National Institute for Health and Care Excellence

Draft for consultation

Babies, children and young people's experience of healthcare

[N] Supporting participation in usual activities

NICE guideline <number>

Evidence reviews underpinning recommendations 1.9.1 to 1.9.7 in the NICE guideline

March 2021

Draft for consultation

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

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ISBN:

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Supporting participation in usual activities

Review question

How can health services support babies, children, and young people to participate in usual activities (for example, family relationships, schooling, peer friendships, social activities)?

Introduction

Babies, children and young people who are unwell, are living with chronic conditions, or who are accessing healthcare services, can find it more difficult to participate in their usual activities. This may include activities of daily living (bathing, showering, eating), interactions with family and friends, social and emotional development, education and schooling, sports, hobbies and interests, social activities and use of social media. This difficulty can be related to specific aspects of their condition, or factors such as access or time taken away from their usual routine for healthcare treatment. In addition, periods of absence from school and families can negatively impact on both family relationships, friendships, and life opportunities.

The aim of this review is to determine how health services can support babies, children, and young people to participate in their usual activities.

Summary of the protocol

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

Table 1: Summary of the protocol

Population	• People <18 years old who have experience of healthcare
	• Studies that use the responses of parents or carers as proxies for their child will be included only if they are responding on behalf of their child or charge, and:
	  ○ the baby or child of the parent or carer is under 5 years old, or
	  ○ there is a clear rationale provided as to why the study is using parents' or carers' views on healthcare as proxies for their child.

Phenomenon of interest	Experience of healthcare, in particular of being supported to participate in usual activities whilst receiving healthcare
Primary outcomes	Themes will be identified from the literature. The committee identified the following potential themes (however, not all of these themes may be found in the literature, and additional themes may be identified): • Access to the digital environment (e.g. for recreational or educational purposes, maintaining contacts with peers and family) • Meeting the educational and learning needs of babies, children and young people during periods of ill health • Minimising the impact of healthcare and health problems on play, education and regular activities (e.g. providing sports equipment) • Providing information on participating in regular activities • Support for promoting or maintaining contact with siblings, peers and partners during hospitalisation (e.g. family accommodation) • Support from appropriate staff to encourage participation in usual activities

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

Methods and process

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

Clinical evidence

Included studies

This was a qualitative review with the aim of:

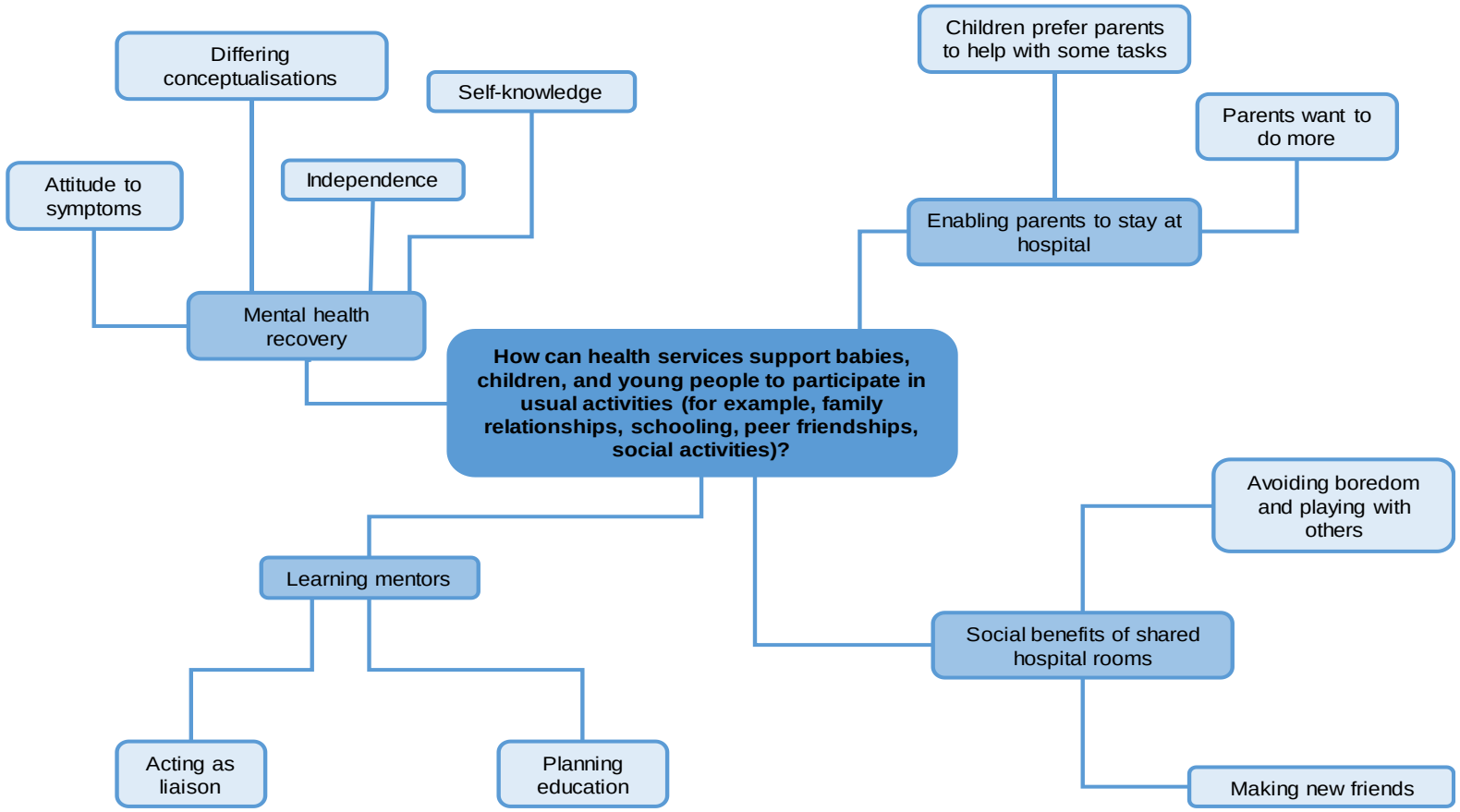
- Understanding how babies, children and young people prefer to be supported to continue with their usual activities by healthcare services.

A systematic review of the literature was conducted using a combined search. Three studies were included in this review, 2 of which used semi-structured interviews to collect data (Curtis 2017 and Law 2020), and 1 which used an open-ended postal questionnaire (Pini 2009). All 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.

1 Excluded studies

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

4 Summary of studies included in the evidence review

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

6 **Table 2: Summary of included studies**

Study	Population	Methods	Themes
Curtis 2017 **Study design** Ethnographic, including observation and semi-structured interview **Aim of the study** To study the impact of spatial aspects of children's hospital wards (single and shared rooms) upon family-centred care Sheffield, UK	N=17 children and young people **Characteristics:** Age (range): 5-16 years old Gender (M/F): 9/ 8	**Recruitment** Participants were recruited opportunistically from 4 wards ensuring sufficient diversity of experience of participants **Data collection** Observation and semi-structured interviews **Analysis** Thematic analysis	• Enabling parents to stay at hospital: Children prefer parents to help with some tasks • Enabling parents to stay: Parents want to do more • Social benefits of shared hospital rooms: Avoiding boredom and playing with others • Social benefits of shared rooms: Making friends
Law 2020 **Study design** Semi-structured interview **Aim of the study** To understand young people's concept of mental health recovery Norfolk and Greater Manchester, UK	N=23 young people **Characteristics:** Age range 14-25 years: • 14-17, n=15 • 18-21, n=5 • 22-25, n=3 Gender (M/F/Non-binary): 4/18/1 • ~34% of the sample in the study were over-18	**Recruitment** Convenience sample from two NHS Trusts **Data collection** Semi-structured interviews **Analysis** Thematic analysis	• Mental health recovery: Attitude to symptoms • Mental health recovery: Differing conceptualisations • Mental health recovery: Independence • Mental health recovery: Self-knowledge

Study	Population	Methods	Themes
Pini 2009 **Study design** Open-ended postal questionnaire **Aim of the study** To report on the role of a learning mentor established at Leeds Hospital Teaching Trust Leeds, UK	N=29 young people and adults **Characteristics:** Age (range): 13-25 years Gender (M/F): Not reported • Study includes participants >18 years of age but does not provide sufficient information to determine composition of sample by age	**Recruitment** Recruitment via postal questionnaires **Data collection** Response to open-ended postal questionnaire **Analysis** Thematic analysis	• Learning mentor: Acting as liaison • Learning mentor: Planning education

F: Female; M: Male; N/n: Number

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

Quality assessment of studies included in the evidence review

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

Main theme 1: Enabling parents to stay at hospital

- Sub-theme 1.1: Children prefer parents to help with some tasks. The overall confidence in this sub-theme was judged to be moderate.
- Sub-theme 1.2: Parents want to do more. The overall confidence in this sub-theme was judged to be moderate.

Main theme 2: Social benefits of shared hospital rooms

- Sub-theme 2.1: Avoiding boredom and playing with others. The overall confidence in this sub-theme was judged to be moderate.
- Sub-theme 2.2: Making new friends. The overall confidence in this sub-theme was judged to be moderate.

Main theme 3: Learning mentors

- Sub-theme 3.1: Acting as liaison. The overall confidence in this sub-theme was judged to be very low.
- Sub-theme 3.2: Planning education. The overall confidence in this sub-theme was judged to be very low.

Main theme 4: Mental health recovery

- Sub-theme 4.1: Attitude to symptoms. The overall confidence in this sub-theme was judged to be low.

- Sub-theme 4.2: Differing conceptualisations. The overall confidence in this sub-theme was judged to be low.
- Sub-theme 4.3: Independence. The overall confidence in this sub-theme was judged to be low.
- Sub-theme 4.4: Self-knowledge. The overall confidence in this sub-theme was judged to be low.

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

Evidence from reference groups and focus groups

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

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

Age groups	• 7-11 years • 11-14 years
Areas covered	• Support from healthcare services • Services which help children and young people to maintain their usual activities
Illustrative quotes	• 'Toys (top trumps, nerf guns)' • 'Have someone to help in the shower – mum, doctors' • 'Have your friend or mum helping you' • 'Wi-Fi available' • 'Using tech to play games' • 'Do homework in hospital' • 'Have friends and family to see us'

See the full evidence summary in appendix M.

Evidence from national surveys

The grey literature review of national surveys provided additional evidence for this review. A summary of the findings is provided 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 • 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 • Word of Mouth Research and Point of Care Foundation. An options appraisal for obtaining feedback on the experiences of children and young people with cancer 2018
Areas covered	• Wi-Fi • Play • Activities • Liaison with school • Social activities

Key findings	
	• Overall, children and young people reported to be satisfied with the Wi-Fi available and the activities offered in the healthcare settings they had visited. Most young children said that staff played with them • A quarter of young children reported that there were not enough age-appropriate things to do in the waiting room • Parents and carers of babies in the intensive care unit reported that they got involved in their baby's care, and that they had as much skin-to-skin contact with their baby as they wanted • A young person with cancer suggested that schools could have done more to tackle misunderstanding and ignorance regarding cancer. • Another young person with cancer said that the school hospital service was not well connected to the local school and that work was set that was inappropriate for the age group

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 preferences of children and young people in relation to their participation in usual activities while accessing healthcare. 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:

- Access to the digital environment (e.g. for recreational or educational purposes, maintaining contacts with peers and family)
- Meeting the educational and learning needs of babies, children and young people during periods of ill health
- Minimising the impact of healthcare and health problems on play, education and regular activities (e.g. providing sports equipment)

- Providing information on participating in regular activities
- Support for promoting or maintaining contact with siblings, peers and partners during hospitalisation (e.g. family accommodation)
- Support from appropriate staff to encourage participation in usual activities

Evidence was identified for most of these themes and related to the presence and role of parents, the social benefit of shared hospital rooms, the concept of mental health recovery, ; and supporting learning through the provision of a learning mentor. The committee did not prioritise any of these themes and considered all the evidence when making their recommendations.

The quality of the evidence

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

The quality of evidence for the sub-themes comprising the themes 'Enabling parents to stay at hospital' and 'Social benefits of shared hospital rooms' was moderate. The evidence was downgraded one level for methodological limitations, coherence of findings and adequacy of data as all sub-themes were informed by only 1 study (Curtis 2017).

The quality of evidence for the sub-themes comprising the themes 'Learning mentors' was very low. The evidence for the sub-themes was downgraded by 3 levels in 3 of the four GRADE-CERQual domains as the data was from a postal questionnaire with a low response rate, included participants up to 25-years old, and did not provide rich data (Pini 2009).

The quality of the evidence for the sub-themes comprising the theme 'Mental health recovery' was low, with 2 of the 4 domains, coherence and relevance, downgraded 2 levels. Only one study contributed to this theme and over 33% of the participants were between the ages of 18 and 25 years (Law 2020).

The review identified moderate quality evidence from children and young people's experience in children's hospitals (Curtis 2017) and very low quality evidence of the experience of teenagers and young adults with cancer receiving education mentoring (Pini 2009). As the evidence was so limited, the committee utilised the evidence alongside their expertise and experience to draft recommendations.

Benefits and harms

The evidence from the systematic review included 4 main themes relating to understanding how babies, children and young people prefer to be supported to continue their usual activities by healthcare services. The committee noted that there would be a difference in 'usual activities' between individual children, and that these would also differ for the same individual at different developmental stages. The committee agreed that it was necessary to determine what the usual activities were for an individual and what was important to them. The committee also agreed that impact of a health condition or accessing healthcare would vary between children and young people, and they should have the opportunity to identify and discuss their goals for the future with healthcare professionals, and how can they be supported in order to achieve these, and how their abilities to participate in usual activities may change over time. The committee therefore made recommendations relating to the identification of usual activities and discussing expectations and goals.

The committee discussed that, based on their knowledge and experience, allowing children and young people to continue with usual activities was beneficial to their wellbeing, and may reduce the boredom, anxiety and distress that can be associated with periods of illness. Some children and young people may need reasonable adjustments to their environment in order to continue with their usual activities. The committee also recommended that, when

supporting participation in usual activities, it was important to recognise that the needs of individuals would vary over time and so this should not be a static decision, and would need to be flexible and adaptable.

The committee noted that there was no evidence about the importance of the digital environment (for example, access to the Wi-Fi password) so that children and young people could stay in touch with friends by using social media and gaming, and for education. However, the committee recognised that this was essential part of everyday life for most children and young people and so included this in their recommendations, although they agreed this should only be in an inpatient setting, as otherwise it would require all settings such as pharmacies and school nurses' offices to provide free Wi-Fi and a password. The committee recognised that access to social media sites might be restricted in some healthcare settings, but agreed that with Wi-Fi children and young people should be able to keep in touch with family and friends by telephone, text or email.

There was evidence from the theme of enabling parents to stay in hospital that parents or carers were willing to participate in the care of their child when there were facilities for them to stay at the hospital, and some children preferred to receive help from their parents for specific tasks like washing. The committee discussed that 'usual activities' included 'usual care' and that it was more reassuring for some children if their usual care could be provided by their parents/carers, as it would be if they were at home. The committee discussed who was defined as a care-givers as it may not only be parents or carers. Older children may want friends or other family members to be involved. The committee agreed that it was important to establish who the child's normal support network is, and provide the infrastructure required to maintain that if appropriate. For some, contact with peers or siblings may be more important than parental support. Drawing from the evidence and utilising their own experience, the committee agreed that the involvement of an individual's usual support networks was crucial in maintaining activities of daily living and other usual activities. The committee therefore considered it important to support and facilitate such involvement in healthcare settings.

There was evidence that children found shared rooms in hospital helpful for making new friends, playing with other people and avoiding boredom, when compared to receiving care in a single room. The committee agreed that social areas were important to enable interaction, and reduce boredom. However, the committee disagreed that all children and young people prefer to stay within a shared room: in their experience many did not want to share a room, and this would be particularly true for older children and young people. However, the committee also noted that, although single rooms can provide privacy, they can also be isolating. The committee agreed that it is important for children and young people to have space for peace and quiet where they can retreat, but also there should be opportunities for children to find social spaces for interacting with others. Due to the small amount of evidence from only 1 study, the committee did not make a recommendation on whether children and young people should be in shared or single rooms. The committee also noted the evidence from the review question on healthcare environment (Evidence Review M). This review had shown that privacy enabled family life to continue for parents and carers of neonates admitted to a neonatal unit.

There was some evidence that children appreciated support to coordinate and continue their education, for example from a learning mentor, and that support such as individualising their timetable to fit around healthcare needs was helpful. The committee agreed that being able to continue their education is very important for children and young people and that it is important to have a person with a role for enabling/providing/supporting education for children in healthcare. The committee had experience of different types of support personnel, and discussed the potential role of a learning mentor, but agreed that the job title wasn't important as long as there was a link between the hospital services and usual education services. The committee were aware that local authorities had a legal duty to provide education and discussed that healthcare professionals could make a referral to the local

authority when a child was admitted to hospital to ensure that education is provided for them. The committee agreed that, for engagement in activities like education and learning, coordination between healthcare, education and social care was crucial, and so made a recommendation about this.

The committee noted that there was evidence from a theme on more specific aspects of healthcare – mental health recovery. The committee noted that over a third of the participants in the mental health recovery study (Law 2020) were over 18 years of age, and that the sub-themes reinforced the recommendations they had already made about individualising expectations and goals for participation in usual activities, and so they did not make any additional recommendations based on this sub-theme.

In addition to the evidence from the systematic review there was evidence from the reference and focus groups and evidence from the national surveys of children and young people's experience. The evidence from the reference groups and focus groups indicated that children and young people would like to continue with many of their usual leisure and social activities (for example seeing family, friends and pets), and liked to have a range of activities to keep them busy and occupied, particularly if an inpatient in a hospital setting. They also recognised the need to continue with education. Children and young people also recognised that it was important to continue with normal activities of daily living such as showering, washing hair, and that they may need help with this if they are ill or in hospital. The committee agreed that these views backed up the evidence from the systematic review and that their recommendations already covered these areas. The reference groups also mentioned the importance of children and young peoples' ability to access Wi-Fi, reinforcing the committee's view on this, and their decision to make a specific recommendation about this.

The evidence from the national surveys also highlighted the importance of good Wi-Fi access, being kept occupied when in an inpatient or outpatient setting, and being able to socialise with other children and access education. The parents of babies reported that it was important to be able to continue providing usual care to their babies, such as nappy changing and feeding. The committee discussed these findings and agreed that their recommendations provided advice on access to social and recreational activities and maintaining activities of daily living.

The committee discussed that a potential harm of the recommendations may be that children who are unwell could be expected to continue with usual activities when they are not able to do this, or do not wish to do it. The committee were also concerned that there may be a limit to what is achievable in certain healthcare settings or situations, and that this would need to be discussed sensitively with children and young people. The committee also noted that there may be considerations where continuing the usual activities of one person, may impact negatively on other people in the same healthcare setting, and this included a possible invasion of privacy (for example if photographs were taken and shared). The committee therefore included advice on recognising other people's privacy in the recommendation.

Religious, cultural and spiritual support had been identified as an important source of support for some children and young people in the review of factors important to the healthcare experience (Evidence review J) and the committee included the recommendations they had made on this topic in the section of the guideline on usual activities.

Cost effectiveness and resource use

There was no existing economic evidence for this review. The committee noted that there was a large variation in practice, and in resources allocated to maintaining usual activities across the health service. Implementing these recommendations may therefore result in resource implications for some services mainly in terms of additional staff time required. This may include time to identify and discuss aspects of their lives that are important to children and young people and facilitating continuation with their usual activities of daily life by liaising

with other services such as social and education services, or by involving their usual support networks. The committee also noted that for some services, recommendations may mean slightly altering their services, although these are likely to be minor changes and easy to implement, such as ensuring passwords are available for Wi-Fi access.

Recommendations supported by this evidence review

This evidence review supports recommendations 1.9.1 to 1.9.7 in the NICE guideline. Recommendation 1.8.8 is supported by evidence in evidence review J Improving experience of healthcare.

References

Curtis 2017

Curtis P, Northcott A. The impact of single and shared rooms on family-centred care in children's hospitals. Journal of Clinical Nursing. 2017 Jun;26(11-12):1584-96.

Law 2020

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

Pini 2009

Pini S. Education mentoring for teenagers and young adults with cancer. British Journal of Nursing. 2009 Nov 26;18(21):1316-9.

Appendices

Appendix A – Review protocol

Review protocol for review question: How can health services support babies, children, and young people to participate in usual activities (for example family relationships, schooling, peer friendships, social activities)?

Table 5: Review protocol

Field	Content
PROSPERO registration number	CRD42019145535
Review title	Supporting participation in usual activities
Review question	How can health services support babies, children, and young people to participate in usual activities (for example family relationships, schooling, peer friendships, social activities)?
Objective	To determine how health services can support babies, children, and young people to participate in usual activities.
Searches	The following databases will be searched: • CCTR • CDSR • Embase • MEDLINE • MEDLINE IN-Process • PsycINFO Searches will be restricted by: • Date: 2009 • Language of publication: English language only • Publication status: Conference abstracts will be excluded because these do not typically provide sufficient information to fully assess risk of bias • Standard exclusions filter (animal studies/low level publication types) will be applied

Field	Content
	• For each search (including economic searches), the principal database search strategy is quality assured by a second information specialist using an adaption of the PRESS 2015 Guideline Evidence-Based Checklist
Condition or domain being studied	Babies, children and young people's experience of healthcare
Population	• People <18 years-old who have experience of healthcare ○ Studies that use the responses of parents or carers as proxies for their child will be included only if they are responding on behalf of their child or charge, and ○ The baby or child of the parent or carer is under-5 years-old, or ○ There is a clear rationale provided as to why the study is using parents' or carers' views on healthcare as proxies for their child. Note: Studies where part of the population is <18 years-old and part of the population is ≥18 years-old will only be included if at least 66% of the sample is less than 18 years-old. Results will be stratified according to the following age groups: • <1 year-old (i.e. 364 days-old or less) • ≥1 to <12 years-old (i.e. 365 days-old to 11 years and 364 days-old) • ≥12 to <18 years-old (i.e. 12 years and 0 days-old to 17 years and 364 days-old)
Phenomenon of interest	Experience of healthcare, in particular of being supported to participate in usual activities whilst receiving healthcare
Comparator/Reference standard/Confounding factors	Not applicable
Types of study to be included	• Systematic reviews of qualitative studies • Studies using qualitative methods: focus groups, semi-structured and structured interviews, observations • Surveys conducted using open ended questions and a qualitative analysis of response. Note: Mixed methods studies will be included but only qualitative data will be extracted and risk of bias assessed. Systematic reviews that include evidence from countries not listed in the search strategy will be excluded if the sources of the themes and evidence from high-income countries cannot be clearly established. Evidence from individual qualitative studies conducted in the high-income countries listed in the search strategy will be included only if no relevant systematic review evidence is identified.

Field	Content

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

Field	Content
	○ Obesity prevention (CG43) ○ Physical activity for children and young people (PH17) ○ Weight management: lifestyle services for overweight or obese children and young people (PH47) • Pregnancy, including routine antenatal, intrapartum or postnatal care: ○ Antenatal and postnatal mental health: clinical management and service guidance (CG192) ○ Antenatal care for uncomplicated pregnancies (CG62) ○ Intrapartum care for healthy women and babies (CG190) ○ Intrapartum care for women with existing medical conditions or obstetric complications and their babies (NG121) ○ Multiple pregnancy: antenatal care for twin and triplet pregnancies (CG129) ○ Postnatal care up to 8 weeks after birth (CG37) ○ Pregnancy and complex social factors: a model for service provision for pregnant women with complex social factors (CG110) • Self-harm: ○ Self-harm in over 8s: long-term management (CG133) ○ Self-harm in over 8s: short-term management and prevention of recurrence (CG16) • Sexual health and contraception ○ Contraceptive services for under 25s (PH51) ○ Sexually transmitted infections and under-18 conceptions: prevention (PH3) ○ Harmful sexual behaviour among children and young people (NG55) • Smoking prevention: ○ Smoking: preventing uptake in children and young people (PH14) ○ Smoking prevention in schools (PH23) ○ Stop smoking interventions and services (NG92) • Transition from children's to adults services for young people using health or social care services (NG43)
Context	UK studies from 2009 onwards will be prioritised for decision making by the committee as those conducted in other countries may not be representative of current expectations about either services or current attitudes and behaviours of healthcare professionals. The committee presumes that due to their

Field	Content
	development, particular circumstances and/or condition, there are some topics that babies, children and young people may not be in a position to pronounce on, and that in these circumstances, it may be necessary to treat the 'indirect' responses of their parents or carers as proxies for their own views on and experiences of healthcare in order to make recommendations. The guideline committee will be consulted on whether a study should be included if it is unclear why parents' or carer's responses are being used instead of their child or charge, and reasons for exclusion if appropriate will be documented. Recommendations will apply to those receiving care in all settings where NHS- or local authority-commissioned healthcare is provided (including home, school, community, hospital, specialist and transport settings). Specific recommendations for groups listed in the Equality Considerations section of the scope may be also be made as appropriate.
Primary outcomes (critical outcomes)	Themes will be identified from the literature. The committee identified the following potential themes (however, not all of these themes may be found in the literature, and additional themes may be identified): • Access to the digital environment (e.g. for recreational or educational purposes, maintaining contacts with peers and family) • Meeting the educational and learning needs of babies, children and young people during periods of ill health • Minimising the impact of healthcare and health problems on play, education and regular activities (e.g. providing sports equipment) • Providing information on participating in regular activities • Support for promoting or maintaining contact with siblings, peers and partners during hospitalisation (e.g. family accommodation) • Support from appropriate staff to encourage participation in usual activities The following themes will not be covered in this review despite relating to supporting participation in usual activities: • Architectural/physical and organisational features of the environment (reviewed in RQ 6.1) • Emotional support by healthcare staff (will be reviewed in RQ 3.2 if relevant) • Pain assessment and management and physical comfort (will be reviewed in RQ 4.1 if relevant)
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.

Field	Content
	• Duplicate screening will not be undertaken for this question. • Full versions of the selected studies will be obtained for assessment. Studies that fail to meet the inclusion criteria once the full version has been checked will be excluded at this stage. Each study excluded after checking the full version will be listed, along with the reason for its exclusion. A standardised form will be used to extract data from studies, including study reference, research question, theoretical approach, data collection and analysis methods used, participant characteristics, second-order themes, and relevant first-order themes (i.e. supporting quotes). One reviewer will extract relevant data into a standardised form, and this will be quality assessed by a senior reviewer.
Risk of bias (quality) assessment	Risk of bias of individual qualitative studies will be assessed using the CASP Qualitative checklist. Risk of bias of systematic reviews of Qualitative studies will be assessed using the CASP (Critical Skills Appraisal Programme) Systematic Review checklist. See Appendix H in Developing NICE guidelines: the manual for further details. The quality assessment will be performed by one reviewer and this will be quality assessed by a senior reviewer.
Strategy for data synthesis	• Extracted second-order study themes and related first-order quotes will be synthesised by the reviewer into third-order themes and related sub-themes. • The GRADE-CERQual (Confidence in the Evidence from Reviews of Qualitative research; Lewin 2015) approach will be used to summarise the confidence in the third-order themes or sub-themes synthesized from the qualitative evidence. The overall confidence in evidence about each theme or sub-theme will be rated on four dimensions: methodological limitations, coherence, adequacy, and relevance. • Methodological limitations refer to the extent to which there were problems in the design or conduct of the studies and will be assessed with the CASP checklist for qualitative studies or systematic reviews as appropriate. Coherence of findings will be assessed by examining the clarity of the data. Adequacy of data will be assessed by looking at the degree of richness and quantity of findings. Relevance of evidence will be assessed by determining the extent to which the body of evidence from the primary studies are applicable to the context of the 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)

Field	Content			
	The committee are aware that children can experience substantial cognitive and developmental change during the ages of 1 and 12, and that there may be (though not necessarily) substantive differences between children in this group depending on the topic about which they are being asked. The committee will therefore be consulted regarding whether data regarding further subgroups within this age range (e.g. 1-5, 6-11) should be used. Subgroup analysis according to any of the groups listed in the Equality Considerations section of the scope will be conducted if there is sufficient data.			
Type and method of review	☐	Intervention		
	☐	Diagnostic		
	☐	Prognostic		
	☒	Qualitative		
	☐	Epidemiologic		
	☐	Service Delivery		
	☐	Other (please specify)		
Language	English			
Country	England			
Anticipated or actual start date				
Anticipated completion date	07 April 2021			
Stage of review at time of this submission	Review stage		Started	Completed
	Preliminary searches		☑	☑
	Piloting of the study selection process		☑	☑
	Formal screening of search results against eligibility criteria		☑	☑
	Data extraction		☑	☑
	Risk of bias (quality) assessment		☑	☑
	Data analysis		☑	☑

Field	Content
Named contact	**5a. Named contact** National Guideline Alliance **5b. Named contact e-mail** Infant&younghealth@nice.org.uk **5c. Organisational affiliation of the review** National Institute for Health and Care Excellence (NICE) and National Guideline Alliance
Review team members	NGA Technical Team
Funding sources/sponsor	This systematic review is being completed by the National Guideline Alliance, which receives funding from NICE.
Conflicts of interest	All guideline committee members and anyone who has direct input into NICE guidelines (including the evidence review team and expert witnesses) must declare any potential conflicts of interest in line with NICE's code of practice for declaring and dealing with conflicts of interest. Any relevant interests, or changes to interests, will also be declared publicly at the start of each guideline committee meeting. Before each meeting, any potential conflicts of interest will be considered by the guideline committee Chair and a senior member of the development team. Any decisions to exclude a person from all or part of a meeting will be documented. Any changes to a member's declaration of interests will be recorded in the minutes of the meeting. Declarations of interests will be published with the final guideline.
Collaborators	Development of this systematic review will be overseen by an advisory committee who will use the review to inform the development of evidence-based recommendations in line with section 3 of Developing NICE guidelines: the manual. Members of the guideline committee are available on the NICE website: https://www.nice.org.uk/guidance/indevelopment/gid-ng10119/documents
Other registration details	-
Reference/URL for published protocol	https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=145535
Dissemination plans	NICE may use a range of different methods to raise awareness of the guideline. These include standard approaches such as: • notifying registered stakeholders of publication • publicising the guideline through NICE's newsletter and alerts • issuing a press release or briefing as appropriate, posting news articles on the NICE website, using social media channels, and publicising the guideline within NICE.
Keywords	Babies; children; education; engagement; experience; family; friends; healthcare; infants; learning; participation; play; qualitative; relationships; support; usual activities; views

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

CASP: Critical Appraisal Skills Programme; CCTR/CENTRAL: Cochrane Controlled Trials Register); CDSR: Cochrane Database of Systematic Reviews; GRADE-CERQual: Grading of recommendations assessment, development and evaluation – confidence in the evidence from reviews of qualitative research; NGA: National Guideline Alliance; NHS: National Health Service; NICE: National Institute for Health and Care Excellence; PRESS: Peer Review of Electronic Search Strategies

Appendix B – Literature search strategies

Literature search strategies for review question: How can health services support babies, children, and young people to participate in usual activities (for example family relationships, schooling, peer friendships, social activities)?

Databases: Embase/Medline/PsycINFO

Date searched: 29/07/2020

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

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

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

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

1

2 **Database: Cochrane Library**

3 Date searched: 29/07/2020

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

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

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

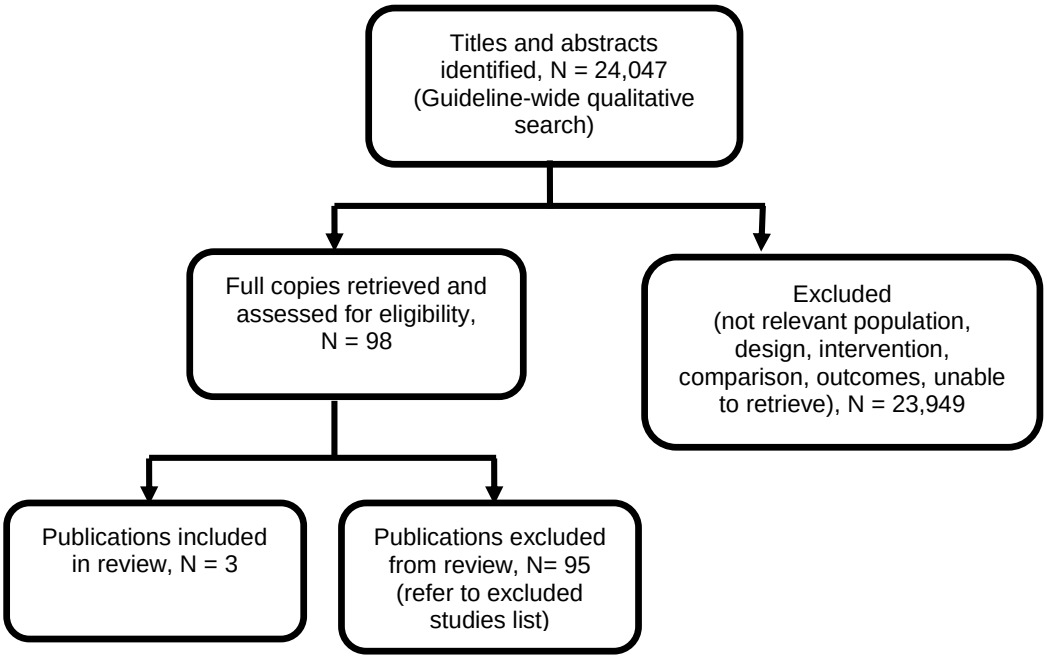
#	Search
135	#133 OR #134
136	#132 not #135
137	#125 not #136
138	#115 AND #137 with Cochrane Library publication date Between Jan 2009 and Aug 2020

1
2

Appendix C – Clinical evidence study selection

Study selection for: How can health services support babies, children, and young people to participate in usual activities (for example family relationships, schooling, peer friendships, social activities)?

Figure 2: Clinical evidence study selection flow chart



Appendix D – Clinical evidence tables

Evidence tables for review question: How can health services support babies, children, and young people to participate in usual activities (for example family relationships, schooling, peer friendships, social activities)?

Table 6: Evidence tables

Study details	Participants	Methods	Themes and findings	Limitations
Full citation Curtis, P., Northcott, A., The impact of single and shared rooms on family-centred care in children's hospitals, Journal of Clinical Nursing, 26, 1584-1596, 2017 **Ref Id** 958530 **Country/ies where the study was carried out** Sheffield, UK **Study type** Ethnographic (observation; semi-structured interview); Qualitative **Aim of the study** To study the impact of spatial aspects of	**Sample size** N=17 children and young people (semi-structured interviews) **Characteristics** Age (range): 5-16 years Gender (M/F): 9/8 All but 2 interviews included mother/female guardian, whilst fathers participated in 8 interviews **Inclusion criteria** • Family with resident child aged 5 or under, or • Family with resident child aged between 5 and 16 **Exclusion criteria**	**Setting** Specialist paediatric inpatient ward **Recruitment** Participants were recruited opportunistically from 4 hospital inpatient wards in one specialist paediatric hospital ensuring sufficient diversity of experience of participants. Sixty families sought for recruitment with 56 families finally recruited: 24 families with a resident child under-5 and 30 families with a resident child aged-5 or over. **Data collection** Study in two phases. First, observation on wards for 2 months in 4 wards (2 surgical, 2 general) about activities of daily life, everyday care tasks (eg. eating); second, semi-structured interviews, with children and parents using participatory methods such as toy characters, pictures and 3D mock-ups of rooms. Focus groups with nurse and support staff also	**Author's themes:** • Role expectations • Family-nurse interactions ○ Family support needs ○ Monitoring child's wellbeing ○ Survey-assess-interact within spatial contexts Data suggested that parents were willing to participate in care of their child when there were facilities for them to stay at the hospital. The data suggested that children preferred to receive help from their parents for specific tasks like washing when they had the when there were facilities for them to stay at the hospital. Study data suggested that children could make new friends, avoided boredom and could play with other people when staying in shared rooms, as compared to staying in single rooms at hospital**.**	**Limitations (assessed using the CASP checklist for qualitative studies).** *Q1: Was there a clear statement of the aims of the research?* Yes. *Q2: Was a qualitative methodology appropriate?* Yes. *Q3: Was the research design appropriate to address the aims of the research?* Yes. *Q4: Was the recruitment strategy appropriate to the aims of the research?* Yes. *Q5: Were the data collected in a way that addressed the research issue?* Yes. Semi-structured interviews justified and audio-recording mentioned. *Q6: Has the relationship between researcher and participants been adequately considered?* No. No description of potential

Study details	Participants	Methods	Themes and findings	Limitations
children's hospital wards (single and shared rooms) upon family-centred care **Study dates** 10-month study period (dates not reported) **Source of funding** Funded as part of Health Education Yorkshire and the Humber LETB Dignity and Respect Initiative, with additional support from Sheffield Children's Hospital NHS Foundation Trust.	Not reported	conducted. All interviews conducted in hospital at time convenient to participants. All groups and interviews audio recorded and both transcribed verbatim and anonymised concurrently. **Analysis** Thematic analysis using NVivo10, a computer-based data analysis package, involving initial reading, creation of initial codes, and development and review of themes.		bias/influence between researcher and participants provided. *Q7: Have ethical issues been taken into consideration?* Yes. Ethical approval gained from National Research ethics service. Written, informed consent obtained from all participants. Written consent for observation was obtained from those children old enough to provide this as well as from family members and nurses. In addition, written consent was also obtained before each interview or focus group. Participants were provided with age appropriate information sheets and invited to ask questions about the study before giving consent. *Q8: Was the data analysis sufficiently rigorous?* Unclear. Detailed account of analysis and methods used. Multiple quotes presented for each theme that has been extracted but no information given on how these quotes were chosen. *Q9: Is there a clear statement of findings?* Yes. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* Yes. 1. Study conducted in UK hospital and findings and representative of

Study details	Participants	Methods	Themes and findings	Limitations
				experience in hospital settings. 2. Small sample size and purposive sampling limits the transferability of the research**.** *Overall judgement of quality:* Minor concerns.
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** Norfolk and Greater Manchester, UK **Study type** Semi-structured interview; qualitative	**Sample size** N=23 young people **Characteristics** Gender: Male, n=4; female, n=18, non-binary=1 Age: 14-17 years-old, n=15; 18-21 years-old, n=5, 22-25-years-old, n=3. Ethnicity: White British, n=20; Asian Pakistani, n-1; White Other, n-1; Other, n=1. Duration of access to MH services: <1-year, n=5; 1-3 years, n=10; 4-7 years, n=4, >7 years, n=4. **Inclusion criteria**	**Setting** NHS Trust **Recruitment** 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	**Author's themes:** • Meaningful activity • Support networks • Access to mental health services • Meaningful alliance • Collaborative approach • Hope and motivation As with adults, young people viewed recovery from mental health difficulties as an individualised continuing journey to stability although there was variation in whether they thought it possible or helpful, and whether the goal of recovery consisted in reduction/disappearance of symptoms or learning to live with them. Goal of recovery for young person not always same as that of others (e.g. health professionals, parents). Being supported to be independent is important to young people. Variation in self-identity - viewing recovery as a return to a version of themselves already encountered (their 'best' self) or as opportunity to discover a version of	**Limitations <u>(assessed using the CASP checklist for qualitative studies)</u>.** *Q1: Was there a clear statement of the aims of the research?* Yes. *Q2: Was a qualitative methodology appropriate?* Yes. *Q3: Was the research design appropriate to address the aims of the research?* 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.

Study details	Participants	Methods	Themes and findings	Limitations
Aim of the study To understand young people's concept of mental health recovery **Study dates** Not reported **Source of funding** Not reported	• Aged between 14 and 25-years old. • Speaks English • Currently receiving services from mental health trusts **Exclusion criteria** Not reported	history of MH difficulties and access of services, understanding of the word 'recovery' generally and what it means to them, and personal experience of recovery including what has helped or hindered recovery. Interviews recorded and transcribed verbatim. **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.	themselves not already encountered (e.g. who can I be?) - may complicate discussions about treatment, and the impact this may have on young person's motivation and engagement may need to be taken this into account.	*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). *Q8: Was the data analysis sufficiently rigorous?* Yes. *Q9: Is there a clear statement of findings?* Yes. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability).* Yes. 1. Yes, discusses in context of literature. 2. Possibly 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** Participants were compensated for their participation in study with a £10 gift card.
Full citation Pini, S., Education mentoring for teenagers and young adults with cancer,	**Sample size** N=29 young people and adults	**Setting** Teaching hospital **Recruitment** Teenage and young adult cancer survivors at a teaching hospital	**Author's themes:** No themes reported, example questionnaire responses presented alongside topic (duty of learning mentor) of question.	**Limitations <u>(assessed using the CASP checklist for qualitative studies)</u>.** *Q1: Was there a clear statement of the aims of the research?* Yes.

Study details	Participants	Methods	Themes and findings	Limitations
British journal of nursing (Mark Allen Publishing), 18, 1316-1319, 2009 **Ref Id** 992214 **Country/ies where the study was carried out** Leeds, UK **Study type** Open-ended questionnaire; Qualitative **Aim of the study** To report on the role of a learning mentor established at Leeds Hospital Teaching Trust **Study dates** Conducted in 2008, no further details provided **Source of funding** Not reported	**Characteristics** Age (range): 13-25 years Gender (M/F): not reported **Inclusion criteria** • Received support from learning mentor **Exclusion criteria** Not reported	recruited through postal questionnaires, which was sent to 75 patients and 10 staff. All staff but only 29 patients completed questionnaire. **Data collection** Postal questionnaire consisted of open-ended questions about the main duties of the learning mentor such as providing course/career advice, acting as liaison between young person and place of education, being an advocate, and arranging work placements. **Analysis** Thematic analysis used but no details provided.	Data suggested that children and young people found having a learning mentor was helpful to them in supporting them in their lives but indicated that more support with what to do after treatment would be desirable, as well as home tuition for college students.	*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?* No. Postal questionnaire had only 39% response rate for patients. *Q5: Were the data collected in a way that addressed the research issue?* No. A face-to-face interview would be more appropriate than postal interview. *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?* Unclear. No mention about approval from ethics committee. *Q8: Was the data analysis sufficiently rigorous?* Unclear. Details not provided. *Q9: Is there a clear statement of findings?* No. Concentrates on

Study details	Participants	Methods	Themes and findings	Limitations
				positive features of learning mentor, inadequate discussion of researcher's arguments and no discussion of credibility of findings. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* Yes. 1. No, does not contextualise findings in literature. 2. Possibly yes. Role of learning mentor can plausibly be extended to other conditions and settings. *Overall judgement of quality:* Serious concerns. **Other information** Learning mentor - purpose is to provide education support in broad terms to 13-25 years-old oncology patients referred to Teenage and Young Adult service. Each new patient treated as individual. Learning mentors integral part of multidisciplinary team allowing them to keep up-to-date with patient's progress/upcoming treatments and promote importance of patient's education.

1 *CASP: Critical Skills Appraisal Programme*

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Appendix E – Forest plots

Forest plots for review question: How can health services support babies, children, and young people to participate in usual activities (for example family relationships, schooling, peer friendships, social activities)?

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

Appendix F – GRADE-CERQual tables

GRADE-CERQual tables for review question: How can health services support babies, children, and young people to participate in usual activities (for example family relationships, schooling, peer friendships, social activities)?

Table 7: Evidence summary (GRADE-CERQual) for theme 1: Enabling parents to stay at hospital

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
Sub-theme 1.1: Children prefer parents to help with some tasks							
1 (Curtis 2017)	Semi-structured interview	Data from 1 study showed that children preferred to receive help from their parents for specific tasks (e.g. washing) when they could stay at the hospital. *'And if you did start to need more help, like if you did have an operation, who do you think you'd want that extra help to come from? Would you be happy for nurses to help you with everything or would there be some things you'd prefer to come from your mum? Gabriel: I think there'd be some things that I'd prefer to come from you, but most of the stuff I'd be happy for nurses to help me with. Interviewer: What sort of things might it be that you'd prefer your mum to help with? Gabriel: Just like changing if I*	Minor concerns[1]	Minor concerns[2]	No or very minor concerns	Minor concerns[3]	MODERATE

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	**Design**		**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
		need to. Washing.' (Curtis 2017, page 12)					
Sub-theme 1.2: Parents want to do more							
1 (Curtis 2017)	Semi-structured interview	Data from 1 study suggested that parents were willing to participate in the care of their own child when there were facilities for them to stay at the hospital. *'We wouldn't have someone else come and change his nappy at home or give him his tea at home, so why would we expect it here?' (Curtis 2017, page 12)*	Minor concerns[1]	Minor concerns[2]	No or very minor concerns	Minor concerns[3]	MODERATE

1 *1 Evidence was downgraded for methodological limitations as per CASP qualitative checklist*
2 *2 Evidence was downgraded for coherence because only one study contributed to the review's findings*
3 *3 Evidence was downgraded for adequacy because study offered moderately rich data*

4 **Table 8: Evidence summary (GRADE-CERQual) for theme 2: Social benefits of shared hospital rooms**

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	**Design**		**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
Sub-theme 2.1: Avoiding boredom and playing with others							
1 (Curtis 2017)	Semi-structured interview	Data from 1 study suggested that children in shared hospital rooms value being able to play with each other compared to when they stay in single rooms. Single rooms were perceived to be boring and limited opportunities to play with other children.	Minor concerns[1]	Minor concerns[2]	No or very minor concerns	Minor concerns[3]	MODERATE

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	**Design**		**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
		'a bit boring' (Curtis 2017, page 14)					
Sub-theme 2.2: Making new friends							
1 (Curtis 2017)	Semi-structured interview	Data from 1 study suggested that children could make new friends when staying in shared hospital rooms, compared to when they stay in single rooms. *'you can have a little chit-chat. Like, if my mum's been talking to them. Like, there were a girl over there with that little girl yesterday and she had blonde hair and we started talking to her about that plane that went missing and then she started asking me what I thought had happened to it and I kept talking to her, so I were quite talkative, but I were only talkative because my mum had obviously been talking to her' (Curtis 2017, page 14)*	Minor concerns[1]	Minor concerns[2]	No or very minor concerns	Minor concerns[3]	MODERATE

1 *1 Evidence was downgraded for methodological limitations as per CASP qualitative checklist*
2 *2 Evidence was downgraded for coherence because only one study contributed to the review's findings*
3 *3 Evidence was downgraded for adequacy because study offered moderately rich data*

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

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Relevance of evidence	Adequacy of Data	Overall Confidence
Sub-theme 3.1: Acting as liaison							
1 (Pini 2009)	Open-ended postal questionnaire	Data from 1 study suggested that children and young people value how learning mentors act as liaisons between them and their main place of education and supportive services (e.g. hospital school, careers advice). *'The learning mentor got in touch with college, asked them to send me work and explained my situation.' (Pini 2009, page 1318)*	Serious concerns[1]	Moderate concerns[2]	Serious concerns[3]	Serious concerns[4]	VERY LOW
Sub-theme 3.2: Planning education							
1 (Pini 2009)	Open-ended postal questionnaire	Data from 1 study showed that children and young people value the help of learning mentors in planning and implementing their education plans. *'The learning mentor helped me a lot to choose my options and decide what paths and decisions were best for me. Also, when I was up to it, the hospital teachers gave me work to do' (Pini 2009, page 1318)*	Serious concerns[1]	Moderate concerns[2]	Serious concerns[3]	Serious concerns[4]	VERY LOW

1 Evidence was downgraded for methodological limitations as per CASP qualitative checklist
2 Evidence was downgraded for coherence because only one study contributed to the review's findings
3 Evidence was downgraded for relevance because study includes participants between 13 and 25 years of age but does not provide sufficient information to determine composition of sample by age
4 Evidence was downgraded for adequacy because study did not offer rich data

Table 10: Evidence summary (GRADE-CERQual) for theme 4: Mental health recovery

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
Sub-theme 4.1: Attitude to symptoms							
1 (Law 2020)	Semi-structured interview	Data from 1 study showed that young people do not all necessarily relate to their mental health symptoms in the same way, with some viewing the goal of recovery as a reduction or elimination of symptoms and others viewing it as coming to accept or cope with them. *'Ways to deal with the symptoms rather than just trying to like get rid of them … you need to find things that work to help you to just be able to cope with them and just kind of accept that they are there' (Law 2020, page 468)*	Minor concerns[1]	Moderate concerns[2]	Moderate concerns[3]	Minor concerns[4]	LOW
Sub-theme 4.2: Differing conceptualisations							
1 (Law 2020)	Semi-structured interview	Data from 1 study showed that recovery from mental health issues can be conceptualised in very different ways by young people, their parents and friends, and healthcare	Minor concerns[1]	Moderate concerns[2]	Moderate concerns[3]	Minor concerns[4]	LOW

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	**Design**		**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
		professionals. Viewing recovery as a journey is pervasive in the way young people think about it, although this conceptualisation may not always be helpful. Furthermore, some young people may not identify with the use of term 'recovery' depending on the pervasiveness of their condition and whether they think it is achievable. *'if you got everyone to sit down on the ward and everybody would say something different because it's different with every person … like everybody's recovery is their own path… two people won't have the exact same recovery path.' (Law 2020, page 466)*					
Sub-theme 4.3: Independence							
1 (Law 2020)	Semi-structured interview	Data from 1 study showed that young people value their independence in recovering from mental health issues and that they view this as important in their recovery. However, being left to one's own devices to recover may also be counterproductive.	Minor concerns[1]	Moderate concerns[2]	Moderate concerns[3]	Minor concerns[4]	LOW

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	**Design**		**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
		'If you've got too much freedom, you don't feel supported. You know wings still need support they need the wind under the wings for support' (Law 2020, page 468)					
Sub-theme 4.4: Self-knowledge							
1 (Law 2020)	Semi-structured interview	Data from 1 study showed that an important factor or goal for young people in recovery from mental health issues is either recapturing the best version of themselves if this indeed is known or has been experienced by them, or if it is not known, discovering what this might be. *'[Recovery is] achieving what you want to achieve, being who you want to be recovery is being the best version of myself' (Law 2020, page 468).*	Minor concerns[1]	Moderate concerns[2]	Moderate concerns[3]	Minor concerns[4]	LOW

1 *1 Evidence was downgraded for methodological limitations as per CASP qualitative checklist*
2 *2 Evidence was downgraded for coherence because only one study contributed to the review's findings*
3 *3 Evidence was downgraded for relevance because ~34% of the sample in the study were over-18*
4 *4 Evidence was downgraded for adequacy because study did not offer rich data*

Appendix G – Economic evidence study selection

Economic evidence study selection for review question: How can health services support babies, children, and young people to participate in usual activities (for example family relationships, schooling, peer friendships, social activities)?

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

Appendix H – Economic evidence tables

Economic evidence tables for review question: How can health services support babies, children, and young people to participate in usual activities (for example family relationships, schooling, peer friendships, social activities)?

No economic evidence was identified for this review.

Appendix I – Economic evidence profiles

Economic evidence analysis for review question: How can health services support babies, children, and young people to participate in usual activities (for example family relationships, schooling, peer friendships, social activities)?

No economic evidence was identified for this review.

Appendix J – Economic analysis

Economic evidence analysis for review question: How can health services support babies, children, and young people to participate in usual activities (for example family relationships, schooling, peer friendships, social activities)?

No economic analysis was conducted for this review question.

Appendix K – Excluded studies

Excluded studies for review question: How can health services support babies, children, and young people to participate in usual activities (for example family relationships, schooling, peer friendships, social activities)?

Clinical studies

Table 11: Excluded studies and reasons for their exclusion

Study	Reason for Exclusion
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	Specific to Duchenne muscular dystrophy
Abbott, David, Jessiman, Patricia, 'It's afforded us a huge flexibility': The impact of 'disabled children's access to childcare pilots' on families with a disabled child in England, Community, Work & Family, 17, 456-466, 2014	Reports impact of access to a childcare programme for children with disabilities and complex needs. Not related to engagement in usual activities in healthcare settings.
Abecassis, I. J., Nerva, J. D., Barber, J., Rockhill, J., Ellenbogen, R. G., Kim, L. J., Sekhar, L. N., Toward a comprehensive assessment of functional outcomes in pediatric patients with brain arteriovenous malformations: the Pediatric Quality of Life Inventory, Journal of Neurosurgery, Pediatrics. 18, 611-622, 2016	Not a qualitative study
Abela, K. M., Wardell, D., Rozmus, C., LoBiondo-Wood, G., Impact of Pediatric Critical Illness and Injury on Families: An Updated Systematic Review, Journal of pediatric nursing, 51, 21-31, 2020	Systematic review. References checked for possible included studies - none were identified.
Abelman, D. D., Mitigating risks of students use of study drugs through understanding motivations for use and applying harm reduction theory: a literature review, Harm reduction journal, 14, 68, 2017	Not related to engagement in family and peer relationships, continuing with social activities and schooling in healthcare settings
Aberdeen, J. N., Burnett, R. K. F., Stewart, H. F., Greenberg, E., The use of patient reported outcome measures by primary medical providers in the pediatric sports population, Orthopaedic Journal of Sports Medicine. Conference: 6th Annual Meeting of the Pediatric Research in Sports Medicine Society, PRiSM, 7, 2019	Conference abstract
Aceijas, C., Waldhausl, S., Lambert, N., Cassar, S., Bello-Corassa, R., Determinants of health-related lifestyles among university students, Perspectives in Public Health, 137, 227-236, 2017	Population not in protocol - University students (usually ≥18 years)
Ackerley, S. J., Gordon, H. J., Elston, A. F., Crawford, L. M., McPherson, K. M., Assessment of quality of life and participation within an outpatient rehabilitation setting, Disability & Rehabilitation, 31, 906-13, 2009	Not related to engagement in family and peer relationships, continuing with social activities and schooling in healthcare settings
Adams, C., Lockton, E., Gaile, J., Earl, G., Freed, J., Implementation of a manualized communication intervention for school-aged children with pragmatic and social communication needs in a randomized controlled trial: the Social Communication Intervention Project, International journal of language & communication disorders / Royal College of Speech & Language Therapists, 47, 245-256, 2012	Not a qualitative study, not related to engagement in family and peer relationships, continuing with social activities and schooling in healthcare settings
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

Study	Reason for Exclusion
Adams, S., Morris, D., Gilmore, G., Frampton, I., A novel parent-supported emotional literacy programme for children, Community practitioner, 83, 27â€• 30, 2010	Not related to engagement in family and peer relationships, continuing with social activities and schooling in healthcare settings
Afridi, S. K., Leschziner, G. D., Ferner, R. E., Prevalence and clinical presentation of headache in a National Neurofibromatosis 1 Service and impact on quality of life, American Journal of Medical Genetics, Part A, 167, 2282-2285, 2015	Not related to engagement in family and peer relationships, continuing with social activities and schooling in healthcare settings
Aggio, D., Smith, L., Fisher, A., Hamer, M., Mothers' perceived proximity to green space is associated with TV viewing time in children: The Growing Up in Scotland study, Preventive Medicine, 70, 46-49, 2015	Not related to engagement in family and peer relationships, continuing with social activities and schooling in healthcare settings
Agnew, T., Shared experience, Nursing Standard, 26, 22-4, 2012	Editorial article
Ahmed, Azza H., Sands, Laura P., Effect of pre- and postdischarge interventions on breastfeeding outcomes and weight gain among premature infants, Journal of Obstetric, Gynecologic, & Neonatal Nursing: Clinical Scholarship for the Care of Women, Childbearing Families, & Newborns, 39, 53-63, 2010	Not a qualitative study
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
Ahrens, W., Bammann, K., Siani, A., Buchecker, K., De Henauw, S., Iacoviello, L., Hebestreit, A., Krogh, V., Lissner, L., Marild, S., Molnar, D., Moreno, L., Pitsiladis, Y., Reisch, L., Tornaritis, M., Veidebaum, T., Pigeot, I., The IDEFICS cohort: Design, characteristics and participation in the baseline survey, International journal of obesity, 35, 53-515, 2011	Not related to engagement in family and peer relationships, continuing with social activities and schooling in healthcare settings
Akhtar, M. A., Honeyman, C., Aziz, F., Greenough, C., Kalyan, R., Hekal, W., The sky's the limit: Raising the quality and scope of communication for children with scoliosis and their families using digital and social media, British journal of neurosurgery, 30 (2), 177, 2016	Conference abstract
Alins Sahun, Y., Camara, K., Gething, K., Gane, J., Schenck, D., Tse, Y., School-based diabetes clinics: QI to engage frequent non-attenders and improve teenager's self-management, Archives of disease in childhood, 103 (Supplement 1), A158, 2018	Conference abstract
Alins Sahun, Y., Camara, K., Gething, K., Shenck, D., Gane, J., Tse, Y., Setting up school-based diabetes clinics to engage adolescents who frequently 'were not brought to clinic' and improve self-management, Archives of Disease in Childhood., 2019	Reports on access to healthcare services
Allard, A., Fellowes, A., Shilling, V., Janssens, A., Beresford, B., Morris, C., Key health outcomes for children and young people with neurodisability: Qualitative research with young people and parents, BMJ open, 4 (4) (no pagination), 2014	Not related to engagement in family and peer relationships, continuing with social activities and schooling in healthcare settings
Alsaleh, F. M., Smith, F. J., Thompson, R., Al-Saleh, M. A., Taylor, K. M., Insulin pump therapy: impact on the lives of children/young people with diabetes mellitus and their parents, International journal of clinical pharmacy, 36, 1023-30, 2014	The study is specific to impact of insulin pump therapy in diabetes
Aman, J., Skinner, T. C., de Beaufort, C. E., Swift, P. G. F., Aanstoot, H. J., Cameron, F., Martul, P., Chiarelli, F.,	Not a qualitative study

Study	Reason for Exclusion
Daneman, D., Danne, T., Dorchy, H., Hoey, H., Kaprio, E. A., Kaufman, F., Kocova, M., Mortensen, H. B., Njolstad, P. R., Phillip, M., Robertson, K. J., Schoenle, E. J., Urakami, T., Vanelli, M., Skovlund, S., Ackerman, R. W., Associations between physical activity, sedentary behavior, and glycemic control in a large cohort of adolescents with type 1 diabetes: The Hvidoere Study Group on Childhood Diabetes, Pediatric diabetes, 10, 234-239, 2009	
Anderson, L., Wilson, J., Williams, G., Cognitive Orientation to daily Occupational Performance (CO-OP) as group therapy for children living with motor coordination difficulties: An integrated literature review, Australian occupational therapy journal, 64, 170-184, 2017	Reported themes not related to engagement in usual activities
Angelis, A., Kanavos, P., Lopez-Bastida, J., Linertova, R., Nicod, E., Serrano-Aguilar, P., Social and economic costs and health-related quality of life in non-institutionalised patients with cystic fibrosis in the United Kingdom, BMC health services research, 15, 428, 2015	Not a qualitative study
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 outside of protocol - School-based health centers in USA
Armitage, S., Swallow, V., Kolehmainen, N., Ingredients and change processes in occupational therapy for children: a grounded theory study, Scandinavian journal of occupational therapy, 24, 208-213, 2017	Phenomenon of interest not in protocol - Improvements from baseline function rather than maintaining usual activities
Armstrong, V. G., Howatson, R., Parent-infant art psychotherapy: A creative dyadic approach to early intervention, Infant mental health journal, 36, 213-222, 2015	Not related to engagement in family and peer relationships, continuing with social activities and schooling in healthcare settings
Arnold, J., Bruce-Low, S., Henderson, S., Davies, J., Mapping and evaluation of physical activity interventions for school-aged children, Public Health, 136, 75-9, 2016	Not related to engagement in family and peer relationships, continuing with social activities and schooling in healthcare settings
Ashbullby, K. J., Pahl, S., Webley, P., White, M. P., The beach as a setting for families' health promotion: A qualitative study with parents and children living in coastal regions in Southwest England, Health and Place, 23, 138-147, 2013	Not related to engagement in family and peer relationships, continuing with social activities and schooling in healthcare settings
Ashfield-Watt, P., Philips, A., Dale, P., Hale, M., McDowell, I., Exploring digital arts-based approaches that empower children and young people with Familial Hypercholesterolaemia (FH), Atherosclerosis Supplements, 28, e6, 2017	Conference abstract
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	Not related to engagement in family and peer relationships, continuing with social activities and schooling in healthcare settings
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
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	Not related to engagement in family and peer relationships, continuing with social activities and schooling in healthcare settings
Baczynska, K. A., Price, L. L., Higlett, M. P., O'Hagan, J. B., Estimating Sun Exposure of Children in Day Care Nurseries in South Oxfordshire, UK, Photochemistry and photobiology, 92, 193-200, 2016	Not related to engagement in family and peer relationships, continuing with social activities and schooling in healthcare settings
Ball, S. L., Newbould, J., Corbett, J., Exley, J., Pitchforth, E., Roland, M., Qualitative study of patient views on a	Population >17 years

Study	Reason for Exclusion
'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	
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	Not a qualitative study
Carlton, J., Identifying potential themes for the Child Amblyopia Treatment Questionnaire, Optometry and vision science : official publication of the American Academy of Optometry, 90, 867-873, 2013	No relevant subject matter - reports on development of QoL instrument
Dantas, Kaliny Oliveira, Neves, Robson da Fonseca, Ribeiro, Katia Suely Queiroz Silva, Brito, Geraldo Eduardo Guedes de, Batista, Marcia do Carmelo, Repercussions on the family from the birth and care of children with multiple disabilities: a qualitative meta-synthesis, Repercussoes do nascimento e do cuidado de criancas com deficiencia multipla na familia: uma metassintese qualitativa., 35, e00157918, 2019	Systematic review. References checked for possible included studies - none were identified.
Dauz Williams, P., Piamjariyakul, U., Carolyn Graff, J., Stanton, A., Guthrie, A. C., Hafeman, C., Williams, A. R., Developmental disabilities: Effects on well siblings, Issues in comprehensive pediatric nursing, 33, 39-55, 2010	Not related to engagement in family and peer relationships, continuing with social activities and schooling in healthcare settings
De Monte, Rachel, Rodger, Sylvia, Jones, Fiona, Broderick, Sarah, Living with juvenile idiopathic arthritis: Children's experiences of participating in home exercise programmes, The British Journal of Occupational Therapy, 72, 357-365, 2009	Specific to juvenile idiopathic arthritis
De Souza, L., Frank, A. O., Patients' experiences of the impact of chronic back pain on family life and work, Disability & RehabilitationDisabil Rehabil, 33, 2011	Population >17 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
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	Not related to engagement in family and peer relationships, continuing with social activities and schooling in healthcare settings
Dow, B. L., Kenardy, J. A., Long, D. A., Le Brocque, R. M., Cognitive/affective factors are associated with children's acute posttraumatic stress following pediatric intensive care, Psychological trauma : theory, research, practice and policy, 11, 55-63, 2019	Country not in protocol: Australia
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	Study conducted in 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

Study	Reason for Exclusion
Dula, G., Seth, A., Jononis, M., Mohamedally, D., Conner, S., Priestman, W., Sebire, N. J., 'reward rush' for gosh: Development of a mobile augmented reality application (APP) to improve patient experience at gosh, Archives of disease in childhood, 103 (Supplement 2), A50-A51, 2018	Conference abstract
Duncombe, R., Evans Fry, R., An innovative app designed to reduce healthcare-related anxiety in young children, Archives of Disease in Childhood, 103 (Supplement 1), A160, 2018	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	Conference abstract
Edwards, M., Lawson, C., Rahman, S., Conley, K., Phillips, H., Uings, R., What does quality healthcare look like to adolescents and young adults? Ask the experts!, Clinical Medicine, Journal of the Royal College of Physicians of London, 16, 146-151, 2016	Population >17 years
Eisen, Isabel, Cunningham, Barbara Jane, Campbell, Wenonah, Al-Busaidi, Batorowicz Bell Bergold Boxall Bruce Burles Capewell Carlsson Carnahan Carter Cheak-Zamora Cheak-Zamora Clark-Ibanez Cluley Coad Collier Connelly Cussen Danker Dassah Dockrell Faircloth Fereday Galloway Germain Gibson Gibson Gillam Goldbart Goodwin Ha Harper Harrington Holliday Jones King Kirk Lal Lamb Lariviere-Bastien Lindsay Lloyd Mahon Molloy Nguyen Obrusnikova Owen Phelan Pinborough-Zimmerman Prins Ripat Savin-Baden Singhal Smith Sunderland Teti Wang Wang Ware Whitney Wiart, Conducting participatory photography with children with disabilities: A literature review, Disability and Rehabilitation: An International, Multidisciplinary Journal, 41, 1943-1954, 2019	Systematic review. References checked for possible included studies - none were identified.
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	Not related to engagement in family and peer relationships, continuing with social activities and schooling in healthcare settings
Ellis, S. J., Drew, D., Wakefield, C. E., Saikal, S. L., Punch, D., Cohn, R. J., Results of a nurse-led intervention: connecting pediatric cancer patients from the hospital to the school using videoconferencing technologies, Journal of pediatric oncology nursing : official journal of the Association of Pediatric Oncology Nurses, 30, 333-341, 2013	Study conducted in Australia
Fager, S. K., Burnfield, J. M., Patients' experiences with technology during inpatient rehabilitation: Opportunities to support independence and therapeutic engagement, Disability and Rehabilitation: Assistive Technology, 9, 121-127, 2014	Population >17 years
Farrugia, E., Edwards, K., Art therapy in hospital waiting rooms, Rheumatology (United Kingdom), 57 (Supplement 8), viii8, 2018	Conference abstract
Fasciano, K., Souza, P., Bielaczyc, A., Englander, S., Building connection and creating community through the development of a young adult cancer conference, Psycho-Oncology, 3), 191-192, 2014	Conference abstract
Fasciano, K., Trevino, K., Waterberg, R., Englander, S., An internet based psychosocial resource for young adults with cancer, Psycho-Oncology, 1), 13-14, 2012	Conference abstract
Fawcett, R., Porritt, K., Stern, C., Carson-Chahhoud, K., Experiences of parents and carers in managing asthma in children: A qualitative systematic review, JBI Database of	Systematic review. References checked for possible included studies - none were identified.

Study	Reason for Exclusion
Systematic Reviews and Implementation Reports, 17, 793-984, 2019	
Fernandez Medina, I. M., Granero-Molina, J., Fernandez-Sola, C., Hernandez-Padilla, J. M., Camacho Avila, M., Lopez Rodriguez, M. D. M., Bonding in neonatal intensive care units: Experiences of extremely preterm infants' mothers, Women & Birth: Journal of the Australian College of MidwivesWomen Birth, 31, 325-330, 2018	Reports mother's experiences rather than mothers reporting babies' experiences as a proxy
Foster, Mandie Jane, Whitehead, Lisa, Maybee, Patricia, Cullens, Victoria, 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	Systematic review with no potentially eligible studies
Franck, L. S., Ferguson, D., Fryda, S., Rubin, N., The child and family hospital experience: Is it influenced by family accommodation?, Medical Care Research and Review, 72, 419-437, 2015	Study conducted in USA
Gathercole, K., Managing cystic fibrosis alongside children's schooling: Family, nurse and teacher perspectives, Journal of child health care, 1367493518814930, 2018	Specific to the management of cystic fibrosis
Gathercole, K. A., The educational experiences of children with cystic fibrosis, Journal of Cystic Fibrosis, 16 (Supplement 1), S39, 2017	Conference abstract
Gettings, S., Franco, F., Santosh, P. J., Facilitating support groups for siblings of children with neurodevelopmental disorders using audio-conferencing: A longitudinal feasibility study, Child and Adolescent Psychiatry and Mental Health, 9 (1) (no pagination), 2015	Not related to engagement in family and peer relationships, continuing with social activities and schooling in healthcare settings
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	Not related to engagement in family and peer relationships, continuing with social activities and schooling in healthcare settings
Heywood, J., Nothing about us without us: involving families in early support, Community practitioner, 82, 26-9, 2009	Not related to engagement in family and peer relationships, continuing with social activities and schooling in healthcare settings
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	Not related to engagement in family and peer relationships, continuing with social activities and schooling in healthcare settings
Kuhn, E. S., Laird, R. D., Family support programs and adolescent mental health: Review of evidence, Adolescent Health, Medicine and Therapeutics, 5, 127-142, 2014	Population of included studies not in protocol. Included studies checked for inclusion.
Lambert, V., Coad, J., Hicks, P., Glacken, M., Social spaces for young children in hospital, Child: care, health and development, 40, 195-204, 2014	Study conducted in Ireland
Lape, E. C., Katz, J. N., Losina, E., Kerman, H. M., Gedman, M. A., Blauwet, C. A., Participant-Reported Benefits of Involvement in an Adaptive Sports Program: A Qualitative Study, PM and R, 10, 507-515, 2018	Not related to engagement in family and peer relationships, continuing with social activities and schooling in healthcare settings
Lester, H., Marshall, M., Jones, P., Fowler, D., Amos, T., Khan, N., Birchwood, M., Views of young people in early intervention services for first-episode psychosis in England, Psychiatric Services, 62, 882-887, 2011	Population not in protocol - Ages 14-35 years with data not presented separately for target population.
Liabo, Kristin, Gray, Kerry, Mulcahy, David, A systematic review of interventions to support looked-after children in school, Child & Family Social Work, 18, 341-353, 2013	Not related to engagement in family and peer relationships, continuing with social activities and schooling in healthcare settings

Study	Reason for Exclusion
Martin Ginis, K. A., Ma, J. K., Latimer-Cheung, A. E., Rimmer, J. H., A systematic review of review articles addressing factors related to physical activity participation among children and adults with physical disabilities, Health Psychology ReviewHealth psychol, 10, 478-494, 2016	Systematic review with no potentially eligible studies
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	Not related to engagement in family and peer relationships, continuing with social activities and schooling in healthcare settings
McMillan, S. S., Wilson, B., Stapleton, H., Wheeler, A. J., Young people's experiences with mental health medication: A narrative review of the qualitative literature, Journal of Mental Health, 2020	Review of experience of mental health medication in young people, no relevant studies
Mueller, C., Wang, Y., Brooks, A., Morant, N., Sullivan, P., Raymont, V., 'Attending to the wound and the person' - patients' experiences and expectations of a newly established traumatic brain injury clinic, Brain Injury, 31, 1863-1870, 2017	Not related to engagement in family and peer relationships, continuing with social activities and schooling in healthcare settings
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	Not related to engagement in family and peer relationships, continuing with social activities and schooling in healthcare settings
Northcott, A., Curtis, P., Reid, J., Family-centred cubicles? issues associated with delivering and receiving care in cubicles, Archives of disease in childhood, 3), A99-A100, 2015	Conference abstract
Pampoulou, Eliada, Collaboration between speech and language therapists and school staff when working with graphic symbols, Child Language Teaching and Therapy, 32, 361-376, 2016	Not related to engagement in family and peer relationships, continuing with social activities and schooling in healthcare settings
Parker, Wendy, Gage, Heather, Sterr, Annette, Williams, Peter, Holiday play for children with disabilities in England: Access, choice and parents' views about integration, International Journal of Disability, Development and Education, 64, 573-595, 2017	Not related to engagement in family and peer relationships, continuing with social activities and schooling in healthcare settings
Pickering, D., Busse, M., Disabled children's services: how do we measure family-centred care?, Journal of child health care : for professionals working with children in the hospital and community, 14, 200-207, 2010	Population not in protocol - Views of healthcare professionals and parents (with no mention of the age of children).
Robinson, S., Children and young people's views of health professionals in England, Journal of child health care : for professionals working with children in the hospital and community, 14, 310-326, 2010	Related to views about staff.Not related to engagement in family and peer relationships, continuing with social activities and schooling in healthcare settings
Runions, K. C., Vithiatharan, R., Hancock, K., Lin, A., Brennan-Jones, C. G., Gray, C., Payne, D., Chronic health conditions, mental health and the school: A narrative review, Health Education Journal, 79, 471-483, 2020	Scoping review. References checked for possible included studies - none were identified.
Schuller, L., Thaker, K., Instant messaging: The way to improve access for young people to their school nurse, Community practitioner : the journal of the Community Practitioners' & Health Visitors' Association, 88, 34, 36-8, 2015	Phenomenon of interest not in protocol - Access to healthcare services
Shorey, S., Ng, E. D., The Lived Experiences of Children and Adolescents with Non-Communicable Disease: A Systematic Review of Qualitative Studies, Journal of pediatric nursing, 51, 75-84, 2020	Review of lived experience of children with non-communicable disease, no relevant studies

Study	Reason for Exclusion
Staniszewska,S., Brett,J., Redshaw,M., Hamilton,K., Newburn,M., Jones,N., Taylor,L., The POPPY study: developing a model of family-centred care for neonatal units, Worldviews on Evidence-Based Nursing, 9, 243-255, 2012	Describes the POPPY model of care, does not include qualitative data on BCYP engagement in usual activities
Stuart, M., Melling, S., Understanding nurses' and parents' perceptions of family-centred care, Nursing children and young people, 26, 16-21, 2014	Population not in protocol - Views of healthcare professionals and parents (with no mention of the age of children).
Swallow, V., Forrester, T., Macfadyen, A., Teenagers' and parents' views on a short-break service for children with life-limiting conditions: a qualitative study, Palliative Medicine, 26, 257-67, 2012	Specific to children with life limiting conditions
Telfer, S., Solomonidis, S., Spence, W., An investigation of teaching staff members' and parents' views on the current state of adaptive seating technology and provision, Disability and rehabilitation, Assistive technology. 5, 14-24, 2010	Not related to engagement in family and peer relationships, continuing with social activities and schooling in healthcare settings
Torres Stone, R. A., Sabella, K., Lidz, C. W., McKay, C., Smith, L. M., The meaning of work for young adults diagnosed with serious mental health conditions, Psychiatric rehabilitation journal, 41, 290-298, 2018	Not related to engagement in family and peer relationships, continuing with social activities and schooling in healthcare settings
Vorster, N., Evans, K., Murphy, N., Kava, M., Cairns, A., Clarke, D., Ryan, M. M., Siafarikas, A., Rowe, P. W., Parkinson, S., Gaynor, O., Chiu, L., Anderson, J., Bayley, K., Jacoby, P., Cross, D., Downs, J., Powered standing wheelchairs promote independence, health and community involvement in adolescents with Duchenne muscular dystrophy, Neuromuscular Disorders, 29, 221-230, 2019	Specific to wheelchair use in DMD; Not related to engagement in family and peer relationships, continuing with social activities and schooling in healthcare settings
Walsh, L., Play in the children's hospital; discreet activity or way of life?, Archives of disease in childhood, 103 (Supplement 2), A46, 2018	Conference abstract
Whale, K., Cramer, H., Joinson, C., Left behind and left out: The impact of the school environment on young people with continence problems, British journal of health psychology, 23, 253-277, 2018	Does not report themes related to Not related to engagement in family and peer relationships, continuing with social activities and schooling in healthcare settings

Economic studies

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

Appendix L – Research recommendations

Research recommendations for review question: How can health services support babies, children, and young people to participate in usual activities (for example family relationships, schooling, peer friendships, social activities)?

No research recommendations were made for this review question.

Appendix M – Evidence from reference groups and focus groups

Reference group and focus group evidence for review question: How can health services support babies, children, and young people to participate in usual activities (for example family relationships, schooling, peer friendships, social activities)?

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

Table 12: Evidence from reference groups and focus groups

Age < 7 years	Age 7-11 Years	Age 11-14 years	Overall quality of the evidence
• There was no evidence from this group for this question.	• Ask us 'What do you like to do?' • Tablets to play with • Toys that you like • Toy maker like Santa • Drawing • Make up video games • Entertainment for inpatients • Have a TV and tech you can use x2 (and engineer to fix TV when they're broken) • Internet / Computers / Computer games • iphones • Play games • Have wi-fi available • Play arts and crafts • Play football – have balls in hospital you can use • Flying glowing insect battle [glow flies] • Toys (top trumps, nerf guns) • Have someone to help in the shower – mum, doctors • Have your friend or mum helping you	• Don't wake us up • Free wi-fi x2 • Dogs/animals • Cards and games • Toys in consultation room • Interactive/games • Having someone to be there (MH services) • Using tech to play games (to take our mind off) • Teddies for comfort • Help to be clean (shower/bath) • *NB: List below from group when questions phrased as 'What services keep us healthy to enable us to do our usual activities?' so evidence is less applicable.* • *Meditating helps us to relax* • *Going to the shops or shopping – shop mobility* • *Travelling – organised weekly trips* • *School/friends can help with mental health*	• Low

Age < 7 years	Age 7-11 Years	Age 11-14 years	Overall quality of the evidence
	• Have an alarm so we can call for help, have special alarms/reminders to remember to brush our teeth and hair etc. • Do homework in hospital • Ask if someone can go to hospital to help you learn – like your teacher. Get your teacher to email work to your parents • Be home schooled • Have someone to help you with spelling – ask your teacher to speak to your doctor for extra homework • Company – have parents to stay • Have friends and family to see us • Understand our food likes/dislikes • Eat ice cream and chocolate • Have sweets and some treats • Read books, need to have/share books in hospital; • Play with dogs • Have cats – animal therapy in hospital • Animals – dogs, cats, ferret, Labrador – good with kids, rabbits, salamander, lizards. (Although some people might be going to the doctors because of an animal so there should be a separate room) • If you cannot sleep – have food, have a lullaby, someone read a bedtime story, take a sleeping tablet • Calm and sleepy lights, 3D projector • Doctors be funny, make me feel happy • Swimming with a broken arm – have something to protect the cast; keep the cast out of the water, sit on special equipment.	• *Feeling happy helps us to have a bright mind* • *Clean helps us to not feel sweaty* • *Dentists/GPs help us know what healthy to eat* • *Reading help us to get comfortable* • *Communicating help us to understand other people* • *Having water helps us to not be dehydrated* • *Seeing eye specialist* • *Sleeping helps us to recharge ourselves for the next day* • *Dentists help us have healthy mouths* • *School help us to be educated* • *Reading – opticians – glasses* • *Eating- dentists – make sure mouth* • *Having a good relationship with your family helps us to feel comforted* • *Hearing ear specialists* • *Having friends helps us to not be lonely* • *Dentists = help to look after our teeth – look at our teeth to make sure they are healthy – give fillings if we need them – stop pain* • *Stress relievers help us to be 100% focused* • *Being well locked after help us to be encouraged to do things. Being relaxed helps us to figure things out.* • *Horse riding – scans for hips and back – to help stay balanced – to know if you need surgery* • *Shower or bath – making sure you don't drown in bathtub.*	

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Appendix N – Evidence from national surveys

Evidence from national surveys for review question: How can health services support babies, children, and young people to participate in usual activities (for example family relationships, schooling, peer friendships, social activities)?

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 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	WIFI: • 41% of 8-15 year olds who used hospital Wi-Fi said that it was 'always' good enough to do what they wanted. PLAY: • Of those children aged 8-11 who wanted to play: ○ 23% - happened a lot ○ 38% - happened a little ○ 39% - did not happen. • 73% of parents of children aged 0-7 said yes, staff played with them ACTIVITIES: • Approximately half of all children and young people (aged 8 to 15) said there were enough things for them to do. • 63% of parents of 0 to 7 year olds said there was enough for them to do	• Low
Child Outcomes Research Consortium.	• No relevant findings were identified for this question	• N/A

Survey	Findings	Overall quality of the evidence
Child- and Parent-reported Outcomes and Experience from Child and Young People's Mental Health Services 2011-2015		
Health and Social Care Information Centre. Children's Dental Health Survey 2013. (Country specific report for England, published 2015)	• No relevant findings were identified for this question	• N/A
HM Inspectorate of Prisons. Children in Custody 2016-2017	• No relevant findings were identified for this question	• N/A
National Children's Bureau. Listening to children's views on health provision 2012	• No relevant findings were identified for this question	• N/A
Opinion Matters. Declare your care survey 2018	• No relevant findings were identified for this question	• N/A
Picker Institute. Children and Young People's Patient Experience Survey 2018.	WIFI: • 36% of parents of 0 to 7 year olds said Wi-Fi was good enough for children to do what they wanted to do	• Low
Picker Institute. Paediatric Emergency Department Survey 2015 and Children and Young People's Outpatient Survey 2015	ACTIVITIES (OUTPATIENTS): • 26% of children and young people aged 8 to 16 thought there was enough age-appropriate things to do in the waiting room	• Low
Picker Institute/NHS England/Bliss. Neonatal Survey 2014 *Results for individual questions were converted into scores on a scale of 1 to 100, with 100 representing the best possible outcome (the scores are not percentages).*	INVOLVEMENT IN CARING FOR THEIR BABY: • Were you involved as much as you wanted in the day-to-day care of your baby, such as nappy changing and feeding? Score = 89 • Did you have as much skin-to-skin contact with your baby as you wanted? Score = 72 • Where possible, did staff arrange your baby's care (such as weighing, bathing) to fit in with your usual visiting times? Score = 74	• Moderate

Survey	Findings	Overall quality of the evidence
	• Overall, did staff help you feel confident in caring for your baby? Score = 89	
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	LIAISION WITH SCHOOL: • 1 teenager suggested it would have been helpful if the hospital could have done more to tackle misunderstanding and ignorance about cancer and treatment for cancer at his school. • Other young person reported that the school hospital service was not well connected to the local school and that work was set that was inappropriate for the age group. Quotes: 'My friends were really good with me and treated me like a normal person, but not everybody knew about my cancer. I imagine that it's worse in a bigger school. The hospital could send someone out to talk at the school to explain what's going on. Because everyone asked me, and it's not something I really want to talk about. If they could explain what I could and couldn't do, that would have helped big time.' (M16) 'They had someone come in but she could only do work that was for the year below me. It was because they're not working with the local secondary school in (hospital).' (F14) 'The school service was ok but they only came on the last day I was there.' (F15) SOCIAL ACTIVITIES: • Some young people aged 13 to 17 years reported that they felt isolated in a room away from other people. Quotes: 'The social aspects: that was not so good. Because in (hospital) all the cancer patients are put in a side room, so you don't see people.' (F14)	• Low

1 *N/A: not applicable*

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