English-language

Study details	Participants	Methods	Themes and findings	Limitations
1055067 **Country/ies where the study was carried out** Multiple countries **Study type** Systematic review **Aim of the study** To explore the current literature and determine the theories behind, mechanisms involved and outcomes of personal health records (PHRs) in babies, children and young people living with a complex medical condition. **Study dates** Search dates: 1946-Aug 2018 **Source of funding** This study received support from Marie Stopes Foundation.	Health condition (k): • Chronic conditions=4 • Intellectual disability=1 • Depressive symptoms=1 • Complex health and palliative needs=1 • Rehabilitation=1 • Autistic Spectrum Disorder=1 Respondents (k): • Children and young people=3 • Parents/caregivers=6 ○ The population of this review included young people up to 24 years old and parents, and views of people > 18 years old and parents will have been included in their results. Our findings have been downgraded for relevance where applicable. **Inclusion criteria** Studies had to: • Evaluate the use of PHRs • Include participants aged 0-24 years old	27 articles were excluded, and 9 articles included for the final review. **Data analysis details** Data was extracted into a previously developed standardised data extraction tool. 3 reviewers independently assessed each article and identified common components before discussing their findings to agree on a final facilitators and barriers to using a PHR. No further details reported. **Quality appraisal of included studies** CASP checklist	disease management. By gaining increased knowledge regarding their condition, children and young people are empowered to ask more questions. Electronic PHRs help children and young people to feel more in control of their condition, promoting partnership in care and facilitating communication outside of regular scheduled appointments (e.g. by healthcare professionals updating information on PHRs). Children and young people preferred paper versions of PHRs when communicating about sensitive issues. They also helped children and young people to be more confident in initiating conversation with healthcare staff. Technology can be both a facilitator and barrier when using PHRs. Electronic PHRs were more acceptable to both children and families if they already were comfortable with the use of technology. When a paper PHR was replaced in paediatric diabetic patients, there was a shift in the responsibility of monitoring symptoms. As parents were less familiar with technology, they increasingly delegated monitoring to their children. Electronic PHRS have to be able to fit in and enhance current practice to be acceptable to patients. For example, children and young people who already	articles. No mention of personal contact with experts. *Q4: Did the review's authors do enough to assess quality of the included studies?* Can't tell. Quality appraisal of studies was done using relevant CASP checklists. Brief written explanation of quality assessment provided along with the results in Table 2. However, no further discussion throughout the paper and no mention of how the rigour was used within the review process. *Q5: If the results of the review have been combined, was it reasonable to do so?* Yes. There is a clear description of inclusion and exclusion criteria and results of all included studies are clearly presented. 2 researchers were involved in synthesis of the data, increasing reliability. However, there is a lack of explanation surrounding the techniques used for data synthesis of qualitative, quantitative and mixed-method studies. *Q6: What are the overall results of the review?* Table presenting the characteristics of included studies is very informative, including details on country, aim of study, study design,

Study details	Participants	Methods	Themes and findings	Limitations
	with any medical condition - Including participants attending children's health services or already transferred to adult health services PHRs could be used by children and young people, or their parents/carers. **Exclusion criteria** - Paper only described the development of PHRs rather than evaluation of them - Articles not in English - Studies on PHRs used for immunisation records - PHRs use in patients over 24 year olds.		have many opportunities to see their healthcare providers were less concerned with communication features of PHRs such as web messaging. The motivation to use PHRs is determined by the perceived need of children, young people and their families to engage with healthcare services. Examples include patients with chronic conditions needing continuing care, those with undiagnosed conditions, children seeing multiple healthcare staff or taking multiple medications, and those with uncontrolled symptoms. Existing engagement with treatment also factored into whether children and young people utilise PHRs. This could be positive, for example higher PHR use was found in children with increased engagement in treatment. Conversely, use of PHRs was perceived to not bring any additional benefits in parents who were already very engaged in their children's care which limited usage. The level of PHR integration with current treatment regimens also impacted engagement with PHRs. Parents and children and young people already using paper PHRs to track symptoms were more accepting of an electronic PHR	methodological rigour and key findings. Would have liked to see the individual PHRs and the target population more clearly. Good description of theories of how PHRs can be used successfully particularly factors that affect the effectiveness of PHRs. The aim of the review was to explore the theories that underpin PHRs, which is evident in the discussion. However, the paper states that most articles didn't focus on this aspect but rather on the views of parents and children using them (much more applicable to our population). *Q7: How precise are the results?* Not applicable. *Q8: Can the results be applied to the local population?* Yes. Children and young people seeking to increase continuity of care for their healthcare conditions. 2 of the 9 studies were UK-based. *Q9: Were all important outcomes considered?* Not applicable. Themes are driven by data. *Q10. Are the benefits worth the harms and costs?* Not applicable. Literature review.

Study details	Participants	Methods	Themes and findings	Limitations
			with a symptom tracker function. Children and young people who were wanting increased autonomy over condition management and to rely less on healthcare professionals were more engaged with PHRs. Coping styles of parents also affected engagement with PHRs - those with avoidance styles engaged less with PHRs but those with approach-orientated coping methods tended to use PHRs more. Parents who were sceptical about whether healthcare professionals would listen to them or have resources to improve current care, as well as parents who were not clear on PHRs purpose, were less likely to use PHRs. Efficient implementation of PHRs to assist children and young people in managing their health involves 2 stage. The first stage involves training of children and young people, along with their families and healthcare professionals. Training should focus on the purpose of PHRs, how to use it, confidentiality and privacy, and potential benefits. By ensuring they have the necessary skills and expectations, children will be motivated to use PHRs and promote their use. The second stage includes using PHR	*Overall judgement of quality:* Minor concerns. **Other information** None.

Study details	Participants	Methods	Themes and findings	Limitations
			with desirable characteristics. The PHR should be easy to use, both complementing and enhancing current condition management. By enabling collaboration in healthcare, the PHR will encourage children and young people to think about their care options, provide access to correct and current information (both in the larger sense of their diagnosis and in the personal sense of their current health status), and provide a channel of communication with healthcare staff outside of normal scheduled appointments. Using PHRs can improve the knowledge and understanding of their condition for children and young people, which can lead to improved self-advocacy skills and active engagement with healthcare services. By increasing the likelihood of asking questions to healthcare staff and initiating conversations about their care, shared-decision making is more effective and likely, and there is an improvement in long-term health outcomes. Barriers to this implementation include: a lack of organisation support in engaging with PHRs including lack of training; unclear data protection procedures; and a lack of desire for autonomy from children and young people themselves. Facilitators to implementation	

Study details	Participants	Methods	Themes and findings	Limitations
			include: organisation support including a designated individual responsible for PHR engagement; implementing a PHR specifically designed to meet the needs of a specific population; and implementing a PHR that complements and/or enhances current condition management.	
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, 04, 04, 2019 **Ref Id** 988400 **Country/ies where the study was carried out** West Midlands, UK **Study type** Qualitative study **Aim of the study**	**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 (years, n): • <1=3 • 1-5=9 • 5-10=1 • 10-15=4 • >15=1 Gender of children: not reported Age of parents (range): 26-55 years Gender of parents: not reported	**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**	**Author's themes:** • Access to appropriate health care • Clinician seen in hospital • Support with allergy management **Findings** Parents accessing emergency services for their child's allergic reaction felt well look after and that they were referred appropriately. However, experiences of those accessing GP services were more varied. In GP surgery's that had made special provisions for children, accessing appointments and advice was quite straightforward. However, others found the process of getting a GP appointment to be difficult and stressful. In the NHS, referrals to specialists have to be done through a hospital A&E or through GP services. Some parents found the process quite	**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 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

Study details	Participants	Methods	Themes and findings	Limitations
To explore the experiences of babies, children and young people in accessing allergy services in the West Midlands. **Study dates** September 2014-June 2016 **Source of funding** This study received support from Wellcome Trust.	**Inclusion criteria** Participants had to: • Be parents of children: ○ Aged 0-16 years old ○ With 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	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 software. Codes were developed using both the interviews themselves and adapted from previous literature.	straightforward. However, others found the process stressful. Parents in this situation were frustrated because their child was receiving inadequate care in primary care but found it difficult to get an appointment with specialists. Parents had to be quite determined to get a referral. Once the referral was made, parents were aware that there would be a wait before seeing a specialist face-to-face, which was a frustrating prospect for some. Follow up care was useful for some, but other parents questioned the usefulness of short consultations and the management of follow up clinics. 16 out of 18 of the parent's interviews were seen in clinic by an allergy specialist nurse, which some were unaware of. Most parents were happy to see a nurse. While most did not express a preference, some parents felt as though there should be a doctor available for consultation if needed, for example if there was a complex condition that the nurse was unfamiliar with. A minority expressly preferred seeing a doctor and were upset when this wasn't possible.	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. *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.

Study details	Participants	Methods	Themes and findings	Limitations
			Overall, parents were pleased with hospital care. Allergy clinics often referred them to other services (e.g. dermatology or dietetic services) that could help provide complete information for managing their child's condition. However, sometimes these referrals were a long time coming which caused parents distress. Even when warranted, it was not always possible to obtain co-ordinated care between specialities.	*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). *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

Study details	Participants	Methods	Themes and findings	Limitations
				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 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** 6/18 (33%) of study participants were parents of children over 5. As these parents are outside of the protocol population, data has not been extracted for parents wherever possible.

Study details	Participants	Methods	Themes and findings	Limitations
Full citation Harper, B., Dickson, J. M., Bramwell, R., Experiences of young people in a 16-18 Mental Health Service, Child and Adolescent Mental Health, 19, 90-96, 2014 **Ref Id** 989439 **Country/ies where the study was carried out** North-West England, UK **Study type** Qualitative study **Aim of the study** To explore young people's experiences of the newly-established 16-18 mental health services (16-18MHS). **Study dates** Not reported. **Source of funding**	**Sample size** N=10 young people **Characteristics** Age (years, n): • 16=1 • 17=5 • 18=8 Gender (M/F): 3/7 Ethnicity: all White-British **Inclusion criteria** Participants had to: • Have prior experience of CAMHS • Have a suitable current mental health status • Be available to participate • Have mental capacity to consent **Exclusion criteria** Not reported.	**Setting** 2 specialist NHS 16-18 MHS. **Sample selection** Purposive sampling. Potential participants were identified by key workers at 2 NHS 16-18 MHS. The study wanted to recruit a small, homogeneous sample in order to obtain rich data source. **Data collection** Individual semi-structured interviews lasting an average of 45 minutes (ranged from 25-80 minutes). The interview schedule was designed according to prior literature on young people's experiences of 16-18MHS and modified from another study that investigated transition from childhood to adulthood. Questions focused on encouraging young people to reflect on their experiences of using 16-18MHS and the schedule was used flexibly to allow the young people to talk about areas that were important to them. Researchers used limited prompts in an effort to expand views and experiences. The schedule was piloted with 2 study participants to ensure	**Author's themes:** • Developmentally attuned services • Power differentials • Continuity and loss in therapeutic relationships **Findings** All participants spoke highly of the collaborative approach that they received from therapist in 16-18MHS, as this was considered to be more in keeping with their developmental ages. Many spoke of their changing needs as they moved into adulthood, mentioning the need for therapists to be able to manage complex issues (for example, self-harm was seen as a specialist issue). Overall, young people have the idea that 16-18MHS staff had skills that CAMHS staff did not. All participants believed that services should be referred based on the developmental need of a patient, rather than their chronological age. Collaboration and independence were seen as important. Previous experiences of CAMHS were described by participants in terms of a 'them and us' dynamic. Many participants felt angry, powerless and disempowered	**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. Interpretive phenomenological analysis used in order to deeply explore participants' personal experiences and views of a particular event. This approach does not make objective statements about analysed data. *Q4: Was the recruitment strategy appropriate to the aims of the research?* Yes. Researchers wanted to recruit a small number of homogenous participants. Key workers from 2 NHS 16-18MHS identified potential participants. Reasons for non-participation given. *Q5: Were the data collected in a way that addressed the research issue?* Yes. Data collected via semi-structured interviews. Topic guide developed using previous literature and was piloted with 2 initial participants. Examples of

Study details	Participants	Methods	Themes and findings	Limitations
First author received support from the NHS as part of their Clinical Psychology training. No other funding reported.		relevance and ease of understanding. After reviewing, data from these interviews was included with the final results. **Data analysis** Interpretative phenomenological analysis. Data was transcribed and researchers were familiarised with the data by reading and re-reading. During this process, preliminary analytical findings were noted before line-by-line coding occurred to summarise findings and higher-order codes were identified. Emergent themes were used to determine emergent cluster themes for each participant. Throughout this process, original quotes from transcripts were identified. After themes had been determined for each participant, superordinate themes were identified across all participant interviews whilst continually being checked for coherence against the evolving analysis.	from the process of diagnosis and reported a lack of being listened to. They were treated 'like a child' and unable to challenge healthcare staff. Most young people reported that this actually exacerbated their mental health problems. Their interactions with CAMHS were seen as blaming their mental health problems, which invalidated their experiences. All interviewees expressed a desire for deeper collaboration and increased independence, as well as acknowledgement of this shift. While all participants felt as though their relationships with therapist in both CAMHS and 16-18MHS were very important, they also reported that this relationship was often ended before they felt ready. Developing relationships with therapists is a gradual process and involves a significant emotional attachment from young people. They experienced significant anxiety and trauma when re-telling their history to a new therapist.	questions are provided. The guide was applied flexibly to allow participants to introduce novel views and experiences. However, no mention of data saturation. *Q6: Has the relationship between researcher and participants been adequately considered?* No. No description of potential bias/influence between researcher and participants. *Q7: Have ethical issues been taken into consideration?* Yes. Study received ethical approval from National Research Ethics Service. Informed consent obtained before interviews with a 2 week cooling off period to change their mind. *Q8: Was the data analysis sufficiently rigorous?* Yes. Very detailed description of analysis and how themes were derived from the raw transcripts. Section detailing the techniques used to mitigate bias in the analysis, including group discussion of themes, independent researcher conducted an analysis audit at each stage. Contradictory data is presented and discussed where appropriate and a good amount of data is presented to support the reported findings. However,

Study details	Participants	Methods	Themes and findings	Limitations
				no explanation of how the data presented were chosen from the original sample. *Q9: Is there a clear statement of findings?* Yes. Good, detailed explanation of findings within the identified themes, with regular referral back to the original research question. Adequate discussion surrounding evidence both for and against the study's findings, as well as the credibility of findings. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* Can't tell. 1. Yes. Details how the study findings fit in with current literature and the UK population, and how they can be used to inform best practice. Ideas and directions for future research presented. 2. No. Interpretative phenomenological analysis is designed to produce rich data on a homogeneous sample. It is not designed to be generalizable. *Overall judgement of quality:* Minor concerns. **Other information** None.

Study details	Participants	Methods	Themes and findings	Limitations
Full citation 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 **Ref Id** 1280080 **Country/ies where the study was carried out** East Anglia and Greater Manchester, UK **Study type** Semi-structured interview; qualitative **Aim of the study** To understand young people's concept of mental health recovery **Study dates**	**Sample size** N=23 young people • n=15 under 18 years • n=8 > 18 years • Only the views of the young people under 18 years old are included in this review. **Characteristics** Age (years, n): • 14-17=15 • 18-21=5 • 22-25=3 Gender (M/F/non-binary): 4/18/1 Ethnicity (n): • White British=20 • Asian Pakistani=1 • White Other=1 • Other=1 Duration of access to mental health services (years, n): • <1=5 • 1-3=10 • 4-7=4 • >7=4 **Inclusion criteria**	**Setting** In the community **Sample selection** Participants recruited using convenience sampling from Norfolk and Suffolk NHS Foundation Trust (n=11) and Greater Manchester Mental Health NHS Foundation Trust (n=12). Referrals received from participants themselves (self-referral) or via youth mental health service professionals. Consent forms obtained or when appropriate, consent forms from parents/guardians obtained where required and assent form from participant. **Data collection** Interview schedule developed with local Youth Council members. Semi-structured organic interviews conducted at location of participants' choice with individual interviews guided by participant's responses to questions. Topics in interview included background history of mental health difficulties and access of services, understanding of the word 'recovery' generally and what it means to them, and	**Author's themes:** • Meaningful alliance with healthcare professionals • Collaborative approach to recovery **Findings** Young people consistently described facilitators and barriers to recovery using the above themes with provision of these promoting recovery (and absence hindering it).	**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?* Can't tell. No justification for use of interview provided. *Q4: Was the recruitment strategy appropriate to the aims of the research?* Yes. *Q5: Were the data collected in a way that addressed the research issue?* Yes. *Q6: Has the relationship between researcher and participants been adequately considered?* Yes. *Q7: Have ethical issues been taken into consideration?* Yes. Ethical approval for study obtained from East of England - Cambridge Central Research Ethics Committee (Ref: 17/EE/0231).

Study details	Participants	Methods	Themes and findings	Limitations
Not reported **Source of funding** Not reported	Participants had to: - Be aged between 14 and 25-years old. - Speak English - Be currently receiving services from mental health trusts **Exclusion criteria** Not reported.	personal experience of recovery including what has helped or hindered recovery. Interviews recorded and transcribed verbatim. **Data analysis** Thematic analysis conducted to understand each participant's unique perspective. Analysis data-driven and coding using participant's own language conducted. Bottom-up approach followed beginning with familiarisation with dataset, then initial independent code generation (by 2 of the authors), search for themes, review of themes for internal and external homogeneity and to ensure coherence, and finally defining and naming of themes. Any discrepancies discussed by all authors. Process of reflexivity used to bracket researchers own beliefs/preconceptions.		*Q8: Was the data analysis sufficiently rigorous?* Yes. *Q9: Is there a clear statement of findings?* Yes. *Q10: Is the research valuable for the UK?* Yes. 1. Yes. Discusses in context of literature. 2. Yes. Nature of topic (mental health recovery) and use of convenience sampling risking sample bias limits applicability of findings to young people generally; also includes 8 participants over-18. *Overall judgement of quality:* Minor concerns. **Other information** Study also involved participants 18-25 years old. However, these participants are outside the protocol population and data was not extracted where possible.
Full citation 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	**Sample size** N=11 children **Characteristics** Age (range): 8-10 years Gender: 9/2	**Setting** Child and Adolescent Mental Health Services **Sample selection** 3 CAMHS services (totalling 6 teams) covering a wide geographical area of England participated in the study. All	**Author's themes:** - Variability in communication - Changing teacher behaviour **Findings** Parents and children reported that there is a need for CAMHS and education services to communicate effectively with	**Limitations (assessed using the <u>CASP checklist for qualitative studies</u>).** *Q1: Was there a clear statement of the aims of the research?* Yes. *Q2: Was a qualitative methodology appropriate?* Yes.

Study details	Participants	Methods	Themes and findings	Limitations
mental health difficulties and their parents, Child and Adolescent Mental Health, 18, 202-209, 2013 **Ref Id** 1060506 **Country/ies where the study was carried out** England, UK **Study type** Qualitative study **Aim of the study** To explore the experiences of children and their parents of joint-working between educational systems and CAMHS. **Study dates** 2005-2008 **Source of funding** This study received support from the Policy Research Programme of the Department of Health in England.	*Described as ethnically, geographically and socio-economically diverse sample but no further details reported.* **Inclusion criteria** Participants had to: • Be children experiencing educational and mental health problems. **Exclusion criteria** Not reported.	families meeting the inclusion criteria were invited to participate. No further details reported. **Data collection** Individual face-to-face semi-structured interviews conducted in participant's homes. Children interviews included forms of participatory interviewing techniques, such as emoticons, drawing, and glitter pens. Children were interviewed with parent's present if they wanted. No further details were reported. **Data analysis** Thematic analysis. Interviews were audio-recorded and transcribed verbatim. NVivo software used to create first and second order codes. 2 researchers familiarised themselves the data by reading the transcripts and listening to the audio recordings. The parent project had a number of aims to the research, so only data relating to perceptions and experiences of joint-working was reported. 29 out of a total 83 second order codes related to joint-working. These codes were examined jointly by the research team and discussed,	each other and with families as ineffective communication results in frustration with services. Both agencies have some shortcomings with communication and suggestions for improvement were made, including 'feedback' and 'maintaining regular' contact. Communication with families should not be neglected and should be done in a respectful and informative manner. However, this does not appear to happen in practice. Some parents reported that they were not well informed on communication between agencies because neither kept them up to date. A key purpose of joint working is to improve teacher behaviour towards children. The involvement of CAMHS professionals in school is seen as promoting changes to the strategies and coping mechanisms of teachers in teaching children with combined mental and educational difficulties.	*Q3: Was the research design appropriate to address the aims of the research?* Yes. Qualitative design justified to expand the amount of literature using children's voices and the lack of validated measurement instruments for children. *Q4: Was the recruitment strategy appropriate to the aims of the research?* Can't tell. Recruitment was through a wider project on joint working between CAMHS and education services. No information given regarding recruitment for this wider study, although sample is geographically varied. No information given regarding non-responders. *Q5: Were the data collected in a way that addressed the research issue?* Can't tell. Interviews took place in the participant's home to put them at ease. Art-based participatory methods utilised with some children to engage them. Detailed description of how saturation was determined and reached. However, very little information given on the content of the interviews and there is no mention of interview guide. *Q6: Has the relationship between*

Study details	Participants	Methods	Themes and findings	Limitations
		identifying 3 key themes across the data.		*researcher and participants been adequately considered?* No. No description of potential bias/influence between researcher and participants. *Q7: Have ethical issues been taken into consideration?* Yes. Study received ethical approval from National Research Ethics Service. Informed consent obtained and participants had to opt-in to study. *Q8: Was the data analysis sufficiently rigorous?* Yes. Very detailed description of analysis and how themes were derived from the raw transcripts. 2 researchers were involved in each stage of the coding to mitigate bias. Contradictory data is presented and discussed where appropriate and a large amount of data is presented to support the reported findings. However, no explanation of how the data presented were chosen from the original sample. *Q9: Is there a clear statement of findings?* Yes. Good, detailed explanation of findings within the identified themes, with regular referral back to the original research question. Adequate discussion surrounding evidence both for and against the study's

Study details	Participants	Methods	Themes and findings	Limitations
				findings. However, very brief discussion around credibility of findings. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* Yes. 1. Yes. Details how the study findings fit in with current literature and the UK population, and how they can be used to inform best practice. No ideas or directions for future research presented. 2. Yes. Small sample size and lack of demographic data limits transferability. Good population size for qualitative study and sampled from a variety of services in a wide geographical area. *Overall judgement of quality:* Moderate concerns. **Other information** Part of a larger project on joint-working between CAMHS and education services. Also includes the views of parents but, due to age of the children and young people and the fact that no information given on children's 'mental health problems and educational difficulties', these are outside of the protocol population and data

Study details	Participants	Methods	Themes and findings	Limitations
				was not extracted where possible.
Full citation 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 **Ref Id** 992313 **Country/ies where the study was carried out** North-West England, UK **Study type** Semi-structured interview; qualitative **Aim of the study** To evaluate the experience of the diabetes 'Transition Pathway' by young	**Sample size** N=11 young people • n=9 for 1 interview • n=2 for 2 interviews **Characteristics** Age (range): 16-18 years (not clear if this was inclusion criteria) Gender: not reported. **Inclusion criteria** Participants had to: • Have used diabetes Transition Pathway Service **Exclusion criteria** Not reported	**Setting** Adolescent diabetes transition clinic **Sample selection** Professionals in each transition pathway team prompted by email when young person would be attending transition session. Participants recruited by professionals using letter which made clear participation in study was voluntary. However, not clear how many NHS Trusts covered by study nor dates participants recruited. **Data collection** Semi-structured interview occurred 3 months after first appointment at 16-25 clinic. Consent for 1-year follow up interview obtained here. No other details reported. **Data analysis** Transcriptions of interviews used Framework Approach of Ritchie & Spencer 1994, a form of thematic analysis. Two researchers independently familiarised themselves with data before identifying key	**Author's themes:** • Experience and organization of transfer • Information and education • Healthcare consultation • Inclusion **Findings** Staff training in communication skills vital to keeping young people engaged with healthcare services so that they can recognise and provide individualised and age-/developmentally- appropriate care. Although young people also valued other things, such as choice of when they transition to 'young adult' services and not having too long appointments, experience of healthcare as personal and age-appropriate appears central to good experience of transition.	**Limitations (assessed using the CASP checklist for qualitative studies).** *Q1: Was there a clear statement of the aims of the research?* Yes. *Q2: Was a qualitative methodology appropriate?* Yes. *Q3: Was the research design appropriate to address the aims of the research?* Yes. *Q4: Was the recruitment strategy appropriate to the aims of the research?* Can't tell. Insufficient information provided about recruitment strategy. *Q5: Were the data collected in a way that addressed the research issue?* No. No details about interview method provided; form of data (e.g. audio recordings) not reported; data saturation not discussed. *Q6: Has the relationship between researcher and participants been adequately considered?* Can't tell. Not discussed in article. *Q7: Have ethical issues been taken into consideration?* Can't tell. Not discussed in article.

Study details	Participants	Methods	Themes and findings	Limitations
people with Type 1 diabetes. **Study dates** Not reported **Source of funding** Study funded by Diabetes UK, registered charity no. 215199.		issues, concepts, and themes together. Initial thematic framework created and refined through iterative process of examining data and refining categories. Data then sorted according to themes ('charting') before superordinate themes established.		*Q8: Was the data analysis sufficiently rigorous?* Can't tell. Details about participant's quotes not provided, so all data could have come from one participant; also no details about age of quoted participants provided; no discussion of researcher's own role, potential bias, and influence during analysis, nor of selection of data. *Q9: Is there a clear statement of findings?* Yes. *Q10: Is the research valuable for the UK?* Yes (if there are similar pathways still in existence) 1. Yes, may have motivated changes to pathway. 2. Yes. Although sparse details provided about participants, will depend on existence of similar pathways in UK. *Overall judgement of quality:* Serious concerns. **Other information** None.
Full citation Robards, F., Kang, M., Usherwood, T., Sanci, L., How Marginalized Young People Access,	**Sample size** K=68 studies. **Characteristics** Type of study (k):	**Setting** Not reported. **Methodological details**	**Author's themes:** • Professionals' knowledge, skills, and attitudes affect engagement	**Limitations (assessed using the CASP checklist for systematic reviews).** *Q1: Did the review address a clearly focused question?* Yes

Study details	Participants	Methods	Themes and findings	Limitations

Engage With, and Navigate Health-Care Systems in the Digital Age: Systematic Review, Journal of Adolescent Health, 365-381, 2018
Ref Id
958204
Country/ies where the study was carried out
Multiple countries
Study type
Systematic review
Aim of the study
To explore the current literature and determine the factors affecting access to, engagement with, and navigation through healthcare systems for marginalised young people in the digital age.
Study dates
Search dates: Jan 2006-Feb 2017
Source of funding
	- Qualitative=44
	- Quantitative=16
	- Mixed-methods=8
	  - This study incorporated all their results (qualitative and quantitative) into a narrative summary, which was then used in the findings of this review.
	Range of sample size: N=3 to 1388
	Respondents (k):
	- Young people=61
	- Professionals=11
	- Parents=7
	  - Although the study notes that their themes were identified by all the participants in their population (marginalised young people up to age 24 years old, parents and healthcare professionals), views of people > 18 years old, parents and health professionals will also have been
		A systematic literature search of 5 online databases (Medline, CINAHL, PyscInfo, The University of Sydney Library database and Google Scholar) for qualitative, quantitative and mixed-methods studies (published between Jan 2006 and Feb 2017) identified 1758 articles. Hand searching of reference lists and a grey literature search identified 38 more articles. The search was conducted in 2 phases. First phase involved a generalised search of the literature for terms relating to access, barriers or navigation of healthcare. The second phase specifically searched for 5 marginalised groups of young people (those who are homeless, living in remote areas, refugees and migrants, identifying as sexual minority, 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	- Service environments and structures need to be welcoming and respectful of all groups of young people
			- Ability to navigate the health system is hindered by complex, fragmented bureaucratic health systems
			Findings
			Marginalised young people wanted clinicians who are able to take time, facilitate communication, deal with sensitive issues carefully, listen with empathy and be respectful of autonomy. Positive characteristics of professionals included: non-judgmental attitude; welcoming; open-minded, unassuming, supportive and encouraging. Trust was a central theme, building trusting relationships with both providers and services. This ability to develop an ongoing personal connection (involved rapport with service providers), continuity of therapeutic relationships, and having a usual source of care was important to marginalised young people. Being taken seriously and being acknowledged was a pervasive theme, as was discrimination by professionals. Marginalized young people may be treated differently and with disrespect.
				Q2: Did the authors look for the right type of papers? Yes
				Q3: Do you think all the important, relevant studies were included? Yes. A wide variety of online databases were used, and the search strategy was devised in collaboration with a librarian from University of Sydney. Reference lists of included studies were checked for relevant studies and a search of the grey literature was conducted. No restrictions were placed on full-text or language of publication. No mention of personal contact with experts. However, only 5 of the 8 marginalised groups of young people 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.

Study details	Participants	Methods	Themes and findings	Limitations
Not reported.	included in their results. Our findings have been downgraded for relevance where applicable. Marginalised group (k): • Homeless=20 • Living in remote areas=14 • Refugees and migrants=11 • LGBTQ=11 • Indigenous populations=4 • Low income=4 • Young offenders=2 • Living with a disability=2 Study country: • United States=24 • Australia=24 • Canada=11 • UK=7 • New Zealand=1 • Portugal=1 **Inclusion criteria** Studies had to: • Be focused on marginalised groups (defined as refugees	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 details** 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, focus of the study, and key limitations in 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.	Culturally appropriate services, cultural sensitivity of staff, use of interpreters, and cultural concepts of health, including traditional indigenous therapeutic practices should be provided. Professionals could be better at managing the health issues that young people from marginalized backgrounds may experience e.g. mental health, trauma, LGBTQ issues. Healthcare for marginalised young people should be welcoming and respectful, including youth-friendly facilities, a choice of creative and physical pursuits. Providing alternative reasons for young people to attend, for example free condoms or needle and syringe exchange, was seen to increase engagement with services. Inclusive language and resources and the use of welcoming signals are important in creating a welcoming atmosphere. Discrimination in organisations can be a barrier to engagement, for example not acknowledging the experiences of LGBTQ individuals. Another barrier to engagement was entitlement (both perceived and actual) - marginalised young people either did not feel entitled to care, were worried they would not be	*Q4: Did the review's authors do enough to assess quality of the included studies?* Yes. Quality appraisal of studies was done using both quantitative and qualitative appraisal tools. Qualitative studies received an average CASP checklist score of 7.96/10 (range 3-10). Each criterion was met by 67% of studies, excepting considering the relationship between interviewer and participants (only 25% of studies addressed this). Quantitative studies received an average Glasziou criteria score of 2.88/5 (range 1-5). Participant demographics and ethical review was well scoring among the studies. However, drop-out rates, sampling, use of validate questionnaires and description of outcome measurements were each addressed by 50% of studies or less. *Q5: If the results of the review have been combined, was it reasonable to do so?* Yes. Thematic analysis applied to the data, with 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,

Study details	Participants	Methods	Themes and findings	Limitations
	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.	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** Quantitative studies: Glasziou criteria; Qualitative studies: CASP checklist; Mixed-methods: both as appropriate.	believed, or were turned away because of behaviour problems. Access to and navigation through complex and fragmented healthcare systems is a challenge for marginalised young people. Young people dislike re-telling their stories to new services. Navigation of the healthcare system is made more difficult by complicated referral and appointment systems. Navigation of healthcare systems was made easier by partnerships between services, clarity of service roles, and services in the same location. Family support and social isolation are very important factors in helping marginalised young people move through healthcare systems, both emotionally and practically. Teachers, youth workers and healthcare professionals were a source of help for young people, providing appointment reminders and transport. Chaotic lives and mental health problems were identified as barriers, as was lack of confidence. Lack of documentation, or difficulty looking after documentation, problems for migrants and homeless young people, was a barrier to access.	including details on country, health issue focus, study design, participant characteristics and summary of findings. However, would have liked to see the marginalised group listed in there as well. Very good qualitative description of the 8 general themes identified across the literature, presented in chronological order i.e. help-seeking, access to healthcare services, engagement with healthcare services, navigation through healthcare services, and future directions for increasing access to healthcare (technology). Further discussion surrounding the variation in the themes between marginalised groups of young people, as well as parental and professional views. *Q7: How precise are the results?* Not applicable. *Q8: Can the results be applied to the local population?* Can't tell. The review incorporates data from a wide range of setting and participants. However, only 7 studies were conducted in the UK. 24 were conducted in the USA, which has a very different healthcare system to here, in which cost plays a very large part to access. Convenience sampling

Study details	Participants	Methods	Themes and findings	Limitations
				used by single services were prevalent within the studies which also affects generalisability. *Q9: Were all important outcomes considered?* Not applicable. Themes are driven by data. *Q10: Are the benefits worth the harms and costs?* Not applicable. Literature review. *Overall judgement of quality:* Minor concerns. **Other information** None.
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	**Sample size** N=86 children and young people • n=57 focus groups • n=29 family case studies **Characteristics** *Focus groups:* Age (range): 7-16 years Gender (M/F): 26/31 Country of origin (n): • Poland=48 • Other=9	**Setting** In the community **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	**Author's themes:** • Differences in provision • Transnational use of health services **Findings** Only having experiences of how healthcare was accessed in their home country led to some families to use more informal approaches to solving healthcare issues, seeking help through friends and family members rather than professional healthcare services. This could be a reason why public healthcare is used less often by recent migrants. Parents reported the importance of learning how	**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 justified. Focus groups used to allow children to encourage each other's views as well as allowing researcher to gauge the level of shared experiences within the sample.

Study details	Participants	Methods	Themes and findings	Limitations
Study type Qualitative study **Aim of the study** To explore the experiences of recently migrated children (from Eastern-Europe) in accessing healthcare services in the UK. **Study dates** May 2008-June 2010 **Source of funding** This study received support from the Economic and Social Research Council.	*Family case studies:* Age [mean (range)]: 11 (8-16) years Gender (M/F): 14/15 Country of origin (n): • Poland=13 • Lithuania=5 • Slovakia=4 • Bulgaria=2 • Romania=2 • Hungary=1 • Russia=1 • Czech Republic=1 **Inclusion criteria** None applied. **Exclusion criteria** Not reported.	children's first language was another one. Children were encouraged to discuss the experiences of a typical migrant family in 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,	the UK healthcare system worked and adapting to make sure they were able to access the services that they wanted. Transnational use of healthcare is attractive solution due to low cost flights and already established relationships with healthcare professionals. Many families maintained registration with doctors and dentists in their home country while also registering in the UK. This transnational usage was often due to uncertainty around long-term residency in the UK. Other times, it was due to perceived structural barriers of healthcare organisation in the UK, trust in healthcare staff and length of waiting times, and limited access to specialists. Some participants had enough money to travel back and pay for private healthcare, which is seen as both a status symbol and guarantee for better care. For families who were healthy and did not need to need to access care in the UK, travelling home for summer or holidays was a good opportunity to have an annual check-up with doctors and dentists, or buy medications that they were unable to get easily in Scotland.	*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 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?* No. Qualitative data collected via audio-recorded focus groups and family case-studies. Interactions were conducted in either English, Polish, Romanian or with a translator depending on preference. No mention of type of translation or how this might affect qualitative data collection. Also no reasoning for why 2 visits were made to families, what questions were asked each visit or if there were discrepancies between each visit. No description of interview guide development or content. No mention of data saturation. *Q6: Has the relationship between researcher and participants been*

Study details	Participants	Methods	Themes and findings	Limitations
		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 transcript texts. 2 researchers coded each transcript for increased reliability.		*adequately considered?* No. No description of potential bias/influence between researcher and participants. *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. Interviews and focus groups were audio-taped with participant consent. However, no description of 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 data is presented to support the reported findings. *Q9: Is there a clear statement of findings?* Yes. Good, detailed explanation of findings within the

Study details	Participants	Methods	Themes and findings	Limitations
				identified themes, with regular referral back to the original research question. Adequate discussion surrounding evidence both for and against the study's findings. Discussion around credibility of findings. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* Yes. 1. Yes. Details how the study findings fit in with current literature and the UK population, and how they can be used to inform best practice. Ideas and directions for future research presented. 2. Probably. Good population size for qualitative study and sampled from a variety of services in a wide geographical area. *Overall judgement of quality:* Serious concerns. **Other information** Parents did participate in family case studies but, due to the age of children, they are outside of the protocol population and data was not extracted where possible.
Full citation Waite-Jones, J. M., Majeed-Ariss, R., Smith, J., Stones, S.	**Sample size** N=25 young people, parents and healthcare professionals	**Setting** Paediatric rheumatology clinic **Sample selection**	**Author's themes:** • Purpose of mobile apps: Monitoring chronic rheumatic	**Limitations (assessed using the CASP checklist for qualitative studies).**

Study details	Participants	Methods	Themes and findings	Limitations
R., Van Rooyen, V., Swallow, V., Young People's, Parents', and Professionals' Views on Required Components of Mobile Apps to Support Self-Management of Juvenile Arthritis: Qualitative Study, JMIR MHealth and UHealth, 6, e25, 2018 **Ref Id** 1063452 **Country/ies where the study was carried out** North England, UK **Study type** Qualitative study **Aim of the study** To explore the views of young people with juvenile arthritis, and the views of their parents, carers and related healthcare professionals, on essential features of a mobile app for the self-management of chronic juvenile arthritis.	• n=9 young people • n=8 parents/carers • n=8 healthcare professionals • Only the views of the young people are included in this review. **Characteristics** Age of young people (years, n): • 10=1 • 11=1 • 13=2 • 14=2 • 15=2 • 17=1 Gender of young people (M/F): 2/7 Age of parents/carers: not reported. Gender of parents/carers (M/F): 2/7 **Inclusion criteria** Participants had to: • Be aged 10-18 years • Have a diagnosis of rheumatic disease	Purposeful sampling from paediatric rheumatology clinic database of large teaching hospital in England conducted by rheumatology nurse specialist, who also invited associated parents, carers and professionals to participate in study. Authors state that attempt made to have variety of participants relative to age, developmental stage, disease type and duration, ethnicity, sex, socioeconomic status and treatment type, although no other details provided. **Data collection** Semi-structured interviews, using participatory approach, conducted with young people and their parents or carers; two focus groups with professionals conducted. Young people given choice of being interviewed separately although only one took this offer up due to their availability. Developmentally-appropriate topic guides used to explore information needs, experience of mobile apps, and opinions about extant mobile apps. Four sample apps - selected on advice of 'user ambassador', one of the authors of the study, and	disease and information sharing **Findings** Self-management app for Juvenile Arthritis should provide young people with ownership and control of an interactive, engaging tool, one that provides information, capacity to monitor symptoms, remind users of important events (e.g. appointments, medication) and provides social support. This may enable young people to develop sense of autonomy via sharing responsibility for management of condition with professionals, and help them to develop good relationship with professionals.	*Q1: Was there a clear statement of the aims of the research?* Yes. *Q2: Was a qualitative methodology appropriate?* Yes. *Q3: Was the research design appropriate to address the aims of the research?* Yes. *Q4: Was the recruitment strategy appropriate to the aims of the research?* Yes. *Q5: Were the data collected in a way that addressed the research issue?* Yes. *Q6: Has the relationship between researcher and participants been adequately considered?* Can't tell. Insufficient details provided. *Q7: Have ethical issues been taken into consideration?* Yes. Ethical approval obtained from NHS Health Research Authority (ref. no. 193786). *Q8: Was the data analysis sufficiently rigorous?* Yes. *Q9: Is there a clear statement of findings?* Yes.

Study details	Participants	Methods	Themes and findings	Limitations
Study dates Not reported **Source of funding** Funded by competitive award through University of Leeds Pump Priming Programme.	**Exclusion criteria** Not reported	relevant to juvenile arthritis - demonstrated to participants to generate discussion about views on strengths/ weaknesses of mobile apps, barriers/facilitators to their use, preferred design, functionality, interaction level, and data sharing arrangements. Opportunity for further comments provided at end of interview. Information from support groups sent to young people and their parents/ carers. Focus groups and interviews lasted 35-60 min, were digitally recorded, and transcribed by one author. **Data analysis** Data analysed using thematic (framework) analysis by 5 researchers (included 2 children's nurse researchers, and 2 child health psychologists). User ambassador involved at every stage of research including analysis. Two transcripts of each interview coded by each of the 5 researchers. Themes discussed, refined and critically evaluated, by all researchers until consensus achieved that themes, sub-themes and quotations accurately reflected views of		*Q10: Is the research valuable for the UK?* Yes. 1. Yes. 2. Possibly yes. Although a single-site study in young people with specific condition, general features of mobile app indicated as desirable by young people appear generalizable to other conditions and context. *Overall judgement of quality:* Minor concerns. **Other information** Young people sent £10 thank you voucher after completion of interview. Study also involved views of parents and healthcare professionals. Due to the age of children, views of parents are outside the protocol population. Healthcare professionals are outside of the protocol. Data for both these respondents was not extracted where possible.

Study details	Participants	Methods	Themes and findings	Limitations
		participants. Five overarching themes initially identified with 2 eventually integrated into the remaining 3 themes.		
Full citation 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 **Ref Id** 994021 **Country/ies where the study was carried out** England and Scotland, UK **Study type** Qualitative study **Aim of the study** To explore the primary and secondary healthcare experiences of young	**Sample size** N=20 children and young people **Characteristics** Age (range): 11-19 years Gender (M/F): 11/9 **Inclusion criteria** Participants had to: • Be aged between 11-20 years old • Either currently experiencing continence issues or had experienced these after the age of 10 years old • Able to speak and understand English. **Exclusion criteria** Not reported.	**Setting** Paediatric continence outpatient clinic **Sample selection** Clinicians at 5 secondary care paediatric continence clinics (4 in England and 1 in Scotland) and through advertising on paediatric continence charity website. No further details reported. **Data collection** Individual semi-structured interviews lasting an average of 65 minutes (range 34-59 minutes), conducted by 1 researcher with extensive experience in qualitative research. 11 participants were interviewed over Skype and 9 via telephone. Participants within 40 miles of Bristol were given the option to be interviewed face-to-face, but none did. 9 young people chose to be interviewed alone, 7 were in a communal area within their house and 4 participants chose to be interviewed with their	**Author's themes:** • Engagement with treatment: the effects of disappointing results **Findings** Participants had varying engagement with treatment. Experiencing treatment failure symptom relapse caused many participants to dis-engage with care. Some avoided taking medication and lying about dosages to parents. One patient felt so frustrated with a lack of progress that they decided no treatment would work and that there was no point in trying. Another participant dis-engaged with treatment in an effort to regain independence.	**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 used to expand the literature surrounding the experiences of young people with continence issues. *Q4: Was the recruitment strategy appropriate to the aims of the research?* Yes. Participants recruited through paediatric continence clinics and an advertisement on paediatric continence charity website, so a diverse sample recruited for the broad study aim. Reasons for non-participation given. *Q5: Were the data collected in a way that addressed the research issue?* Yes. Interviews were conducted via telephone or Skype, depending on their preference. Qualitative data

Study details	Participants	Methods	Themes and findings	Limitations
people with continence issues. **Study dates** February 2015-January 2016 **Source of funding** This study received support from the Medical Research Council.		parents/carers present. The interview schedule was based on prior literature on treatment, management and impact of continence problems for children and young people. Areas included attending appointments, treatment experiences and views on continence. The guide was used as an initial point for discussion but was flexible to allow space to explore any new or unexpected areas participants may identify. Additionally, an activity pack was developed to be used before and during interviews, complete with graphic depictions of possible topic areas. This was sent to participants before their interview along with an explanation of how it could be used and allowed children to write/draw possible thoughts regarding continence. The research compiled field notes after each interview, detailing environment, participant behaviour and any thoughts on the interviews. **Data analysis** Inductive thematic analysis. Interviews were audio-recorded and transcribed verbatim before being loaded		collected via audio-recorded semi-structured interview as well as an arts-based activity pack. Topic guide developed using literature search, refined after the first 5 interviews, and applied flexibly to allow participants to introduce novel concepts. The activity-book was given to participants before the interview in order for them to start to think about questions, views and experiences. The researcher made field notes after the interview on environment and personal reflections, limiting recall bias. No mention of data saturation. *Q6: Has the relationship between researcher and participants been adequately considered?* No. No description of potential bias/influence between researcher and participants. *Q7: Have ethical issues been taken into consideration?* Yes. Ethical approval received from National Research Ethics Service Committee South West - Central Bristol. Informed consent obtained (parental consent and child assent for those under 16 years old). *Q8: Was the data analysis sufficiently rigorous?* Can't tell.

Study details	Participants	Methods	Themes and findings	Limitations
		into NVivo10. Early data analysis during the initial 5 interviews was used to modify the interview schedule as new areas of interest were identified. Each transcript was read, and data was free coded across the 5 transcripts. A selection of 3 transcripts were also independently free-coded by 2 other researchers. Codes were discussed with all members of the research team to further refine the coding. After this period, data collection and analysis were conducted in parallel. The original agree codes were used, with any new codes identified in subsequent interviews added after discussion with the research team.		Adequate description of analysis and how themes were derived from the raw transcripts. No explanation of how raw data presented was selected from the original sample although adequate data is presented for each theme and contradictory data is presented. Multiple researchers carried out analysis of the initial 3 transcripts but after that appears to be 1 researcher with discussion if new themes added. 1 field researcher carried out all interviews, and there is no critical examination of their own role in the process. *Q9: Is there a clear statement of findings?* Yes. Good, detailed explanation of findings within the identified themes, with regular referral back to the original research question. Adequate discussion surrounding evidence both for and against the study's findings, as well as the credibility of findings. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 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 Yes.

Study details	Participants	Methods	Themes and findings	Limitations
				Broad sampling strategy and study met targeted sample size. However, lack of demographic data means sample cannot be determined to be generalizable. *Overall judgement of quality:* Minor concerns. **Other information** None.

CAMHS: Child and Adolescent Mental Health Service; CASP: Critical Skills Appraisal Programme; CHI-ESQ: Commission for Health Improvement Experience of Service Questionnaire; CINAHL: Cumulative Index to Nursing and Allied Health Literature; F: Female; M: Male; N: Number; NHS: National Health Service; PHR: Personal health record; SD: Standard deviation; 16-18MHS: 16-18 Mental health service

Appendix E – Forest plots

Forest plots for review question: What factors promote, or present barriers to, continuity of care 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 factors promote, or present barriers to, continuity of care for babies, children and young people?

Table 7: Evidence summary (GRADE-CERQual) for theme 1: Individuals

Study information		Description of theme or finding	CERQUAL Quality assessment				
No of studies	**Design**		**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
Sub-theme 1.1: Knowledge of healthcare system							
3 (Law 2020, Robards 2018, Sime 2014)	Participatory-based focus group, family case study, semi-structured interviews, systematic review	Evidence from 2 studies and 1 systematic review shows that adequate knowledge of healthcare systems is important in helping children and young people navigate complicated referral and appointment systems. Additionally, knowing what care and what services are available to babies, children and young people is important for continuity of healthcare. In terms of international continuity of care, recent migrants are more likely to utilise informal support networks available to them in the UK as they are unaware of how the health system works, assuming structural barriers and limited access to specialists in the NHS system. *'Well, you can't buy antibiotics in Scotland, but you can in Romania, so my mum always buys stuff when we go back.' (Sime 2014, page 91)*	Minor concerns[1]	No/very minor concerns	Minor concerns[2]	No/very minor concerns	HIGH
Sub-theme 1.2: Support							

Study information		Description of theme or finding	CERQUAL Quality assessment				
No of studies	Design		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
3 (Diwakar 2019, Law 2020, Robards 2018)	Semi-structured interviews, systematic review	Evidence from 2 studies and 1 systematic review showed that external support is important in continuity and co-ordination of healthcare for babies, children and young people. This is especially highlighted in marginalised young people. Examples include teachers, youth workers and professionals providing appointment reminders and transport to and from appointment. Determination of parents/carers to get a referral can factor into continuity and co-ordination of care, either enhancing it if they are or fragmenting it if they are not. *'They (youth service) helped show my mum how to help me and sent letters to the school and my mum and the GP [general practitioner]' (Law 2020, page 470).*	Minor concerns[1]	No/very minor concerns	Minor concerns[2]	No/very minor concerns	HIGH
Sub-theme 1.3: Personal lives							
1 (Robards 2018)	Systematic review	Evidence from 1 systematic review showed that personal lives of young people can impact continuity and co-ordination of healthcare. Chaotic personal lives and lack of family support are important factors how babies, children and young people navigate healthcare systems. Intentional or unintentional discrimination of marginalised young people, such as services not acknowledging individuals with	Minor concerns[1]	No/very minor concerns	Moderate concerns[2]	Minor concerns[3]	MODERATE

Study information		Description of theme or finding	CERQUAL Quality assessment				
No of studies	Design		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
		protected characteristics or not using inclusive language can cause babies, children and young people to disengage from healthcare services. On the other hand, culturally appropriate services, use of interpreters and awareness of cultural concepts of health can increase engagement. No quotes presented for this theme.					
Sub-theme 1.4: Results							
2 (O'Reilly 2013, Whale 2017)	Participatory-based activity, semi-structured interview	Evidence from 2 studies showed that results of healthcare treatment are an important factor in continuity of care for children and young people. Positive impacts increased engagement with services while treatment failure causes young people to disconnect from treatment. *'I think it was because I'd been on them [the medication] for so long, I didn't feel like they were doing anything. I've never actually tried it [the new medication]. I've never actually properly tried it […] I just decided that it wouldn't work either' (Whale 2017, page 5)*	Moderate concerns[4]	No/very minor concerns	No/very minor concerns	Serious concerns[5]	VERY LOW

1 Evidence was downgraded due to minor concerns about methodological limitations as per CASP qualitative checklist and CASP systematic review checklist
2 Evidence was downgraded due to moderate concerns of the relevance of evidence as evidence only contains a systematic review which includes views of children and young people (up to the age of 24 years old), parents and health professionals
3 Evidence was downgraded for adequacy because studies together offered moderately rich data
4 Evidence was downgraded due to moderate concerns about methodological limitations as per CASP qualitative checklist
5 Evidence was downgraded for adequacy because studies together did not offer rich data

Table 8: Evidence summary (GRADE-CERQual) for theme 2: Healthcare professionals

Study information		Description of theme or finding	CERQUAL Quality assessment				
No of studies	**Design**		**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
Sub-theme 2.1: Inter-service communication							
3 (Diwakar 2019, Law 2020, O'Reilly 2013)	Participatory-based activity, semi-structured interview	Evidence from 3 studies showed that inter-service communication is a facilitator for the co-ordination of children and young people's healthcare services. *'they've referred me to different services for when I leave here they don't only look at the mental health side of things, they look at everything they look at my accommodation, my education… they'll sort everything out, it's not just the mental health' (Law 2020, page 470)*	Moderate concerns[1]	No/very minor concerns	No/very minor concerns	Minor concerns[2]	MODERATE
Sub-theme 2.2: Collaboration with babies, children and young people							
4 (Diffin 2019, Harper 2014, Price 2011, Robards 2018)	Semi-structured interview, systematic review	Evidence from 2 studies and 2 systematic reviews showed that collaboration between healthcare professionals and service users is important for promoting partnership in care. This became more important as children moved into adulthood, desiring greater independence. Young people report want to be taken seriously, acknowledged and able to challenge healthcare staff. *'I had 9 doctors telling me erm they diagnosed me with 9 different things in a day and I was absolutely fuming because they wouldn't listen to me, it was like it didn't matter cause I was a child' (Harper 2014, page 93)*	Minor concerns[3]	No/very minor concerns	Moderateconcerns[4]	No/very minor concerns	MODERATE

Study information		Description of theme or finding	CERQUAL Quality assessment				
No of studies	**Design**		**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
Sub-theme 2.3: Communication							
4 (Davison 2017, Diffin 2019, O'Reilly 2013, Waite-Jones 2018)	Questionnaire, semi-structured interview, focus groups, participatory-based activity, systematic review	Evidence from 3 studies and 1 systematic review showed that the amount of communication children, young people and their families had with healthcare services impact their engagement. Technology may be a way of decreasing these communication barriers, allowing contact between patients and healthcare providers outside of regularly scheduled appointments. Examples include professionals updating information of electronic personal health records for babies, children and young people to see. *'Your doctor can write something in [the app] maybe that you can read. Or...automatically send some leaflets or something to your house.' (Waite-Jones 2018, page 5)*	Moderate concerns[1]	No/very minor concerns	Minor concerns[5]	No/very minor concerns	MODERATE
Sub-theme 2.4: Relationships with healthcare professionals							
5 (Harper 2014, Law 2020, Price 2011, Robards 2018, Sime 2014)	Semi-structured interview, participatory-based activity, family case study, systematic review	Evidence from 4 studies and 1 systematic review showed that forging relationships with healthcare professionals and having a usual source of care is important for continuity, especially in marginalised young people. Trust is a large component of this relationship. Children and young people invest large amounts of emotional attachment when developing a rapport with clinicians. Ending clinical	Minor concerns[2]	No/very minor concerns	No/very minor concerns	No/very minor concerns	HIGH

Study information		Description of theme or finding	CERQUAL Quality assessment				
No of studies	**Design**		**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
		relationships before children and young people were ready was reported by mental health service users, which then caused distress when they had to tell their story to a new professional and 'start from scratch'. *'It's hard trusting all these strangers and having to go over and over your story with everyone…moving around is unnecessary when you get the right person then it works' (Harper 2014, page 94)*					

1 Evidence was downgraded due to moderate concerns about methodological limitations as per CASP qualitative checklist
2 Evidence was downgraded for adequacy because studies together offered moderately rich data
3 Evidence was downgraded due to minor concerns about methodological limitations as per CASP qualitative checklist and CASP systematic review checklist
4 Evidence was downgraded due to moderate concerns of the relevance of evidence as evidence contains 2 systematic review. One of these includes views of children and young people (up to the age of 24 years old), parents and health professionals, the other includes 3 studies on the views of children and young people (up to the age of 24 years old) and 6 studies on the views of parents
5 Evidence was downgraded due to minor concerns of the relevance of evidence as systematic review includes 3 studies on the views of children and young people (up to the age of 24 years old) and 6 studies on the views of parents

Table 9: Evidence summary (GRADE-CERQual) for theme 3: Practical

Study information		Description of theme or finding	CERQUAL Quality assessment				
No of studies	**Design**		**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
Sub-theme 3.1: Co-location							
1 (Robards 2018)	Systematic review	Evidence from 1 systematic review showed that colocation of services made it easier for marginalised young people to navigate healthcare systems. No quotes presented for this theme.	Minor concerns[1]	No/very minor concerns	Moderate concerns[2]	Serious concerns[3]	VERY LOW

Study information		Description of theme or finding	CERQUAL Quality assessment				
No of studies	Design		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
Sub-theme 3.2: Appointment times							
2 (Davison 2017, Diwakar 2019)	Questionnaire, semi-structured interview	Evidence from 2 studies showed that the appointment times can be a barrier to continuity and co-ordination of care of babies, children and young people, in both the length of follow-up appointments and the scheduling of appointments. *'They [CAMHS} say ah you can have an appointment soon and we'll ring up like a few weeks later and the doctor's too busy […] it takes months like to get an appointment and when we do they put it at like a silly time like in the middle of school' (Davison 2017, page 102)*	Moderate concerns[4]	No/very minor concerns	Serious concerns[5]	Moderate concerns[3]	VERY LOW
Sub-theme 3.3: Referrals							
2 (Diwakar 2019, Law 2020)	Semi-structured interview	Evidence from 2 studies showed a variety of experiences of referral systems. While some parents/carers of babies, children and young people found gaining a referral to be a simple process others found it difficult and stressful. Parents of babies, children and young people report having to be very determined to gain referrals from primary care services. *'I'd sat and refused to leave until I had a referral…because a friend of mine actually told me they can't refuse to refer you. So, I said, 'I'm not leaving now until he gets the*	Moderate concerns[4]	No/very minor concerns	Minor concerns[5]	Moderate concerns[6]	VERY LOW

Study information		Description of theme or finding	CERQUAL Quality assessment				
No of studies	**Design**		**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
		referral'.' (Diwakar 2019, page 360, parental proxy)					
Sub-theme 3.4: Waiting times							
3 (Davison 2017, Diwakar 2019, Sime 2014)	Questionnaire, semi-structured interview, participatory-based focus group, family case study	Evidence from 3 studies show that the length of waiting times for appointments can be a barrier to continuity of healthcare. Long waiting times could be frustrating for children and young people and their families, causing them to access other avenues of healthcare (both formal and informal). *'They listen to me but I've been waiting for about four months now to get a reply and I still haven't.' (Davison 2017, page 102)*	Moderate concerns[7]	No/very minor concerns	No/very minor concerns	Minor concerns[8]	MODERATE

1 Evidence was downgraded due to minor concerns about methodological limitations as per CASP systematic review checklist
2 Evidence was downgraded due to serious concerns of the relevance of evidence as evidence systematic review includes 3 studies on the views of children and young people (up to the age of 24 years old) and 6 studies on the views of parents
3 Evidence was downgraded for adequacy because studies together did not offer rich data
4 Evidence was downgraded due to moderate concerns about methodological limitations as per CASP qualitative checklist
5 Evidence was downgraded due to moderate concerns of the relevance of evidence as evidence contains views of parental proxies on very specific subject (allergy pathways)
6 Evidence was downgraded for adequacy because studies together offered some rich data
7 Evidence was downgraded due to moderate concerns about methodological limitations as per CASP qualitative checklist
8 Evidence was downgraded for adequacy because studies together offered moderately rich data

Table 10: Evidence summary (GRADE-CERQual) for theme 4: Technological

Study information		Description of theme or finding	CERQUAL Quality assessment				
No of studies	**Design**		**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
Sub-theme 4.1: Ease of use							
2 (Diffin 2019, Waite-	Focus groups, semi-	Evidence from 1 study and 1 systematic review showed that children and young people and their	Minor concerns[1]	No/very minor concerns	Serious concerns[2]	Minor concerns[3]	VERY LOW

Study information		Description of theme or finding	CERQUAL Quality assessment				
No of studies	Design		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
Jones 2018)	structured interviews, systematic review	parents/carers will use technology to aid continuity of care if they are easy to use. For example, when physical personal health records were replaced by electronic ones, more children started to monitor their own symptoms as parents were unfamiliar with the technology. Implementation of such a service should include training for service users and their families to ensure that they have the necessary skills to fully utilise the service. No quotes presented for this theme.					
Sub-theme 4.2: Complements current healthcare management							
1 (Diffin 2019)	Systematic review	Evidence from 1 systematic review showed that children and young people and their parents/carers will use technology to aid continuity of care if it supplements or enhances current healthcare management. For example, children and young people who are already in frequent contact with their healthcare team are less concerned with communication features of electronic health records such as web message. No quotes presented for this theme.	Minor concerns[1]	No/very minor concerns	Serious concerns[2]	Minor concerns[3]	VERY LOW

1 Evidence was downgraded due to minor concerns about methodological limitations as per CASP qualitative checklist and CASP systematic review checklist
2 Evidence was downgraded due to serious concerns of the relevance of evidence as systematic review includes 3 studies on the views of children and young people (up to the age of 24 years old) and 6 studies on the views of parents
3 Evidence was downgraded for adequacy because studies together offered moderately rich data

Appendix G – Economic evidence study selection

Economic evidence study selection for review question: What factors promote, or present barriers to, continuity of care 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 factors promote, or present barriers to, continuity of care 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 factors promote, or present barriers to, continuity of care 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 factors promote, or present barriers to, continuity of care 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 factors promote, or present barriers to, continuity of care for babies, children and young people?

Clinical studies

Table 11: 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 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 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
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	Phenomenon of interest not in protocol - no themes relating to continuity of healthcare
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	Narrative review

Study	Reason for Exclusion
effective management strategies, Journal of perioperative practice, 20, 198-202, 2010	
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 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

Study	Reason for Exclusion
	relating to continuity of healthcare
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 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 continuity 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: 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	Conference abstract

Study	Reason for Exclusion
stroke, Developmental Medicine and Child Neurology, 3), 14-15, 2010	
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 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 continuity of healthcare
Best, Paul, Gil-Rodriguez, Elena, Manktelow, Roger, Taylor, Brian J., Seeking help from everyone and no-one: Conceptualizing the online help-seeking process among adolescent males, Qualitative health research, 26, 1067-1077, 2016	Phenomenon of interest not in protocol - no themes relating to 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

Study	Reason for Exclusion
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
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 continuity 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
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, 36-9, 41, 2015	Phenomenon of interest not in protocol - no themes relating to continuity of healthcare
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 continuity of healthcare

Study	Reason for Exclusion
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 Gastroenterology and Nutrition, 67 (Supplement 1), S184-S185, 2018	Conference abstract
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 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

Study	Reason for Exclusion
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 continuity of healthcare
Evans-Lacko, S., Gronholm, P., Roberts, R., Laurens, K., Stigma and other barriers to health and social care services among youth in Greater London, Psychiatrische Praxis. Conference: 9th International Conference of the European Network for Mental Health Service Evaluation, ENMESH, 38, 2011	Conference abstract
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.
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 engaging, British Journal of Social Work, 48, 578-595, 2018	Phenomenon of interest not in protocol - no themes relating to continuity of healthcare
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 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 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.
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	Phenomenon of interest not in protocol - no themes relating to continuity of healthcare

Study	Reason for Exclusion
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 continuity of healthcare
Heath, G., Greenfield, S., Redwood, S., The meaning of 'place' in families' lived experiences of paediatric outpatient care in different settings: A descriptive phenomenological study, Health and Place, 31, 46-53, 2015	Phenomenon of interest not in protocol - no themes relating to continuity 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.
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 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 continuity of healthcare
Leavey, Gerard, Rothi, Despina, Paul, Rini, Trust, autonomy and relationships: The help-seeking preferences of young people in	Phenomenon of interest not in protocol - no themes

Study	Reason for Exclusion
secondary level schools in London (UK), Journal of Adolescence, 34, 685-693, 2011	relating to continuity of healthcare
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 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 prepare marginalized youth for a transition to recovery in adulthood, Psychiatric rehabilitation journal, 41, 258-265, 2018	Population not in protocol - aged 18-75 years
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 continuity of healthcare

Study	Reason for Exclusion
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
Neill, S. J., Jones, C. H., Lakhanpaul, M., Roland, D. T., Thompson, M. J., Parents' help-seeking behaviours during acute childhood illness at home: A contribution to explanatory theory, Journal of child health care : for professionals working with children in the hospital and community, 20, 77-86, 2016	Phenomenon of interest not in protocol - no themes relating to continuity of healthcare
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 continuity 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 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

Study	Reason for Exclusion
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 continuity 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 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
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.
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 continuity 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 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	Country: Canada

Study	Reason for Exclusion
parents' varied experiences with specialised services for children with developmental disabilities, British Journal of Learning Disabilities, 43, 168-177, 2015	
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: 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.
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 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 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 continuity of healthcare

Study	Reason for Exclusion
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: 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	This systematic review included mainly quantitative studies. Qualitative studies were checked for inclusion, but these were not relevant 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 continuity of healthcare
Turnbull, J., Pope, C., Martin, D., Lattimer, V., Do telephones overcome geographical barriers to general practice out-of-hours services? Mixed-methods study of parents with young children, Journal of Health Services & Research Policy, 15, 21-7, 2010	Phenomenon of interest not in protocol - no themes relating to 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 Department over Primary Care: a Qualitative Metasynthesis, Journal of General Internal Medicine, 34, 2610-2619, 2019	Population not in protocol - Adult population only
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 continuity 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
Wales, Jackie, Brewin, Nicola, Raghavan, Raghu, Arcelus, Jon, Exploring barriers to South Asian help-seeking for eating disorders, Mental Health Review Journal, 22, 40-50, 2017	Population not in protocol - participants ≥18 years
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	Phenomenon of interest not in protocol - no themes relating to continuity of healthcare
Watts, R., Zhou, H., Shields, L., Taylor, M., Munns, A., Ngune, I., Family-centered care for hospitalized children aged 0-12 years: A	Phenomenon of interest of included studies not in

Study	Reason for Exclusion
systematic review of qualitative studies, JBI Database of Systematic Reviews and Implementation Reports, 12, 204-283, 2014	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 paper
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 continuity of healthcare
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, 02, 02, 2012	Phenomenon of interest not in protocol - no themes relating to continuity of healthcare

Economic studies

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

Appendix L – Research recommendations

Research recommendations for review question: What factors promote, or present barriers to, continuity of care 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 factors promote, or present barriers to, continuity of care 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 12: Evidence from reference groups and focus groups

Age < 7 years	Age 7-11 Years	Age 11-14 years	Overall quality of the evidence
• Do you want to see the same person every time or would you mind if you had to see different doctors every time? ○ Yes - 'I want to see the same doctor every time because if there was a new doctor they might be not nice. Makes you less nervous and scared' - 'Because they might not hurt me if they know me' - 'Because I like my doctor' - 'I went to see a doctor and they were very kind and the next time [a different doctor] was a bit mean so I want to be with the first one' - 'They will be friendly and might not hurt you' ○ Not sure - 'Need to know they are going to help you every time - what if they don't respect me?'	• Is it important to see the same doctor every time you go? ○ 2 agreed - 'Kind doctor who helps you so you want to go back' - 'Good to see the same person, means you can trust them' x2 - 'If you see the same person every time - it makes me feel happy… if you can't see the same person, because you're in a rush or something or go in the morning, you might not be able to' - 'The doctor knows me, and they know my past so won't have to explain again'	• What helps with continuity of care? ○ 'Seeing the same people every time' ○ 'Don't lose details for an appointment – avoid repetition' ○ 'Don't do things twice – like taking blood'	• Low

Age < 7 years	Age 7-11 Years	Age 11-14 years	Overall quality of the evidence
- 'I don't mind because I just care they are kind to me' ○ No - 'If I did see a doctor and they were rude to me I wouldn't want to see them again. If I saw a different doctor every time but they were kind to me, I would be fine to see a different one every time' - 'Because I'm just used to different doctors'			

Appendix N – Evidence from national surveys

Evidence from national surveys for review question: What factors promote, or present barriers to, continuity of care 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	• No relevant findings were identified for this question	• N/A
Care Quality Commission. Children and young people's inpatient and day case survey 2018	KNOWLEDGE OF MEDICAL HISTORY: • 58% parents of 0-15 year olds said staff were aware of their child's medical history DISCHARGE FROM HOSPITAL: • 79% of children 8-15 years old were given information on how to look after themselves at home; 69% knew what was going to happen next, and 72% knew who to talk to if they were worried	• Low
Child Outcomes Research Consortium. Child- and Parent-reported Outcomes and Experience from Child and Young People's Mental Health Services 2011-2015	• No relevant findings were identified for this question	• N/A
Health and Social Care Information Centre. Children's Dental Health Survey 2013. (Country specific report for England, published 2015)	• No relevant findings were identified for this question	• N/A
HM Inspectorate of Prisons.	• No relevant findings were identified for this question	• N/A

Survey	**Findings**	**Overall quality of the evidence**
Children in Custody 2016-2017		
National Children's Bureau. Listening to children's views on health provision 2012	DISCHARGE FROM TERTIARY CARE: • Disabled young people aged 15-21 recommended that at the stage of discharge from tertiary care after diagnosis, thought must be given to the way in which care packages impact on family life and ensure that they do not dis-empower families or young people. CONTINUITY OF CARE FOR CARE LEAVERS: • A consultation with young people in care and care leavers (age not specified) recommended that they should have twice a year check-ups (even when they leave care) and these should be up to 18 years of age and not stop at 16; carers should have more training on health and the young people should have the same health worker for health assessments, and a health folder that has all young people's health information in it.	• Moderate
Opinion Matters. Declare your care survey 2018	ADMISSION/ DISCHARGE/ TRANSFER: • Of young people who had raised a concern or made a complaint, in 31% the subject had related to admission, discharge or transfer, or a lack of communication between services such as their GP, hospital, or care services	• Low
Picker Institute. Children and Young People's Patient Experience Survey 2018	DISCHARGE FROM HOSPITAL: • 71% of parents of 0-7 years old knew what was going to happen next, and 79% knew who to talk to if they were worried about their child	• Low
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*	KNOWLEDGE OF MEDICAL HISTORY: • In your opinion, was important information about your baby passed from one member of staff to another? Score = 84 • Did the staff give you conflicting information about your baby's condition or care? Score = 67	• Moderate

Survey	Findings	Overall quality of the evidence
representing the best possible outcome (the scores are not percentages).	DISCHARGE FROM THE NEONATAL UNIT: • Were you offered overnight accommodation with your baby at the hospital before they left the neonatal unit? Score = 95 • Did you feel prepared for your baby's discharge from neonatal care? Score = 86 • Were you given enough information on what to expect in terms of your baby's progress and recovery? Score = 76	
Word of Mouth Research and Point of Care Foundation. An options appraisal for obtaining feedback on the experiences of children and young people with cancer 2018	• No relevant findings were identified for this question	• N/A

N/A: not applicable