

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

### [M] Healthcare environment

*NICE guideline NG204*

*Evidence reviews underpinning recommendations 1.1.1, 1.1.2 and 1.8.1 to 1.8.4 in the NICE guideline*

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*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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# Healthcare environment

## Review question

What features of the environment in which healthcare is provided are important to babies, children and young people to improve their experience of care?

## Introduction

The healthcare environment encountered by babies, children and young people when accessing healthcare services can be central to their overall experience of healthcare.

Healthcare environments need to provide a balance between the need for practical and clinical activities or procedures to take place within them, while creating an environment that can contribute to a good experience. This may be particularly difficult to achieve if babies, children and young people receive healthcare treatment or consultation in environments not specifically designed for them.

The aim of this review is to determine what features of the healthcare environment are important to babies, children and young people, and should therefore be included in designs or provided to improve the experience of care.

## 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**

<b>Population</b>	<ul style="list-style-type: none"> <li>• People &lt;18 years-old who have experience of healthcare</li> <li>• Studies that use the views of parents or carers as proxies will be included only if they are responding on behalf of their child or charge, and             <ul style="list-style-type: none"> <li>○ The baby or child of the parent or carer is under 5 years-old, or</li> <li>○ There is a clear rationale provided as to why the study is using parents' or carers' views on and experiences of healthcare as proxies for their child.</li> </ul> </li> </ul>
<b>Phenomenon of interest</b>	Experience of healthcare, in particular the physical environment in which it is provided.
<b>Primary outcome</b>	<p>Themes will be identified from the literature. The committee identified the following potential themes (however, not all of these themes may be found in the literature, and additional themes may be identified):</p> <ul style="list-style-type: none"> <li>• Architectural, physical or design features of the environment such as:             <ul style="list-style-type: none"> <li>○ Age- and gender- appropriate healthcare environment (e.g. different wards for children and young people, single-sex accommodation)</li> <li>○ Ambience of healthcare environment (e.g. lighting, peace and quiet, privacy, windows)</li> </ul> </li> <li>• Availability of recreational materials (e.g. computer games, reading materials, toys)</li> <li>• Freedom to move around healthcare environment (e.g. hospital)</li> <li>• Provision of amenities or equipment (e.g. access to toilets, age-specific playrooms and facilities, multi-faith prayer rooms, outdoor spaces, single or multiple occupancy rooms, private rooms, storage space, use of wheelchair)</li> </ul>

For further details see the review protocol in appendix A.

## Methods and process

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

Declarations of interest were recorded according to [NICE's conflicts of interest policy](#).

## Clinical evidence

### Included studies

This was a qualitative review with the aim of:

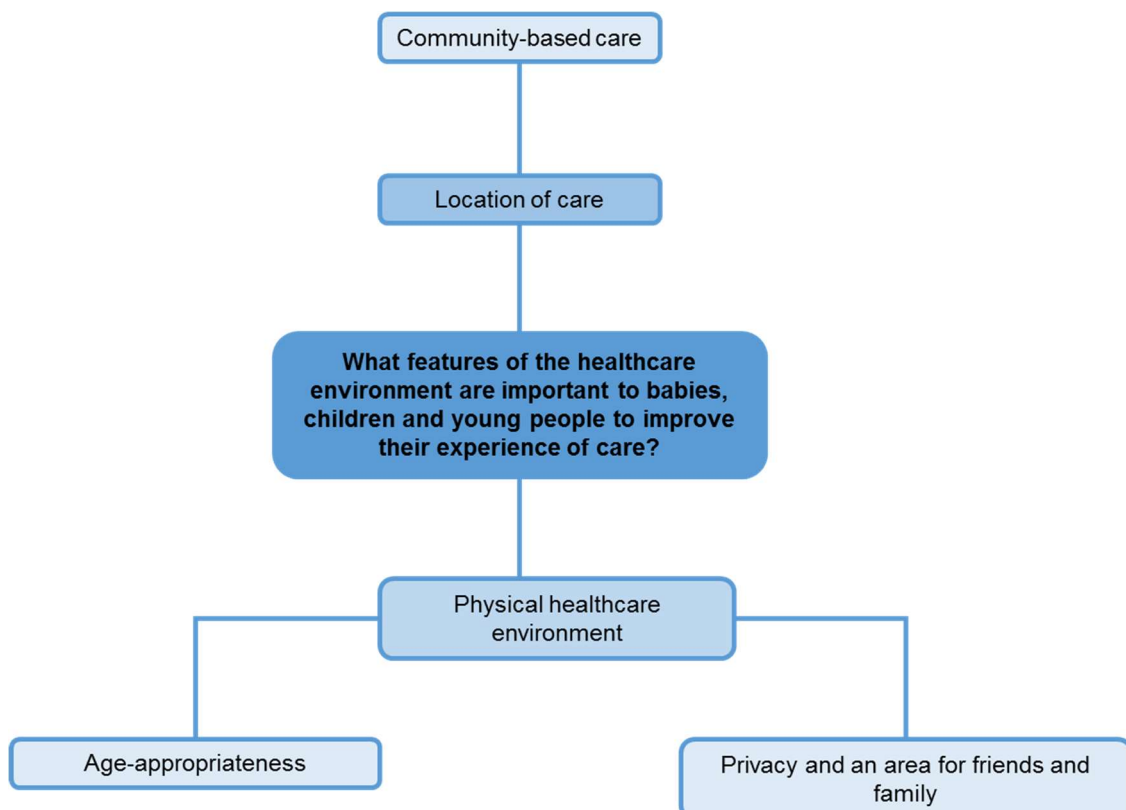
- Understanding which features of the healthcare environment are important to babies, children and young people.

A systematic review of the literature was conducted using a combined search. Eight studies were included for this review (Boyden 2012, Brown 2009, Dean 2015, Flacking 2013, Heath 2015, Hunt 2015, McKenzie 2010, and Wood 2018). All studies utilised a qualitative design, with 5 of them conducting semi-structured interviews, and 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.

## Excluded studies

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

## Summary of studies included in the evidence review

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

**Table 2: Summary of included studies**

Study	Population	Methods	Themes
<p>Boyden 2012</p> <p><b>Study design</b> Semi-structured interview</p> <p><b>Aim of the study</b> To explore views and experiences of children and young people with learning disability regarding Chesterfield CAMHS</p> <p>Derbyshire, UK</p>	<p>N=7 children and young people</p> <p><b>Characteristics</b> Age (range): 11-17 years</p> <ul style="list-style-type: none"> <li>• 11 years-old, n=1</li> <li>• 12 years-old, n=2</li> <li>• 13 years-old, n=1</li> <li>• 14 years-old, n=2</li> <li>• 17 years-old, n=1</li> </ul> <p>Gender (M/F): 5/2</p>	<p><b>Recruitment</b> Convenience sample from community and known by member of CAMHS team</p> <p><b>Data collection</b> Semi-structured interviews with participants at convenient location (e.g. home), visual aids used to assist expression</p> <p><b>Analysis</b> Thematic analysis</p>	<ul style="list-style-type: none"> <li>• Physical healthcare environment: Age appropriateness</li> <li>• Physical healthcare environment: Privacy and an area for friends and family</li> </ul>
<p>Brown 2009</p> <p><b>Study design</b> Semi-structured questionnaire</p> <p><b>Aim of the study</b> To describe experiences of children and young people admitted to a hospital ward</p> <p>Bristol, UK</p>	<p>N=28</p> <ul style="list-style-type: none"> <li>• n=2 children</li> <li>• n=13 parents or carers</li> <li>• n=13 nursing staff</li> </ul> <p>Data from parental proxies (carers) were included because children had learning disabilities. Data from nursing staff were not extracted nor included in this review.</p> <p><b>Characteristics</b> Age of children: not reported</p> <p>Gender (M/F): not reported</p>	<p><b>Recruitment</b> Purposive sampling of children with learning disability, aged 2-19 years, and admitted to hospital ward for more than 24 hours, their families and associated staff</p> <p><b>Data collection</b> Semi-structured questionnaire, 20-30 min, for all participants, with 2 days of child discharge. Interviews transcribed.</p> <p><b>Analysis</b> Thematic analysis</p>	<ul style="list-style-type: none"> <li>• Physical healthcare environment: Privacy and an area for friends and family</li> </ul>



Study	Population	Methods	Themes
<p>Dean 2015</p> <p><b>Study design</b> Semi-structured interview</p> <p><b>Aim of the study</b> To explore experience of young people aged 13-18 admitted to acute adult hospital ward</p> <p>England, UK</p>	<p>N=8 young people</p> <p><b>Characteristics</b> Age (range): 13-18 years at time of admission</p> <ul style="list-style-type: none"> <li>• 13 years-old, n=1</li> <li>• 14 years-old, n=1</li> <li>• 15 years-old, n=1</li> <li>• 16 years-old, n=2</li> <li>• 17 years-old, n=2</li> <li>• 18 years-old, n=1</li> </ul> <p>Gender (M/F): 3/5</p>	<p><b>Recruitment</b> Snowballing sampling beginning with university staff who initially identified adolescents that had been admitted to adult wards while aged ≤19 years old</p> <p><b>Data collection</b> Semi-structured interviews with single researcher</p> <p><b>Analysis</b> Hermeneutic phenomenology using Colaizzi's 7-stage process of analysis</p>	<ul style="list-style-type: none"> <li>• Physical healthcare environment: Privacy and an area for friends and family</li> </ul>
<p>Flacking 2013</p> <p><b>Study design</b> Ethnographic, including observation and interview</p> <p><b>Aim of the study</b> To explore the impact of place and space on mother's experiences and practices related to feeding their preterm babies in Neonatal Intensive Care Units (NICUs) in Sweden and England</p> <p>North-West England and Sweden, UK</p>	<p>N=30 families (30 mothers, 7 fathers) of 36 preterm babies<sup>1</sup></p> <p><b>Characteristics</b> Gestational age of child at birth (range): 23-35 weeks</p> <p>Gender of child (M/F): 13/23</p>	<p><b>Recruitment</b> Purposeful sampling of parents of pre-term babies admitted to 1 of 4 NICUs (2 in Sweden and 2 in England)</p> <p><b>Data collection</b> Observation with field notes in rooms among parents, babies and staff, and follow-up interviews with parents/staff. Spradley's 9-dimension framework guided initial observations with more focused observations used to elicit more details</p> <p><b>Analysis</b> Grounded theory by 2 researchers</p>	<ul style="list-style-type: none"> <li>• Physical healthcare environment: Privacy and an area for friends and family</li> </ul>
<p>Heath 2015</p> <p><b>Study design</b> Semi-structured interview</p>	<p>N=15</p> <ul style="list-style-type: none"> <li>• n=8 young people</li> <li>• n=7 parents</li> </ul> <p>Data from parents not extracted nor included in this review</p>	<p><b>Recruitment</b> Purposive sampling of families known to General Paediatric clinic</p> <p><b>Data collection</b></p>	<ul style="list-style-type: none"> <li>• Location of care: Community-based care</li> <li>• Physical healthcare environment: Age appropriateness</li> </ul>

Study	Population	Methods	Themes
<p><b>Aim of the study</b> To examine the experience and impact of introducing new, community-based paediatric outpatient clinics for NHS service users</p> <p>West Midlands, UK</p>	<p><b>Characteristics</b> Age of young people: not reported</p> <p>Gender of young people (M/F): not reported</p>	<p>Interviews conducted at home or hospital with participants asked to describe their last outpatient appointment experience.</p> <p><b>Analysis</b> Descriptive phenomenology according to Giorgi's method</p>	
<p>Hunt 2015</p> <p><b>Study design</b> Focus group</p> <p><b>Aim of the study</b> To identify important issues affecting children with life limiting conditions and their families, as well as service providers, with respect to the goals and design of 'The Big Study'</p> <p>West Midlands, UK</p>	<p>N=7 young people</p> <p><b>Characteristics</b> Age (range): 13-18 years</p> <p>Gender (M/F): 6/1</p>	<p><b>Recruitment</b> Convenience sampling as part of consultation for 'the Big Study' project.</p> <p><b>Data collection</b> Two participatory focus groups using post-it notes and postcards.</p> <p><b>Analysis</b> Themes created from notes on content used in combination with data and notes produced during focus groups.</p>	<ul style="list-style-type: none"> <li>Physical healthcare environment: Age appropriateness</li> </ul>
<p>McKenzie 2010</p> <p><b>Study design</b> Semi-structured interview</p> <p><b>Aim of the study</b> To explore how young people</p>	<p>N=4 young people</p> <p><b>Characteristics</b> Age (range): 13-15 years</p> <p>Gender (M/F): 1/3</p>	<p><b>Recruitment</b> Participants recruited via the local Youth Forum</p> <p><b>Data collection</b> Semi-structured interviews using topic guide after participation in a structured intervention involving a tour of the hospital</p> <p><b>Analysis</b> Qualitative content analysis</p>	<ul style="list-style-type: none"> <li>Physical healthcare environment: Age appropriateness</li> </ul>

Study	Population	Methods	Themes
experience the hospital environment  South-West England, UK			
Wood 2018  <b>Study design</b> Semi-structured interview  <b>Aim of the study</b> To determine whether adolescents and their families can articulate their experiences of their intensive care unit (ICU) or high dependency unit (HDU) visit, and to identify the factors that are important to them during such visits  England, UK	N=17 <ul style="list-style-type: none"> <li>• n=8 young people</li> <li>• n=9 mothers</li> </ul> <p>Data from parents not extracted nor included in this review</p> <p><b>Characteristics</b></p> <p>Age of adolescent at interview:</p> <ul style="list-style-type: none"> <li>• 14 years-old, n=1</li> <li>• 15 years-old, n=3</li> <li>• 16 years-old, n=2</li> <li>• 17 years-old, n=2</li> <li>• 19 years-old, n=1</li> </ul> <p>Gender of adolescent (M/F): not reported</p>	<b>Recruitment</b> Purposive sampling by local specialist nurses at participating hospitals  <b>Data collection</b> Face-to-face interviews, 30-90 min, with topic guides in home or hospital  <b>Analysis</b> Thematic (Framework) analysis	<ul style="list-style-type: none"> <li>• Physical healthcare environment: Age appropriateness</li> </ul>

N/n: number; NICU: neonatal intensive care unit.

<sup>1</sup>Flacking 2013 conducted in NICUs in England and Sweden, details only for English arm of study.

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: Location of care

- Sub-theme 1.1: Community-based care. The overall confidence in this sub-theme was judged to be moderate.

### Main theme 2: Physical healthcare environment

- Sub-theme 2.1: Age-appropriateness. The overall confidence in this sub-theme was judged to be moderate.
- Sub-theme 2.2: Privacy and an area for friends and family. The overall confidence in this sub-theme was judged to be moderate.

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

### Evidence from reference groups and focus groups

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

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

<b>Age groups</b>	<ul style="list-style-type: none"> <li>• 7-11 years</li> <li>• 11-14 years</li> </ul>
<b>Areas covered</b>	<ul style="list-style-type: none"> <li>• Factors important to a good healthcare experience</li> </ul>
<b>Illustrative quotes</b>	<ul style="list-style-type: none"> <li>• ‘Colourful – rainbows, multicolour’</li> <li>• ‘Climbing frame (to keep me busy whilst waiting)’</li> <li>• ‘Spiderman’</li> <li>• ‘Ironman’</li> <li>• ‘Nightlight’</li> <li>• ‘Soft beds’</li> <li>• ‘Comfy’</li> <li>• ‘Clean/hygienic’</li> </ul>

See the full evidence summary in appendix M.

### Evidence from national surveys

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

**Table 4: Summary of the evidence from national surveys**

<b>National surveys</b>	<ul style="list-style-type: none"> <li>• Care Quality Commission. Children and young people’s inpatient and day case survey 2018</li> <li>• Child Outcomes Research Consortium. Child- and Parent-reported Outcomes and Experience from Child and Young People’s Mental Health Services 2011-2015</li> <li>• National Children’s Bureau. Listening to children’s views on health provision 2012</li> <li>• Picker Institute/NHS England/Bliss. Neonatal Survey 2014</li> </ul>
<b>Areas covered</b>	<ul style="list-style-type: none"> <li>• Ward facilities</li> <li>• Equipment</li> <li>• Sleep/overnight stays</li> <li>• Cleanliness</li> <li>• Facilities/waiting area</li> <li>• Hospital environment</li> </ul>
<b>Key findings</b>	<ul style="list-style-type: none"> <li>• More than half of the young people were satisfied with the ward facilities and, overall, they preferred to stay in teenage or adolescent wards rather than in children’s or adult wards</li> </ul>

	<ul style="list-style-type: none"><li>• Children and young people reported they have appropriate equipment, although parents of children with long-term conditions reported poorer experience</li><li>• Less than half children and young people said that it was quiet enough to sleep, and parents and carers of babies in the neonatal unit reported that the hospital offered them accommodation to stay overnight</li><li>• Children and young people reported to be satisfied with the cleanliness, and said that the facilities were comfortable</li><li>• Some young people were not satisfied with the hospital environment, and reported that 'there is nothing to do', or 'unpleasant smells or uncomfortable beds'</li></ul>
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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 features of the environment which can improve children and young people's experience of healthcare, and the experience of parents and carers of babies and young children. 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:

- Architectural, physical or design features of the environment such as:
  - Age- and gender- appropriate healthcare environment (e.g. different wards for children and young people, single-sex accommodation)
  - Ambience of healthcare environment (e.g. lighting, peace and quiet, privacy, windows)
- Availability of recreational materials (e.g. computer games, reading materials, toys)
- Freedom to move around healthcare environment (e.g. hospital)

- Provision of amenities or equipment (e.g. access to toilets, age-specific playrooms and facilities, multi-faith prayer rooms, outdoor spaces, single or multiple occupancy rooms, private rooms, storage space, use of wheelchair)

The themes that were identified related to the location of care and the physical healthcare environment, age-appropriateness, privacy and the presence of family and friends. The committee did not prioritise any of these themes above other ones, 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 overall confidence in the review findings was moderate. All sub-themes were downgraded for methodological limitations. The sub-theme 'Community-based care', which comprises the 'Location of Care' theme was rated as moderate overall, as only one study contributed to the review finding.

The two sub-themes from the theme 'Physical healthcare environment' were both rated as moderate. The sub-theme 'Age appropriateness' was rated as moderate because there were some concerns about the methodology of the included studies and the relevance of the evidence. The setting and population of the studies varied widely and included a critical care unit (Wood 2018), a general paediatric outpatient clinic (Heath 2015), general hospital (McKenzie 2010), and an evaluation of services for life-limiting conditions (Hunt 2015).

The sub-theme 'Privacy and an area for friends and family' was rated as moderate because there were some concerns about the methodology of the included studies and the coherence of the evidence for the review finding.

Finally, there were concerns over the applicability of some of the evidence. For example, one study examined parents' experiences of the neonatal intensive care unit (NICU) environment in a multi-national study, which may not be applicable to the population of all babies, children and young people in the UK (Flacking 2013).

Overall, due to the small amount and poor quality of the evidence, the committee also used their knowledge and experience when drafting the recommendations.

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

Although the committee were aware that the environment for each baby, child or young person would often be primarily determined by clinical need or the healthcare setting (for example, hospital inpatient wards would provide different facilities compared to a GP waiting room), they discussed that the features of the healthcare environment would still need to meet the needs of babies, children and young people. The committee discussed that some of their recommendations would, however, only be applicable to an inpatient environment, and so they included this detail in some of the recommendations. Evidence from a wide-range of settings (including ICU, hospital wards and community outpatient clinics) showed that children and young people preferred to be cared for in an age-appropriate healthcare environment. In particular, young people thought it was important to have designated areas that are designed for adolescents. Some of the committee members were aware that young people often feel overlooked as paediatric areas of hospitals are mainly designed to appeal to very young children. The committee discussed the evidence and noted that providing an age and developmentally appropriate environment was important. They acknowledged that the preferences of children or young people may differ, for example older children may prefer to be cared for on adult wards, but agreed that that children's and young people's preferences as well as those of parents and carers (acting as proxies for babies and young children) should be taken into consideration wherever possible.

From their own experience, the committee highlighted that accessibility and adaptability were important, and this included accessibility for parents or carers, and therefore they included this in their recommendation too.

The evidence from the sub-theme of privacy and family and friends had shown that children and young people valued privacy, and the committee agreed that this was important to allow dignity. The evidence suggested that the presence of friends and family was important to most babies, children and young people feeling comfortable in their healthcare environment, and that, in an inpatient setting, convenient visiting hours and a pleasant environment for visitors was important. Drawing from the evidence and discussing their experience as healthcare providers and users, the committee agreed that it was important that there is provision for parents or carers to be present and support babies, children and young people while they receive healthcare. However, the committee also noted that, in some cases, the presence of the family could be detrimental, and that some children and young people may not want their families present all the time. The committee noted that, while there is often provision for parents or carers to be present in paediatric areas, it is not always the case in other areas where healthcare is provided, and that young people may receive care outside paediatric settings from 16 years of age, or when specialist care is required, such as maternity care. The committee therefore recommended that a healthcare environment should support all these factors that were important to improve healthcare experience. Based on stakeholder feedback, the committee also agreed that it was important to provide inpatients with information on the ward facilities and routine which could make them feel more at home.

There was evidence from the theme on physical environment that young children preferred an environment in which they could play, and that young people reported being bored, so the committee added to their recommendation that easily accessible and age-appropriate play and recreation opportunities should be available. This would both reduce boredom, but also may help reduce anxiety.

The evidence from a study exploring the experiences of young people admitted to adult wards (Dean 2015) suggested that a feeling of safety was an important factor and that young people did not always feel safe in this environment, particularly where adults were able to enter their personal space. The committee therefore also included a recommendation that babies, children and young people should feel safe in their environment. The evidence also showed that young people felt safer in a healthcare environment they could trust, therefore the committee agreed that it would be beneficial to convey confidence by supporting a smooth healthcare process, and they included this in a recommendation.

The evidence showed that many young people did not like noise – this included coughing, staff whispering, equipment beeps and alarms and people crying. The committee discussed that although the evidence came from only one study which explored the experience of young people admitted to adult wards (Dean 2015), this finding was in alignment with their personal experience that noise is an important factor that can impair the healthcare experience of babies, children and young people. The committee discussed the importance of sleep for the wellbeing of babies, children and young people, and noted the impact noise can have on sleep, and so recommended that noise levels should be kept low, particularly at night.

The evidence from parents of babies on a neonatal unit showed that they preferred comfortable furniture and furnishings and a 'homely' environment. The committee discussed other factors that had been identified by the evidence as important – this included having enough room so the environment didn't feel cramped, having adequate signposting and the availability and accessibility of recreation facilities and spaces-, and therefore the committee included these features in their recommendations.

In addition to the evidence from the systematic review, there was also evidence from the reference and focus groups and from the national surveys of children and young people's experience. The feedback from the younger children (aged 7 to 11) was mainly about the

availability of separate spaces for play and activities, which the committee agree had already been included in the recommendations. Additional areas identified by the 7-11 year olds were concerns about curtains around beds not being soundproof, their dislike of bad smells, the importance of cleanliness and being able to access windows to see outside. The feedback from the 11-14 year olds was more focused on comfort, a calm environment and adequate space, but there was also a strong message that the environment should be clean and hygienic, and the committee included cleanliness and calmness in their recommendations. Both age groups had mentioned the use of call bells – to summon help, or to indicate if they needed a treatment or procedure to stop. The committee therefore included call-bells as an example in their recommendation on feeling safe.

The national surveys highlighted that the environment should be age-appropriate, with greater satisfaction from young people aged 12 to 15 years accommodated on a teenage ward, compared to a children's or adult ward. The committee agreed that this reflected their experience. The committee noted that only 40% of children and young people in one survey reported that it was quiet enough to sleep on a ward and this reinforced the evidence from the systematic review. Children and young people also reported issues with comfort, smells and broken toys. A specific issue relating to appropriate equipment or adaptations was reported by the parents of children with developmental disability, mental health conditions, neurological conditions or other long term conditions. Feedback from parents of babies focussed on the suitability of the environment for them to visit and stay close to their babies. The committee agreed that their recommendations already included the need for an age-appropriate, comfy and quiet environment, with adaptations made to meet individual needs, and also the need for family-centred care for babies.

The committee discussed any potential harms identified by the evidence and from their recommendations, and identified the risk that, if 'rooming-in' facilities are provided, parents or carers may feel pressurised to stay with babies, children and young people all the time, even when it may not be beneficial for their wellbeing (for example, parents with other children at home). A concern was also raised that open visiting times, separate play areas and access for multiple visitors may lead to a safeguarding risk. The committee discussed that safeguarding was an over-arching consideration which surmounted all other recommendations and therefore made an over-arching recommendation at the beginning of the guideline concerning the need to consider safeguarding issues in all settings.

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

There was no existing economic evidence for this review. The committee explained that the recommendations in this area should bring consistency in practice across the health service. The committee noted that changing or redesigning healthcare environments could be an expensive process, and although some changes may be easy to facilitate, others may require considerable resources to implement. The committee explained that the majority of services are designed within the standards implied by the recommendations in this area. It was also noted that any additional expense would be outweighed by the potential long-term benefits and would represent a cost-effective use of resources. The committee agreed that the healthcare environment can contribute to positive health outcomes in addition to improvements in the experience of care and quality of life improvements. Also, it was noted that once redesigned, healthcare environments would benefit thousands of babies, children and young people.

The committee noted that some healthcare organisations may have resources or access to charity or grant funding to implement these changes while others do not, and so this may increase the disparity in healthcare experience between different providers.



## **Recommendations supported by this evidence review**

This evidence review supports recommendations 1.1.1, 1.1.2 and 1.8.1 to 1.8.4 in the NICE guideline.

## References

### **Boyden 2013**

Boyden, P., Muniz, M., Laxton-Kane, M., Listening to the views of children with learning disabilities: An evaluation of a learning disability CAMHS service, *Journal of Intellectual Disabilities*, 17, 51-63, 2013

### **Brown 2009**

Brown, Freddy Jackson, Guvenir, Jane, The experiences of children with learning disabilities, their carers and staff during a hospital admission, *British Journal of Learning Disabilities*, 37, 110-115, 2009

### **Dean 2015**

Dean, L., Black, S., Exploring the experiences of young people nursed on adult wards, *British journal of nursing (Mark Allen Publishing)*, 24, 229-236, 2015

### **Flacking 2013**

Flacking, R., & Dykes, F., 'Being in a womb' or 'playing musical chairs': the impact of place and space on infant feeding in NICUs, *BMC pregnancy and childbirth*, 13(1), 179, 2013

### **Heath 2015**

Heath, G., Greenfield, S., Redwood, S., The meaning of 'place' in families' lived experiences of paediatric outpatient care in different settings: A descriptive phenomenological study, *Health and Place*, 31, 46-53, 2015

### **Hunt 2015**

Hunt, A., Brown, E., Coad, J., Staniszewska, S., Hacking, S., Chesworth, B., Chambers, L., 'Why does it happen like this?' Consulting with users and providers prior to an evaluation of services for children with life limiting conditions and their families, *Journal of child health care : for professionals working with children in the hospital and community*, 19, 320-333, 2015

### **McKenzie 2010**

McKenzie, S., Norrish, S., Parker, L., & Frampton, I., Young people and healthcare. Part I: Experience of the hospital environment, *Pediatric health*, 4(2), 157-166, 2010

### **Wood 2018**

Wood, D., Geoghegan, S., Ramnarayan, P., Davis, P. J., Pappachan, J. V., Goodwin, S., Wray, J., Eliciting the experiences of the adolescent-parent dyad following critical care admission: a pilot study, *European Journal of Pediatrics*, 177, 747-752, 2018

# Appendices

## Appendix A – Review protocol

**Review protocol for review question: What features of the environment in which healthcare is provided are important to babies, children and young people to improve their experience of care?**

**Table 5: Review protocol**

Field	Content
PROSPERO registration number	CRD42019145439
Review title	Healthcare environment
Review question	What features of the environment in which healthcare is provided are important to babies, children and young people to improve their experience of care?
Objective	To determine what features of the environment in which healthcare is provided are important to babies, children and young people to improve their experience of care.
Searches	<p>The following databases will be searched:</p> <ul style="list-style-type: none"> <li>• CCTR</li> <li>• CDSR</li> <li>• Embase</li> <li>• MEDLINE</li> <li>• MEDLINE IN-Process</li> <li>• PsycINFO</li> </ul> <p>One broad, guideline-wide, search will be conducted for qualitative questions, capturing the population and the settings. A UK filter will be applied to identify relevant UK studies and a systematic review filter will be applied to the remainder of the results to identify relevant reviews that include evidence from non-UK high-income countries. If no systematic reviews of this type are identified, then a more focused search may be conducted to identify studies conducted in the following high-income countries: Australia, Austria, Belgium, Canada Denmark, Finland, France, Germany, Greece, Iceland, Ireland, Italy, Liechtenstein, Luxembourg, Malta, Monaco, Netherlands, New Zealand, Norway, Portugal, Spain, Sweden, Switzerland, and USA.</p> <p>Searches will be restricted by:</p> <ul style="list-style-type: none"> <li>• Date: 2009</li> <li>• Language of publication: English language only</li> </ul>

Field	Content
	<ul style="list-style-type: none"> <li>• Publication status: Conference abstracts will be excluded because these do not typically provide sufficient information to fully assess risk of bias</li> <li>• Standard exclusions filter (animal studies/low level publication types) will be applied</li> <li>• 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</li> </ul>
Condition or domain being studied	<ul style="list-style-type: none"> <li>• Babies, children's and young people's experience of healthcare</li> </ul>
Population	<ul style="list-style-type: none"> <li>• People &lt;18 years-old who have experience of healthcare</li> <li>• Studies that use the views of parents or carers as proxies will be included only if they are responding on behalf of their child or charge, and               <ul style="list-style-type: none"> <li>○ The baby or child of the parent or carer is under-5 years-old, or</li> <li>○ There is a clear rationale provided as to why the study is using parents' or carers' views on and experiences of healthcare as proxies for their child.</li> </ul> </li> </ul> <p>Note: Studies where part of the population is &lt;18 years-old and part of the population is ≥18 years-old will only be included if it is clear that the themes are supported by evidence from the former group only.</p>
Phenomenon of interest	Experience of healthcare, in particular the physical environment in which it is provided
Comparator/Reference standard/Confounding factors	Not applicable
Types of study to be included	<ul style="list-style-type: none"> <li>• Systematic reviews of qualitative studies</li> <li>• Studies using qualitative methods: focus groups, semi-structured and structured interviews, observations</li> <li>• Surveys conducted using open ended questions and a qualitative analysis of responses</li> </ul> <p>Note: Mixed methods studies will be included but only qualitative data will be extracted and risk of bias assessed. Systematic reviews that include evidence from both high- and non-high income countries, as defined by the World Bank, will only be included if the source of themes and evidence from high-income countries can be clearly established. Evidence from individual qualitative studies conducted in the high-income countries listed in the search strategy will be included only if no relevant systematic review evidence is identified.</p>
Other exclusion criteria	<p><b>STUDY DESIGN</b></p> <ul style="list-style-type: none"> <li>• Studies using quantitative methods only (including surveys that report only quantitative data)</li> <li>• Surveys using mainly closed questions or which quantify open ended answers for analysis</li> </ul> <p><b>TOPIC OF STUDY</b></p> <p>Studies on the following topics will also be excluded:</p> <ul style="list-style-type: none"> <li>• Non-NHS commissioned health promotion interventions</li> </ul>

Field	Content
	<ul style="list-style-type: none"> <li>• Physical environment in which non-NHS commissioned health promotion interventions are delivered</li> <li>• Views and experiences of healthcare professionals and service managers</li> <li>• Views and experiences of people reporting only on social care planning and shared decision making</li> </ul> <p>Studies that focus explicitly on the following topics rather than focussing on the views on and experiences of babies, children and young people in healthcare will be excluded as they are covered by the following NICE guidelines:</p> <ul style="list-style-type: none"> <li>• Child abuse and maltreatment: <ul style="list-style-type: none"> <li>○ Child abuse and neglect (NG76)</li> <li>○ Child maltreatment: when to suspect maltreatment in under 18s (CG89)</li> </ul> </li> <li>• Community engagement <ul style="list-style-type: none"> <li>○ Community engagement (NG44)</li> </ul> </li> <li>• Drug misuse in children and young people: <ul style="list-style-type: none"> <li>○ Alcohol: school-based interventions (PH7)</li> <li>○ Alcohol-use disorders: diagnosis, assessment and management of harmful drinking and alcohol dependence (CG115)</li> <li>○ Alcohol-use disorders: prevention (PH24)</li> <li>○ Drug misuse prevention: targeted interventions (NG64)</li> </ul> </li> <li>• End of life care for infants, children and young people with life-limiting conditions: planning and management (NG61)</li> <li>• Immunisations: reducing differences in uptake in under 19s (PH21)</li> <li>• Oral health promotion: general dental practice (NG30)</li> <li>• Physical activity and weight management: <ul style="list-style-type: none"> <li>○ Maternal and child nutrition (PH11)</li> <li>○ Obesity prevention (CG43)</li> <li>○ Physical activity for children and young people (PH17)</li> <li>○ Weight management: lifestyle services for overweight or obese children and young people (PH47)</li> </ul> </li> <li>• Pregnancy, including routine antenatal, intrapartum or postnatal care: <ul style="list-style-type: none"> <li>○ Antenatal and postnatal mental health: clinical management and service guidance (CG192)</li> <li>○ Antenatal care for uncomplicated pregnancies (CG62)</li> <li>○ Intrapartum care for healthy women and babies (CG190)</li> <li>○ Intrapartum care for women with existing medical conditions or obstetric complications and their babies (NG121)</li> <li>○ Multiple pregnancy: antenatal care for twin and triplet pregnancies (CG129)</li> <li>○ Postnatal care up to 8 weeks after birth (CG37)</li> </ul> </li> </ul>

Field	Content
	<ul style="list-style-type: none"> <li>○ Pregnancy and complex social factors: a model for service provision for pregnant women with complex social factors (CG110)</li> <li>● Self-harm:               <ul style="list-style-type: none"> <li>○ Self-harm in over 8s: long-term management (CG133)</li> <li>○ Self-harm in over 8s: short-term management and prevention of recurrence (CG16)</li> </ul> </li> <li>● Sexual health and contraception               <ul style="list-style-type: none"> <li>○ Contraceptive services for under 25s (PH51)</li> <li>○ Sexually transmitted infections and under-18 conceptions: prevention (PH3)</li> <li>○ Harmful sexual behaviour among children and young people (NG55)</li> </ul> </li> <li>● Smoking prevention:               <ul style="list-style-type: none"> <li>○ Smoking: preventing uptake in children and young people (PH14)</li> <li>○ Smoking prevention in schools (PH23)</li> <li>○ Stop smoking interventions and services (NG92)</li> </ul> </li> <li>● Transition from children's to adults services for young people using health or social care services (NG43)</li> </ul>
Context	<p>UK studies from 2009 onwards will be prioritised for decision making by the committee as those conducted in other countries may not be representative of current expectations about either services or current attitudes and behaviours of healthcare professionals. The committee presumes that due to their development, particular circumstances and/or condition, there are some topics that babies, children and young people may not be in a position to pronounce on, and that in these circumstances, it may be necessary to treat the 'indirect' views of their parents or carers as proxies for their own views on and experiences of healthcare in order to make recommendations. The guideline committee will be consulted on whether a study should be included if it is unclear why parents' or carer's views are being reported instead of their child or charge, and reasons for exclusion if appropriate will be documented. The topic about which the children or young people are talking about should be generalizable to the wider healthcare context (e.g. a study on the views on and experience of communication with healthcare professionals whilst receiving chemotherapy would be included, whilst a study on experience of chemotherapy would be too narrow and not generalizable to wider healthcare context and therefore excluded). Recommendations will apply to those receiving care in all settings where NHS- or local authority- commissioned healthcare is provided (including home, school, community, hospital, specialist and transport settings). Specific recommendations for groups listed in the Equality Considerations section of the scope may be also be made as appropriate.</p>
Primary outcomes (critical outcomes)	<p>Themes will be identified from the literature. The committee identified the following potential themes (however, not all of these themes may be found in the literature, and additional themes may be identified):</p> <ul style="list-style-type: none"> <li>● Architectural, physical or design features of the environment such as:           <ul style="list-style-type: none"> <li>○ Age- and gender- appropriate healthcare environment (e.g. different wards for children and young people, single-sex accommodation)</li> <li>○ Ambience of healthcare environment ( e.g. lighting, peace and quiet, privacy, windows)</li> </ul> </li> <li>● Availability of recreational materials (e.g. computer games, reading materials, toys )</li> </ul>

Field	Content
	<ul style="list-style-type: none"> <li>• Freedom to move around healthcare environment (e.g. hospital)</li> <li>• Provision of amenities or equipment (e.g. access to toilets, age-specific playrooms and facilities, multi-faith prayer rooms, outdoor spaces, single or multiple occupancy rooms, private rooms, storage space, use of wheelchair)</li> </ul> <p>The following themes will not be covered in this review despite relating to the healthcare environment:</p> <ul style="list-style-type: none"> <li>• Access to the digital environment, e.g. for recreation or education purposes or for maintaining contacts with peers and family (reviewed in RQ 7.1)</li> <li>• Involvement of children in the design of the environment (reviewed in RQ 5.1)</li> <li>• Quality of food, access to food and snacks, times when food is available; meeting individual needs (both in terms of nutritional value and individual taste) as well as any cultural and religious requirements (reviewed in RQ 4.1)</li> </ul>
Secondary outcomes (important outcomes)	Not applicable
Data extraction (selection and coding)	<ul style="list-style-type: none"> <li>○ All references identified by the searches and from other sources will be uploaded into STAR and de-duplicated. Titles and abstracts of the retrieved citations will be screened to identify studies that potentially meet the inclusion criteria outlined in the review protocol.</li> <li>○ Duplicate screening will not be undertaken for this question.</li> <li>○ Full versions of the selected studies will be obtained for assessment. Studies that fail to meet the inclusion criteria once the full version has been checked will be excluded at this stage. Each study excluded after checking the full version will be listed, along with the reason for its exclusion. A standardised form will be used to extract data from studies, including study reference, research question, theoretical approach, data collection and analysis methods used, participant characteristics, second-order themes, and relevant first-order themes (i.e. supporting quotes). One reviewer will extract relevant data into a standardised form, and this will be quality assessed by a senior reviewer.</li> </ul>
Risk of bias (quality) assessment	Risk of bias of individual qualitative studies will be assessed using the CASP Qualitative checklist. Risk of bias of systematic reviews of qualitative studies will be assessed using the CASP (Critical Skills Appraisal Programme) Systematic Review checklist. See Appendix H in <a href="#">Developing NICE guidelines: the manual</a> for further details. The quality assessment will be performed by one reviewer and this will be quality assessed by a senior reviewer.
Strategy for data synthesis	<ul style="list-style-type: none"> <li>• Extracted second-order study themes and related first-order quotes will be synthesised by the reviewer into third-order themes and related sub-themes.</li> <li>• The GRADE-CERQual (Confidence in the Evidence from Reviews of Qualitative research; Lewin 2015) approach will be used to summarise the confidence in the third-order themes or sub-themes synthesised from the qualitative evidence. The overall confidence in evidence about each theme or sub-theme will be rated on four dimensions: methodological limitations, coherence, adequacy, and relevance.</li> <li>• Methodological limitations refer to the extent to which there were problems in the design or conduct of the studies and will be assessed with the CASP checklist for qualitative studies or systematic reviews as appropriate. Coherence of findings will be assessed by examining the clarity of the data. Adequacy of data will be assessed by looking at the degree of richness and quantity of findings. Relevance of evidence will be assessed by determining</li> </ul>

Field	Content		
	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	<p>If there is sufficient data, views and experiences will be analysed separately by the following age ranges:</p> <ul style="list-style-type: none"> <li>• &lt;1 year-old (i.e. 364 days-old or less)</li> <li>• ≥1 to &lt;12 years-old (i.e. 365 days-old to 11 years and 364 days-old)</li> <li>• ≥12 to &lt;18 years-old (i.e. 12 years and 0 days-old to 17 years and 364 days-old)</li> </ul> <p>The committee are aware that children can experience substantial cognitive and developmental change during the ages of 1 and 12, and that there may be (though not necessarily) substantive differences between children in this group depending on the topic about which they are being asked. The committee 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.</p>		
Type and method of review	<input type="checkbox"/>	Intervention	
	<input type="checkbox"/>	Diagnostic	
	<input type="checkbox"/>	Prognostic	
	<input checked="" type="checkbox"/>	Qualitative	
	<input type="checkbox"/>	Epidemiologic	
	<input type="checkbox"/>	Service Delivery	
	<input type="checkbox"/>	Other (please specify)	
Language	English		
Country	England		
Anticipated or actual start date	04 September 2019		
Anticipated completion date	07 April 2021		
Stage of review at time of this submission	Review stage	Started	Completed
	Preliminary searches		
	Piloting of the study selection process		
	Formal screening of search results against eligibility criteria		
	Data extraction		



Field	Content
	Risk of bias (quality) assessment
	Data analysis
Named contact	<p><b>5a. Named contact</b> National Guideline Alliance</p> <p><b>5b. Named contact e-mail</b> Infant&amp;younghealth@nice.org.uk</p> <p><b>5e Organisational affiliation of the review</b> National Institute for Health and Care Excellence (NICE) and National Guideline Alliance</p>
Review team members	NGA Technical Team
Funding sources/sponsor	This systematic review is being completed by the National Guideline Alliance, which receives funding from NICE.
Conflicts of interest	All guideline committee members and anyone who has direct input into NICE guidelines (including the evidence review team and expert witnesses) must declare any potential conflicts of interest in line with NICE's code of practice for declaring and dealing with conflicts of interest. Any relevant interests, or changes to interests, will also be declared publicly at the start of each guideline committee meeting. Before each meeting, any potential conflicts of interest will be considered by the guideline committee Chair and a senior member of the development team. Any decisions to exclude a person from all or part of a meeting will be documented. Any changes to a member's declaration of interests will be recorded in the minutes of the meeting. Declarations of interests will be published with the final guideline.
Collaborators	Development of this systematic review will be overseen by an advisory committee who will use the review to inform the development of evidence-based recommendations in line with section 3 of <a href="#">Developing NICE guidelines: the manual</a> . Members of the guideline committee are available on the NICE website: <a href="https://www.nice.org.uk/guidance/indevelopment/gid-ng10119/documents">https://www.nice.org.uk/guidance/indevelopment/gid-ng10119/documents</a>
Other registration details	-
Reference/URL for published protocol	<a href="https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=145439">https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=145439</a>
Dissemination plans	<p>NICE may use a range of different methods to raise awareness of the guideline. These include standard approaches such as:</p> <ul style="list-style-type: none"> <li>• notifying registered stakeholders of publication</li> <li>• publicising the guideline through NICE's newsletter and alerts</li> <li>• issuing a press release or briefing as appropriate, posting news articles on the NICE website, using social media channels, and publicising the guideline within NICE.</li> </ul>
Keywords	Architecture; babies; building design; children; environment; experience; general practitioner; GP; healthcare; hospital; infants; physical environment; qualitative; views.
Details of existing review of same topic by same authors	Not applicable

Field	Content	
Current review status	<input checked="" type="checkbox"/>	Ongoing
	<input type="checkbox"/>	Completed but not published
	<input type="checkbox"/>	Completed and published
	<input type="checkbox"/>	Completed, published and being updated
	<input type="checkbox"/>	Discontinued
Additional information		
Details of final publication	<a href="http://www.nice.org.uk">www.nice.org.uk</a>	

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

## Appendix B – Literature search strategies

**Literature search strategies for review question: What features of the environment in which healthcare is provided are important to babies, children and young people to improve their experience of care?**

**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 prepubescent\$).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 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.

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

#	Searches
73	limit 72 to (yr="2009 - current" and english language)
74	exp United Kingdom/
75	(national health service* or nhs*).ti,ab,in,ad,cq.
76	(english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab.
77	(gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or wels*).ti,ab,jx,in,ad,cq.
78	(bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or Carlisle* or "Carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worchester not (massachusetts* or boston* or harvard*)) or ("worchester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))).ti,ab,in,ad,cq.
79	(bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's").ti,ab,in,ad,cq.
80	(aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's").ti,ab,in,ad,cq.
81	(armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's").ti,ab,in,ad,cq.
82	or/74-81
83	((exp africa/ or exp americas/ or exp antarctic regions/ or exp arctic regions/ or exp asia/ or exp oceania/) not (exp united kingdom/ or europe/)) use ppez
84	((exp "arctic and antarctic"/ or exp oceanic regions/ or exp western hemisphere/ or exp africa/ or exp asia/ or exp "australia and new zealand"/) not (exp united kingdom/ or europe/)) use emez
85	83 or 84
86	82 not 85
87	73 and 86
88	Letter/ use ppez
89	letter.pt. or letter/ use emez
90	note.pt.
91	editorial.pt.
92	Editorial/ use ppez
93	News/ use ppez
94	news media/ use psyh
95	exp Historical Article/ use ppez
96	Anecdotes as Topic/ use ppez
97	Comment/ use ppez
98	Case Report/ use ppez
99	case report/ or case study/ use emez
100	Case report/ use psyh
101	(letter or comment*).ti.
102	or/88-101
103	randomized controlled trial/ use ppez
104	randomized controlled trial/ use emez
105	random*.ti,ab.
106	cohort studies/ use ppez
107	cohort analysis/ use emez

#	Searches
108	cohort analysis/ use psych
109	case-control studies/ use ppez
110	case control study/ use emez
111	or/103-110
112	102 not 111
113	animals/ not humans/ use ppez
114	animal/ not human/ use emez
115	nonhuman/ use emez
116	"primates (nonhuman)"/
117	exp Animals, Laboratory/ use ppez
118	exp Animal Experimentation/ use ppez
119	exp Animal Experiment/ use emez
120	exp Experimental Animal/ use emez
121	animal research/ use psych
122	exp Models, Animal/ use ppez
123	animal model/ use emez
124	animal models/ use psych
125	exp Rodentia/ use ppez
126	exp Rodent/ use emez
127	rodents/ use psych
128	(rat or rats or mouse or mice).ti.
129	or/112-128
130	87 not 129
131	meta-analysis/
132	meta-analysis as topic/
133	systematic review/
134	meta-analysis/
135	(meta analy* or metanaly* or metaanaly*).ti,ab.
136	((systematic or evidence) adj2 (review* or overview*).ti,ab.
137	((systematic* or evidence*) adj2 (review* or overview*).ti,ab.
138	(reference list* or bibliograph* or hand search* or manual search* or relevant journals).ab.
139	(search strategy or search criteria or systematic search or study selection or data extraction).ab.
140	(search* adj4 literature).ab.
141	(medline or pubmed or cochrane or embase or psychlit or 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 psych
153	150 or 151 or 152
154	73 and 153
155	154 not 130
156	155 not 129

## Database: Cochrane Library

Date searched: 29/072020

#	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

#	Search
51	MeSH descriptor: [Transportation of Patients] this term only
52	MeSH descriptor: [Adolescent, Hospitalized] this term only
53	MeSH descriptor: [Child, Hospitalized] this term only
54	MeSH descriptor: [Hospitalization] this term only
55	MeSH descriptor: [Inpatients] this term only
56	MeSH descriptor: [Outpatients] this term only
57	(hospital* or inpatient* or outpatient*):ti,ab,kw
58	(health* near/3 (care or center* or centre* or clinic* or facility or facilities or service* or setting* or specialist*)):ti,ab,kw
59	((dental or communit* or emergency or hospital* or home or intensive or high-dependen* or mental* or primary or secondary or tertiary) near/3 (care or health*)):ti,ab,kw
60	(emergency near/2 room*):ti,ab,kw
61	(ambulance* or CAMHS or dentist* or dietics or dieti*ian or hospice* or NICU or nutritionist* or orthodont* or ophthalmolog* or (outreach near/2 team*) or pharmacy or pharmacies or physio* or SCBU or SENCO or telemedicine*):ti,ab,kw
62	((virtual* or online) near/2 (physician* or clinician* or doctor*)):ti,ab,kw
63	(communit* near/3 (p*ediatric* or nurs*)):ti,ab,kw
64	(home near/3 visit*):ti,ab,kw
65	((walk-in or "urgent care") near/2 (centre* or center* or clinic* or service*)):ti,ab,kw
66	("speech and language therap*"):ti,ab,kw
67	(general practice*):ti,ab,kw
68	(health* and (nursery or nurseries or school*)):ti,ab,kw
69	(respite near/2 care):ti,ab,kw
70	(foster care or "looked after children" or "children in care"):ti,ab,kw
71	#12 OR #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20 OR #21 OR #22 OR #23 OR #24 OR #25 OR #26 OR #27 OR #28 OR #29 OR #30 OR #31 OR #32 OR #33 OR #34 OR #35 OR #36 OR #37 OR #38 OR #39 OR #40 OR #41 OR #42 OR #43 OR #44 OR #45 OR #46 OR #47 OR #48 OR #49 OR #50 OR #51 OR #52 OR #53 OR #54 OR #55 OR #56 OR #57 OR #58 OR #59 OR #60 OR #61 OR #62 OR #63 OR #64 OR #65 OR #66 OR #67 OR #68 OR #69 OR #70
72	MeSH descriptor: [Adverse Childhood Experiences] this term only
73	MeSH descriptor: [Attitude to Health] explode all trees
74	MeSH descriptor: [Patient Satisfaction] explode all trees
75	MeSH descriptor: [Community Participation] explode all trees
76	MeSH descriptor: [Patient Acceptance of Health Care] this term only
77	MeSH descriptor: [Patient Preference] this term only
78	MeSH descriptor: [Attitude to Death] this term only
79	MeSH descriptor: [Health Knowledge, Attitudes, Practice] this term only
80	MeSH descriptor: [Patient Advocacy] this term only
81	MeSH descriptor: [Consumer Advocacy] this term only
82	MeSH descriptor: [Narration] this term only
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



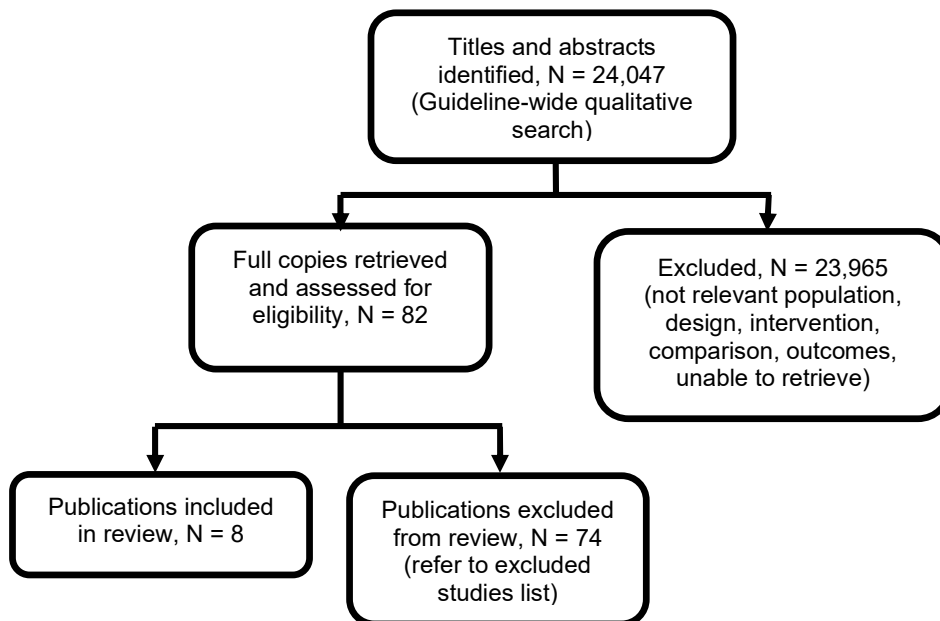
#	Search
96	(theme* or thematic):ti,ab,kw
97	(qualitative):ti,ab,kw
98	(questionnaire*):ti,ab,kw
99	(ethnological research):ti,ab,kw
100	(ethnograph*):ti,ab,kw
101	(ethnonursing):ti,ab,kw
102	(phenomenol*):ti,ab,kw
103	(life stor* or women* stor*):ti,ab,kw
104	(grounded near (theor* or study or studies or research or analys*s)):ti,ab,kw
105	((data near/1 saturat*) or participant observ*):ti,ab,kw
106	(field near (study or studies or research)):ti,ab,kw
107	(biographical method):ti,ab,kw
108	(theoretical sampl*):ti,ab,kw
109	((purpos* near/4 samp** or (focus near group*)):ti,ab,kw
110	(account or accounts or unstructured or openended or open ended or text* or narrative*):ti,ab,kw
111	(life world or life-world or conversation analys*s or personal experience* or theoretical saturation):ti,ab,kw
112	((lived or life) near experience*):ti,ab,kw
113	(narrative analys*s):ti,ab,kw
114	#93 OR #94 OR #95 OR #96 OR #97 OR #98 OR #99 OR #100 OR #101 OR #102 OR #103 OR #104 OR #105 OR #106 OR #107 OR #108 OR #109 OR #110 OR #111 OR #112 OR #113
115	#11 AND #71 AND #92 AND #114 with Cochrane Library publication date Between Jan 2009 and Aug 2020
116	MeSH descriptor: [United Kingdom] explode all trees
117	(national health service* or nhs*):ti,ab,kw
118	(english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) near/5 english)):ti,ab,kw
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

#	Search
131	MeSH descriptor: [Oceania] explode all trees
132	#126 OR #127 OR #128 OR #129 OR #130 OR #131
133	MeSH descriptor: [United Kingdom] explode all trees
134	MeSH descriptor: [Europe] this term only
135	#133 OR #134
136	#132 not #135
137	#125 not #136
138	#115 AND #137 with Cochrane Library publication date Between Jan 2009 and Aug 2020

## Appendix C – Clinical evidence study selection

**Study selection for: What features of the environment in which healthcare is provided are important to babies, children and young people to improve their experience of care?**

**Figure 2: Study selection flow chart**



## Appendix D – Clinical evidence tables

Evidence tables for review question: What features of the environment in which healthcare is provided are important to babies, children and young people to improve their experience of care?

Table 6: Evidence tables

Study details	Participants	Methods	Themes and findings	Limitations
<p><b>Full citation</b></p> <p>Boyden, P., Muniz, M., Laxton-Kane, M., Listening to the views of children with learning disabilities: An evaluation of a learning disability CAMHS service, Journal of Intellectual Disabilities, 17, 51-63, 2013</p> <p><b>Ref Id</b></p> <p>987405</p> <p><b>Country/ies where the study was carried out</b></p> <p>Derbyshire, UK</p> <p><b>Study type</b></p> <p>Semi-structured interview; qualitative</p> <p><b>Aim of the study</b></p>	<p><b>Sample size</b></p> <p>N=7 children and young people</p> <p><b>Characteristics</b></p> <p>Age (range): 11-17 years</p> <ul style="list-style-type: none"> <li>• 11 years-old, n=1</li> <li>• 12 years-old, n=2</li> <li>• 13 years-old, n=1</li> <li>• 14 years-old, n=2</li> <li>• 17 years-old, n=1</li> </ul> <p>Gender (M/F): 5/2</p> <p><b>Inclusion criteria</b></p> <ul style="list-style-type: none"> <li>• Experience of learning disability CAMHS</li> <li>• Moderate learning disability</li> <li>• Received input from mental health team in past 3 months</li> </ul>	<p><b>Setting</b></p> <p>Community</p> <p><b>Recruitment</b></p> <p>Convenience sample of children and young people with a moderate learning disability aged 11-17 years living in the community and known to member of the CAMHS team. Participants had received input from service in past 3 months regarding wide range of issues (e.g. anger, puberty).</p> <p><b>Data collection</b></p> <p>Semi-structured interviews, 30-45 min, conducted at home of participant, school or in clinic; visual aids (e.g. picture of face) used to aid participants to express their opinions.</p> <p><b>Analysis</b></p> <p>Transcripts analysed using thematic analysis.</p>	<p><b>Author's themes:</b></p> <ul style="list-style-type: none"> <li>• Practicalities of meeting with the service</li> </ul> <p>Participants had varying preferences for where they met professionals depending on whether it was quiet, afforded privacy, or allowed family to participate (e.g. home). One participant said it was important to have choice of whether to have session at all.</p>	<p><b>Limitations (assessed using the CASP checklist for qualitative studies).</b></p> <p><i>Q1: Was there a clear statement of the aims of the research? Yes.</i></p> <p><i>Q2: Was a qualitative methodology appropriate? Yes.</i></p> <p><i>Q3: Was the research design appropriate to address the aims of the research? Yes.</i></p> <p><i>Q4: Was the recruitment strategy appropriate to the aims of the research? Yes.</i></p> <p><i>Q5: Were the data collected in a way that addressed the research issue? Yes.</i></p> <p><i>Q6: Has the relationship between researcher and participants been adequately considered? Yes.</i></p>

Study details	Participants	Methods	Themes and findings	Limitations
<p>To explore views and experiences of children and young people with learning disability regarding Chesterfield CAMHS</p> <p><b>Study dates</b> Not reported, after 2008</p> <p><b>Source of funding</b> Study reports received no specific grant</p>	<ul style="list-style-type: none"> <li>• Suitable verbal skills to engage in 20-40 min interview</li> <li>• Ability to contribute novel information and express their opinion</li> </ul> <p><b>Exclusion criteria</b> Not reported</p>			<p><i>Q7: Have ethical issues been taken into consideration? Yes.</i></p> <p><i>Q8: Was the data analysis sufficiently rigorous? Yes.</i></p> <p><i>Q9: Is there a clear statement of findings? Yes.</i></p> <p><i>Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability) Yes. 1. Yes, provides context and discussion. 2. Possibly yes, study examines local CAMHS albeit from 2012.</i></p> <p><i>Overall judgement of quality: No or very minor concerns.</i></p>
<p><b>Full citation</b></p> <p>Brown, Freddy Jackson, Guvenir, Jane, The experiences of children with learning disabilities, their carers and staff during a hospital admission, British Journal of Learning Disabilities, 37, 110-115, 2009</p> <p><b>Ref Id</b></p> <p>1053799</p>	<p><b>Sample size</b> N=28</p> <ul style="list-style-type: none"> <li>• n=2 children</li> <li>• n=13 parents or carers</li> <li>• n=13 nursing staff</li> </ul> <p>Data from parental proxies (carers) were included because children had learning disabilities. Data from nursing staff not extracted nor included in this review.</p>	<p><b>Setting</b> General hospital ward</p> <p><b>Recruitment</b> Purposive sampling of 13 children who met inclusion criteria with relevant carers and staff. Thirteen children's carers and 13 thirteen nursing staff, plus 2 children, were interviewed.</p> <p><b>Data collection</b> Semi-structured interview, 20-30 min, using questionnaire, of child, their families, or hospital</p>	<p><b>Author's themes:</b></p> <ul style="list-style-type: none"> <li>• Ward environment and individual room</li> </ul> <p>Hospital admission process was felt by many parents, nurses and children to be easier when the child had own room, which afforded privacy and a barrier from the intensity of the healthcare environment (e.g. noise).</p>	<p><b>Limitations (assessed using the CASP checklist for qualitative studies).</b></p> <p><i>Q1: Was there a clear statement of the aims of the research? Yes.</i></p> <p><i>Q2: Was a qualitative methodology appropriate? Yes.</i></p> <p><i>Q3: Was the research design appropriate to address the aims of the research? Yes.</i></p>

Study details	Participants	Methods	Themes and findings	Limitations
<p><b>Country/ies where the study was carried out</b> Bristol, UK</p> <p><b>Study type</b> Semi-structured questionnaire; qualitative</p> <p><b>Aim of the study</b> To describe experiences of children and young people admitted to a hospital ward</p> <p><b>Study dates</b> 10-month study period, dates not reported</p> <p><b>Source of funding</b> Not reported</p>	<p><b>Characteristics</b> Not reported</p> <p><b>Inclusion criteria</b></p> <ul style="list-style-type: none"> <li>• Child with learning disability</li> <li>• Aged 2-19 years</li> <li>• Admitted to general hospital ward ≤24</li> </ul> <p><b>Exclusion criteria</b></p> <ul style="list-style-type: none"> <li>• Admitted to general hospital less than 24 hours</li> </ul>	<p>staff within 2 days of child's discharge. Interviews transcribed.</p> <p><b>Analysis</b> Thematic analysis</p>		<p><i>Q4: Was the recruitment strategy appropriate to the aims of the research? Yes.</i></p> <p><i>Q5: Were the data collected in a way that addressed the research issue? Yes.</i></p> <p><i>Q6: Has the relationship between researcher and participants been adequately considered? Unclear. No discussion of this in article.</i></p> <p><i>Q7: Have ethical issues been taken into consideration? Yes. Approval from NHS Trust Research Ethic Committee and results feedback to participants.</i></p> <p><i>Q8: Was the data analysis sufficiently rigorous? Unclear. Very minimal details provided of methods.</i></p> <p><i>Q9: Is there a clear statement of findings? Yes.</i></p> <p><i>Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability) Yes. 1. Contextualises findings in discussion of literature. 2. Possibly yes. Study conducted in specific population and only 2</i></p>

Study details	Participants	Methods	Themes and findings	Limitations
				<p>children interviewed severely limits transferability of findings.</p> <p><i>Overall judgement of quality: Moderate concerns</i></p>
<p><b>Full citation</b></p> <p>Dean, L., Black, S., Exploring the experiences of young people nursed on adult wards, British journal of nursing (Mark Allen Publishing), 24, 229-236, 2015</p> <p><b>Ref Id</b></p> <p>988325</p> <p><b>Country/ies where the study was carried out</b></p> <p>UK</p> <p><b>Study type</b></p> <p>Semi-structured interview; qualitative</p> <p><b>Aim of the study</b></p> <p>To explore the experiences of young people who have been admitted to acute adult hospital wards.</p>	<p><b>Sample size</b></p> <p>N=8 young people</p> <p><b>Characteristics</b></p> <p>Age (range): 13-18 years at time of admission</p> <ul style="list-style-type: none"> <li>• 13 years-old, n=1</li> <li>• 14 years-old, n=1</li> <li>• 15 years-old, n=1</li> <li>• 16 years-old, n=2</li> <li>• 17 years-old, n=2</li> <li>• 18 years-old, n=1</li> </ul> <p>Gender (M/F): 3/5</p> <p><b>Inclusion criteria</b></p> <p>Aged 12-19 when admitted to adult ward.</p> <p><b>Exclusion criteria</b></p> <p>Not reported.</p>	<p><b>Setting</b></p> <p>Adult hospital ward</p> <p><b>Recruitment</b></p> <p>Snowballing sampling. University staff identified adolescents that had been admitted to adult wards while aged ≤19 years old and would be willing to participate in the research study. These initial participants were asked to identify friends fitting the same criteria.</p> <p><b>Data collection</b></p> <p>Semi-structured face-to-face interviews with single researcher. Participants were allowed to choose where the interviews took place, all were conducted at participants' home. Interviews were facilitated using an interview guide (summary of questions provided in the paper), recorded and transcribed verbatim.</p> <p><b>Analysis</b></p> <p>Hermeneutic phenomenology using Colaizzi's 7-stage</p>	<p><b>Author's themes:</b></p> <ul style="list-style-type: none"> <li>• Expectations, first impressions and environment</li> <li>• Feeling scared</li> </ul> <p>Participants did not have a strong recollection about their expectations of an adult ward, beyond the age of their fellow inpatients. First impressions consisted of the physical environment, other patients, the staff and noise levels. Adolescents found the environment unsettling with an array of noises including coughing, staff whispering, equipment beeps and alarms and people crying. Two participants mentioned that the wards were mixed-sex and that was 'extremely uncomfortable'. The freedom of other patients to walk around led to opposite genders entering patients bays which was 'not nice' and 'disturbing'. Participants felt very different from the other people on the wards, which was isolating when they were feeling better and wanted to socialise. Visiting times were restricted and adolescents commented that it was an unpleasant environment for friends</p>	<p><b>Limitations (assessed using the CASP checklist for qualitative studies).</b></p> <p><i>Q1: Was there a clear statement of the aims of the research? Yes.</i></p> <p><i>Q2: Was a qualitative methodology appropriate? Yes.</i></p> <p><i>Q3: Was the research design appropriate to address the aims of the research? Yes.</i></p> <p><i>Q4: Was the recruitment strategy appropriate to the aims of the research? Probably not.</i></p> <p>Snowballing sampling used by asking University colleagues and initial participants. Rationalised in terms of time and cost restraints. However, risk of recruitment bias is high with this sort of sampling. Only identified emergency admissions, no limit on the amount of time since the admission and no limits placed on how long participants had spent on the ward.</p>

Study details	Participants	Methods	Themes and findings	Limitations
<p><b>Study dates</b> 2004-2010</p> <p><b>Source of funding</b> Not reported.</p>		<p>process of analysis (full details provided in research paper) with Attride-Stirling analytical tool to assist. Basic themes were identified from the data, grouped together into organising themes and finally organised into global themes.</p>	<p>to come to, which further limited their visitors. Invasion of personal space and being unable to escape were common responses of participants, leading to them feeling scared. They also felt stress around a sense of responsibility for the other inpatients when there were no healthcare staff around. Participants mentioned that their experience would have been better if they had been allowed to have visitors at any time of the day, especially parents until they fell asleep.</p>	<p><i>Q5: Were the data collected in a way that addressed the research issue?</i> Yes. Semi-structured interviews justified and audio-recording mentioned. Data saturation is discussed and method described. Participants were able to choose interview setting in order to feel comfortable. Description of interview guide included.</p> <p><i>Q6: Has the relationship between researcher and participants been adequately considered?</i> No. No description of potential bias/influence between researcher and participants.</p> <p><i>Q7: Have ethical issues been taken into consideration?</i> Yes. Ethical approval gained from University ethics committee. Written, informed consent obtained from all participants. Opportunity for counselling provided after interviews.</p> <p><i>Q8: Was the data analysis sufficiently rigorous?</i> Unsure. 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. Appears as</p>



Study details	Participants	Methods	Themes and findings	Limitations
				<p>though only 1 researcher carried out the coding and analysis and no examination on what impact it may have had or potential bias. No discussion of contradictory opinions or views.</p> <p><i>Q9: Is there a clear statement of findings?</i> Probably. Clear and explicit findings presented and discussed in relation to the original research question. However, no discussion regarding credibility of findings and little evidence presented against researcher's findings.</p> <p><i>Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)</i> Unsure. 1. Probably. Good discussion on how the evidence fits in with current literature and discussion about future research directions. 2. Probably not. Small sample size and limitations on the population limits the transferability of the research.</p> <p><i>Overall judgement of quality:</i> Moderate concerns</p> <p><b>Other information</b> One participant was 18 years-old - data not extracted. Also to</p>

Study details	Participants	Methods	Themes and findings	Limitations
				note - adolescents sometimes chose to be nursed in adults wards but the experience was different from that expected.
<p><b>Full citation</b> Flacking, R., Dykes, F., 'Being in a womb' or 'playing musical chairs': The impact of place and space on infant feeding in NICUs, BMC Pregnancy ChildbirthBMC pregnancy and childbirth, 13 (no pagination), 2013</p> <p><b>Ref Id</b> 683610</p> <p><b>Country/ies where the study was carried out</b> England, UK</p> <p><b>Study type</b> Ethnographic (fieldwork and observation); qualitative</p> <p><b>Aim of the study</b> To explore the impact of physical NICU environment on new mother's experiences of feeding their babies in</p>	<p><b>Sample size</b> N=37 parents (30 mothers and 7 fathers) of 36 babies (UK arm of study only)</p> <p><b>Characteristics</b> For English NICUs only:</p> <ul style="list-style-type: none"> <li>• Mean birth weight: 1825</li> <li>• Mean length of stay: 46 days</li> <li>• 6 sets of twins</li> </ul> <p><b>Inclusion criteria</b></p> <ul style="list-style-type: none"> <li>• Baby born pre-term (&lt; 37 weeks)</li> <li>• Baby admitted to NICU</li> </ul> <p><b>Exclusion criteria</b></p> <ul style="list-style-type: none"> <li>• Parents with a history of serious healthcare complications</li> <li>• Parents unable to speak English/Swedish</li> </ul>	<p><b>Setting</b> Neonatal intensive care unit</p> <p><b>Recruitment</b> Purposeful sampling based on strategy of maximum variation. Purposeful sampling allowed parents to followed throughout hospital experience.</p> <p><b>Data collection</b> Six months of ethnographic study, involving observation and fieldwork of parents, babies and staff in NICU rooms with follow-up interviews with parents. Field notes were taken during the observation periods and interviews were audio-recorded if possible. Observer maintained a 'moderate' level of participation throughout. Spradley's 9-dimension framework guided the initial observations before more focused observations were used to elicit more details if needed.</p> <p><b>Analysis</b> Grounded theory approach. Field notes and interviews transcribed and inputted into</p>	<p><b>Author's themes:</b></p> <ul style="list-style-type: none"> <li>• The hotel room</li> <li>• The safe corner</li> <li>• The musical chair</li> </ul> <p>A term for a room that mothers asked for/were offered for prolonged periods of time, either by themselves, to share with fathers or to share with another new mother, at some point during their time in the NICU. Babies in NICU B (England) had to be independent of monitors to be placed with parents in these rooms. Not that many rooms available so they had to be negotiated for, meaning timing varied between individuals. Women mentioned that the timing for being allocated a room greatly impacted their sense of 'being a proper carer'. The physical environment varied greatly between NICUs. 'Homely and warmer rooms' were considered to have painted walls, paintings, curtains, cupboards, shower, television, and water boiler. These facilities were lacking in some NICUs rooms. Mothers mentioned the room being a shield, preventing other people from watching or entering their space. This increased privacy</p>	<p><b>Limitations (assessed using the CASP checklist for qualitative studies).</b> 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. Rationale for purposeful sampling and theoretical sampling given. No information given why some individuals refused but only 3 so unlikely to affect study bias. Q5: Were the data collected in a way that addressed the research issue? Unsure. Researchers used a mixture of semi-structured interviews and observation of parents and nurses. Field notes were taken for observation and interviews were recorded where possible. A moderate level of participation</p>

Study details	Participants	Methods	Themes and findings	Limitations
<p>both Sweden and England.</p> <p><b>Study dates</b> September 2009-February 2010 (English sites)</p> <p><b>Source of funding</b> This study received funding from Åkerham and Engström Foundation, Uppsala University.</p>	<ul style="list-style-type: none"> <li>Parents unwilling to participate</li> </ul>	<p>MaxQDA (qualitative software package). Transcripts were initially coded into emerging concepts, before being grouped into preliminary codes. These were constantly compared to already identified concepts. Codes, their properties and dimensions formed a continuously developing framework to guide future observations. Theoretical coding was conducted by one reviewer, with frequent discussions with a second. Codes were condensed into sub-categories and categories, leading the themes and linkages. Conducted as a comparative ethnographic study so process oscillated between open and theoretical coding. Once data had been collected and preliminary themes identified, data from the start of the collection period was re-analysed in increase the rigour of the study. The field-work journal was used for discussion with the second author.</p>	<p>was described as 'enabling family life'. The hotel room also protected the new-borns from too many outside stimuli and disturbances, which some mother's witnessed in their breastfeeding behaviour. The sense of privacy also help mothers to rest after childbirth and become accustomed to their new role. However, potential isolation was identified as a disadvantage for these 'hotel rooms'. A term for a private place/space. In NICU C (England), these were comfortable chairs placed by the incubators or cots (bigger chairs were static). In NICU D (England) there were few chairs by the incubators or cots. However, mothers could have assigned chairs depending on size of room and the position of the cot within the room. A chair signalled that parents would visit their babies, staying as close as possible and potentially holding them while there. In NICU C, the staff created a homely atmosphere with ornaments and flowery curtains. In NICU D, the environment was classed as 'cold' and clinical due to the lack of decorating, colour of the walls and curtains. Breastfeeding screens were not in place but could be placed next to mothers if needed. Some mother's felt that they were imposing by asking to staff for screens, leading to stress and</p>	<p>was used in the observation, described as a balance between being a participator and observer. The observer was dressed in non-staff clothing, usually sat in the corner of the room and would not carry out any aspect of care. However, they might help out with small tasks sometimes e.g. fetching items. Mentions that Spadley-s 9-dimension framework for data collection was used but no rationale given. The lack of information regarding the semi-structured interviews that is concerning.</p> <p><i>Q6: Has the relationship between researcher and participants been adequately considered?</i> No. No description of potential bias/influence between researcher and participants. This especially increases the potential for bias in the observation data collection.</p> <p><i>Q7: Have ethical issues been taken into consideration?</i> Yes. Approved by National Research Ethics Services and University of Central Lancashire ethics committee. Informed consent obtained from parents.</p>

Study details	Participants	Methods	Themes and findings	Limitations
			<p>anxiety about breastfeeding in public. English mothers had an aversion to revealing their breasts, which led to minimal skin to skin contact with their child and hindered breastfeeding. Socialising between women was very common in these areas, leading to both positive and negative sequelae. Advantages included sharing information and support. Disadvantages included comparisons of oneself with other new mothers. Mothers were not able to stay in the safe corner but had to return to the bed in the maternity unit, disrupting opportunity for bonding and closeness.</p> <p>A term for a place/space with too few facilities to allow parents to be present, close or have privacy. Only found in NICU D (England). No reclining chairs, instead had wooden or plastic chairs. In the high-dependency room and the nursery, these chairs were placed around a central table where staff stored paperwork. Parent's had no ownership of this space and did not have the opportunity to spend quality time with their baby. Similarly, they were not allowed to eat or drink anything apart from water while in the NICU. Lack of comfortable sitting options, harsh lighting and noise were identified as factors preventing attuned breastfeeding. Mothers could spend a long time and there</p>	<p><i>Q8: Was the data analysis sufficiently rigorous?</i> Unclear. Grounded theory approach used and rationale given. During the initial stage of coding, a constant comparative method was applied, which created a continually developing framework for later data. The data collection for the whole study was 11 months so the initial data underwent second analysis after codes had been finalised. Themes were only developed by one research, one with over 10 years' experience in neonatal care. Although themes were developed in consultation with the other author (less experienced in neonatal care) and a fieldwork diary was kept and discussed alongside the analysis, introduces pre-conceptions and biases which cannot be overlooked.</p> <p><i>Q9: Is there a clear statement of findings?</i> Probably. Findings are well described, related to the original research question and current literature with discussion about conflicting views/experiences within the sample. There is adequate discussion surrounding credibility of research, particularly data collection and</p>

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			<p>was no acknowledgement of their babies behavioural milestones. There was less socialising between the mothers in NICU D, due to the small amount of time mothers spent there, transfer of babies and the amount of space existing between cots. Mothers tended to mimic other people's feeding and holding habits, without understanding why.</p>	<p>analysis. Limitations to the evidence presented along with steps taken to limit these biases.</p> <p><i>Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)</i> Yes. 1. Yes. Details how the study findings fit in with current literature and how they can be used to increase attuned feeding in the NICU environment. 2. Probably. Purposeful sampling of 2 NICU populations in England suggests transferability.</p> <p><i>Overall judgement of quality:</i> Moderate concerns</p> <p><b>Other information</b> Multi-country study conducted in NICUs in Sweden and England. Data only extracted for the English study sites.</p>
<p><b>Full citation</b> Heath, G., Greenfield, S., Redwood, S., The meaning of 'place' in families' lived experiences of paediatric outpatient care in different settings: A descriptive</p>	<p><b>Sample size</b> N=15</p> <ul style="list-style-type: none"> <li>• n = 8 young people</li> <li>• n=7 parents</li> </ul> <p>Data from parents not extracted nor included in this review</p>	<p><b>Setting</b> Paediatric outpatient clinic in hospital, health centre or children's centre</p> <p><b>Recruitment</b> Purposive sampling of families recruited in General Paediatric clinic or by letter according to</p>	<p><b>Author's themes:</b></p> <ul style="list-style-type: none"> <li>• A therapeutic environment</li> <li>• Time wasted, time saved</li> <li>• Adolescents' needs - All is forgotten</li> <li>• My community, not the community</li> </ul>	<p><b>Limitations (assessed using the CASP checklist for qualitative studies).</b> <i>Q1: Was there a clear statement of the aims of the research?</i> Yes.</p> <p><i>Q2: Was a qualitative methodology appropriate?</i> Yes.</p>

Study details	Participants	Methods	Themes and findings	Limitations
<p>phenomenological study, Health and Place, 31, 46-53, 2015</p> <p><b>Ref Id</b> 989549</p> <p><b>Country/ies where the study was carried out</b> West Midlands, UK</p> <p><b>Study type</b> Semi-structured interview; qualitative</p> <p><b>Aim of the study</b> To examine the experience and impact of introducing new, community-based paediatric outpatient clinics for NHS service users</p> <p><b>Study dates</b> Not reported</p> <p><b>Source of funding</b> NIHR funding through the Collaborations for Leadership in Applied Health Research and</p>	<p><b>Characteristics</b> Age of young people: not reported Gender of young people (M/F): not reported</p> <p><b>Inclusion criteria</b> • Attended appointment at General Paediatric community outpatient clinic</p> <p><b>Exclusion criteria</b> Not reported</p>	<p>experience of attending outpatient appointments in 1 of 3 settings (hospital, health centre, children's centre) and varied according to age, sex, ethnicity, employment status, and distance of home to main hospital. Informed consent from parents of participating young children, and informed assent from children, obtained.</p> <p><b>Data collection</b> Majority of semi-structured interviews conducted at participant's preferred location (e.g. home) and time, with only 3 in hospital. Participants asked to describe their experience of last outpatient appointment with follow up questions to clarify understanding or prompt for detail. Researcher asked participants to explain commonly used descriptive words to reveal participant's experience. Interviews audio-recorded and transcribed verbatim.</p> <p><b>Analysis</b> Descriptive phenomenology according to Giorgi's method, with the aim of remaining open to phenomenon by recognising existing understandings and</p>	<p>Families liked community clinic for its relative convenience, saving time and money, with some seeing slightly less high-quality of care as trade off compared to that obtained in hospital. Children liked open-plan and vibrant design of community centre but some adolescents and young people felt that there was nothing for them to occupy themselves with. Health status may affect perception of whether place of care is appropriate or not. Families value clinic being part of their community and experience them as more empathic towards their own circumstances.</p>	<p><i>Q3: Was the research design appropriate to address the aims of the research? Yes.</i></p> <p><i>Q4: Was the recruitment strategy appropriate to the aims of the research? Yes.</i></p> <p><i>Q5: Were the data collected in a way that addressed the research issue? Yes.</i></p> <p><i>Q6: Has the relationship between researcher and participants been adequately considered? Yes.</i></p> <p><i>Q7: Have ethical issues been taken into consideration? Yes.</i></p> <p><i>Q8: Was the data analysis sufficiently rigorous? Yes.</i></p> <p><i>Q9: Is there a clear statement of findings? Yes.</i></p> <p><i>Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability) Yes. 1. Yes, contextualizes in literature 2. Yes, study in community-based general paediatric clinic</i></p> <p><i>Overall judgement of quality: No or very minor concerns</i></p>

Study details	Participants	Methods	Themes and findings	Limitations
<p>Care for Birmingham and Black Country (CLAHRC-BBC) programme</p>		<p>using them as source of insight. Transcript analysed and divided into meaning units in order to reveal lived (though not necessarily articulated) meaning. Individual and general structures of experience compared and differences highlighted.</p>		
<p><b>Full citation</b>            Hunt, A., Brown, E., Coad, J., Staniszewska, S., Hacking, S., Chesworth, B., Chambers, L., 'Why does it happen like this?' Consulting with users and providers prior to an evaluation of services for children with life limiting conditions and their families, Journal of child health care : for professionals working with children in the hospital and community, 19, 320-333, 2015</p> <p><b>Ref Id</b>            989827</p> <p><b>Country/ies where the study was carried out</b>            West Midlands, U.K</p>	<p><b>Sample size</b>            N=7 young people</p> <p><b>Characteristics</b>            Age (range): 13-18 years            Gender (M/F): 6/1            Six participants had physical disability (5 wheelchair users)</p> <p><b>Inclusion criteria</b>            Not reported</p> <p><b>Exclusion criteria</b>            Not reported</p>	<p><b>Setting</b>            Recruited from previous project</p> <p><b>Recruitment</b>            Part of project 'The Big Study', which aimed to assess the extent to which supportive and palliative care services meet the needs of life limited children and young people. Consultation with children at a special needs school invited by teacher on behalf of research team.</p> <p><b>Data collection</b>            Focus groups with children: Three researchers divided children into two groups with facilitated activities who produced post-it notes and postcards. Individual telephone interviews conducted if wanted. Third researcher moved between tables making notes and assisting individuals if help needed. All interviews digitally recorded.</p>	<p><b>Author's themes</b></p> <ul style="list-style-type: none"> <li>• Quality of environment</li> </ul> <p>Children and young people demonstrated an interest in the quality of hospital environments. In their discussions, young people provided their opinion comparing two local hospitals of which most of them had experience, with one being favoured over the other because it appeared to be (and in fact had been) designed with children and young people in mind. For children and young people in school environments, there was a preference for keeping and refurbishing their current environment rather than having it replaced.</p>	<p><b>Limitations (assessed using the CASP checklist for qualitative studies).</b>  <i>Q1: Was there a clear statement of the aims of the research?</i> Yes.</p> <p><i>Q2: Was a qualitative methodology appropriate?</i> Yes.</p> <p><i>Q3: Was the research design appropriate to address the aims of the research?</i> Yes.</p> <p><i>Q4: Was the recruitment strategy appropriate to the aims of the research?</i> Yes.</p> <p><i>Q5: Were the data collected in a way that addressed the research issue?</i> Yes.</p> <p><i>Q6: Has the relationship between researcher and participants been adequately considered?</i> Yes.</p>

Study details	Participants	Methods	Themes and findings	Limitations
<p><b>Study type</b> Participatory-based focus group; qualitative</p> <p><b>Aim of the study</b> To identify important issues affecting children with life limiting conditions and their families, as well as service providers, with respect to the goals and design of 'The Big Study'</p> <p><b>Study dates</b> Not reported, between 2008 and 2012</p> <p><b>Source of funding</b>  Big Lottery Research Programme Development Grant C878A693.</p>		<p><b>Analysis</b> Themes created from notes on content used (rather than transcriptions) in combination with data and notes produced during focus group activities.</p>		<p><i>Q7: Have ethical issues been taken into consideration? Yes.</i></p> <p><i>Q8: Was the data analysis sufficiently rigorous? Can't tell.</i> Thematic analysis of notes on content produced (e.g. art) during focus group in combination with data (e.g. post-it notes) and third researcher's notes made during focus group activities; no transcription of conversation.</p> <p><i>Q9: Is there a clear statement of findings? Yes.</i></p> <p><i>Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)</i> Possibly yes. 1. Yes, discusses in UK healthcare context. 2. Yes but limited by demographics (age and gender) of participants, concentration on one type of condition and regional study.</p> <p><i>Overall judgement of quality: Moderate concerns</i></p>
<p><b>Full citation</b>  McKenzie, S., Norrish, S., Parker, L., Frampton, I., Consulting with young people about healthcare. Part I: Experience of the</p>	<p><b>Sample size</b> N=4 young people</p> <p><b>Characteristics</b> Age (range): 13-15 years Gender (M/F): 1/3</p>	<p><b>Setting</b> Youth forum</p> <p><b>Recruitment</b> Identified via the local Youth Forum. No further details reported.</p>	<p><b>Author's themes:</b></p> <ul style="list-style-type: none"> <li>• Physical space and environment <ul style="list-style-type: none"> <li>○ Environmental advantages</li> <li>○ environmental drawbacks</li> </ul> </li> <li>• Patients' needs <ul style="list-style-type: none"> <li>○ Needs met</li> </ul> </li> </ul>	<p><b>Limitations (assessed using the CASP checklist for qualitative studies).</b> <i>Q1: Was there a clear statement of the aims of the research? Yes.</i></p>



Study details	Participants	Methods	Themes and findings	Limitations
<p>hospital environment, Pediatric Health, 4, 157-166, 2010</p> <p><b>Ref Id</b> 991150</p> <p><b>Country/ies where the study was carried out</b> South-West England, UK</p> <p><b>Study type</b> Semi-structured interview; qualitative</p> <p><b>Aim of the study</b> To explore the views and experience of adolescents on the hospital environment</p> <p><b>Study dates</b> Not reported</p> <p><b>Source of funding</b> Study funding received from the Real Ideas Organisation</p>	<p>All British Caucasian</p> <p><b>Inclusion criteria</b></p> <ul style="list-style-type: none"> <li>• Aged 13-18 years</li> <li>• Have parental/guardian consent</li> <li>• Be living in family home</li> <li>• Currently be in full-time education</li> </ul> <p><b>Exclusion criteria</b></p> <ul style="list-style-type: none"> <li>• Not able to understand or speak fluent English</li> <li>• Moderate to severe learning disability</li> <li>• Known pre-existing health issues with previous inpatient admissions</li> </ul>	<p><b>Data collection</b> 20-40 minutes semi-structured interviews were conducted after participants went on a tour of the hospital and audio-recorded. Facilitated by a topical outline developed from relevant literature and validated by a Clinical Psychologist. Recorded interviews were transcribed verbatim and all participant responses were numbered.</p> <p><b>Analysis</b> Inductive thematic analysis. Codes were assigned to emerging themes which were then developed into a coding scheme. Once consistency was achieved this scheme was applied to the rest of the transcripts.</p>	<ul style="list-style-type: none"> <li>○ Unmet needs</li> </ul> <p>Participants offered positive comments on the availability of specific areas/departments that were designed with adolescent in mind, particularly the adolescent ward. Some other areas catering for a range of ages (e.g. GUM clinic) was also seen positively. Participants mentioned that the hospital layout and size of the grounds was a big disadvantage. Signposts and map were especially problematic. Additionally, the size of some departments (e.g. A&amp;E) and general ambience was criticised. Adolescents enjoyed seeing the different ways the hospital catered for different age groups, especially areas for young children and the adolescent ward. Individuals mentioned some departments and areas that could have been improved. Participants thought that areas of the hospital were designed to appeal to the very young and adult population, but not adolescents. Additionally, they felt as though space and facilities were lacking in certain areas e.g. A&amp;E.</p>	<p><i>Q2: Was a qualitative methodology appropriate? Yes.</i></p> <p><i>Q3 Was the research design appropriate to address the aims of the research? Unsure. Data is from adolescents who specifically had no previous inpatient admissions. Instead, they had taken a tour of the hospital environment.</i></p> <p><i>Q4: Was the recruitment strategy appropriate to the aims of the research? Probably not. Very small sample size, very similar characteristics reported and only information on recruitment was that it was done via local Youth Forum.</i></p> <p><i>Q5: Were the data collected in a way that addressed the research issue? Unsure. Individual interview process well described and justified. Information on the interview schedule was not given but it was noted that it had been validated by a Clinical Psychologist. No mention of data saturation.</i></p> <p><i>Q6: Has the relationship between researcher and participants been adequately considered? No. No description of potential bias/influence</i></p>

Study details	Participants	Methods	Themes and findings	Limitations
				<p>between researcher and participants.</p> <p><i>Q7: Have ethical issues been taken into consideration?</i> Unsure. No details reported apart from noting that informed consent was obtained prior to interview.</p> <p><i>Q8: Was the data analysis sufficiently rigorous?</i> Unsure. Detailed description of analysis given. Contradictory data is taken into account throughout and multiple quotes provided for each theme. However, there is a lack of discussion surrounding the researcher's reflexivity and no information regarding how data that was presented was chosen. No mention of how many researchers were involved in the analysis.</p> <p><i>Q9: Is there a clear statement of findings?</i> No. The findings are well described and discussed in relation to the original research question. Adolescent views and quotes are very similar between themes, suggesting a lack of data due to very small sample size. Researcher bias is acknowledged as a possibility and was 'explored' but no further information given beyond that.</p>

Study details	Participants	Methods	Themes and findings	Limitations
				<p><i>Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)</i>            Unsure. 1. Probably. Good discussion on how the evidence fits in with current literature and discussion about future clinical practice implications. 2. No. Small sample size and very specific population characteristics limits the transferability of the research.</p> <p><i>Overall judgement of quality: Serious concerns</i></p>
<p><b>Full citation</b></p> <p>Wood, D., Geoghegan, S., Ramnarayan, P., Davis, P. J., Pappachan, J. V., Goodwin, S., Wray, J., Eliciting the experiences of the adolescent-parent dyad following critical care admission: a pilot study, <i>European Journal of Pediatrics</i>, 177, 747-752, 2018</p> <p><b>Ref Id</b></p>	<p><b>Sample size</b> N=17</p> <ul style="list-style-type: none"> <li>• n=8 young people</li> <li>• n=9 mothers</li> </ul> <p>Data from parents not extracted nor included in this review</p> <p><b>Characteristics</b> Age of adolescent at interview (Paediatric or adult intensive care unit [PICU, AICU]): 14 years-old, n=1 (PICU); 15 years-old, n=3 (PICU); 16 years-old, n=2 (AICU,</p>	<p><b>Setting</b> Intensive care unit</p> <p><b>Recruitment</b> Purposive sampling used with eligible participants/families contacted by local specialist nurses who were known to them at each participating hospital to seek consent to be contacted and to invite them to interview. Opportunities to discuss participation further provided and consent obtained from participants (parents/carers if aged under 18) prior to interview. Fourteen</p>	<p><b>Author's themes:</b></p> <ul style="list-style-type: none"> <li>• Environment</li> </ul> <p>While some participants reported the environment of ICU as unimportant when experiencing acute illness, others discussed the influence of other patients (age differences) and availability of appropriate equipment on their experience of the ICU environment during admission. Marked differences in age (when admitted with patients considered either too young or old) made some young people feel weird or like the minority. Adolescent participants who had experienced admission to</p>	<p><b>Limitations (assessed using the CASP checklist for qualitative studies).</b></p> <p><i>Q1: Was there a clear statement of the aims of the research? Yes.</i></p> <p><i>Q2: Was a qualitative methodology appropriate? Yes.</i></p> <p><i>Q3: Was the research design appropriate to address the aims of the research? Yes.</i></p> <p><i>Q4: Was the recruitment strategy appropriate to the aims of the research? Yes.</i></p>

Study details	Participants	Methods	Themes and findings	Limitations
<p>994200</p> <p><b>Country/ies where the study was carried out</b> England, UK</p> <p><b>Study type</b> Semi-structured interview; qualitative</p> <p><b>Aim of the study</b> To determine whether adolescents and their families can articulate their experiences of their intensive care unit (ICU) or high dependency unit (HDU) visit, and to identify the factors that are important to them during such visits</p> <p><b>Study dates</b> Not reported</p> <p><b>Source of funding</b> Great Ormond Street Hospital Children's Charity Clinical Research Starter Grant V0015</p>	<p>1 PICU); 17 years-old, n=2 (1 AICU, 1 PICU); 19 years-old, n=1 (AICU)</p> <p>Details: Discharged via ward and no ongoing treatment required, n=2; discharged via ward and ongoing treatment required, n=3; on-going treatment required, n=1; discharged back to ward and on-going treatment required, n=2; will have on-going contact with hospital, n=1</p> <p><b>Inclusion criteria</b> Eligible participants were:</p> <ul style="list-style-type: none"> <li>• Aged 10-17 years-old</li> <li>• Admitted as emergency to adult or paediatric ICU or HDU in 1 of 4 UK hospitals (2 adult, 2 paediatric) for at least 24 hours in previous 12 months</li> <li>• At least 2-months post-ICU admission</li> <li>• Awake for some of their ICU stay, and their parents/carers</li> </ul>	<p>families satisfied inclusion criteria and agreed to be contacted by researchers. Five families could not be contacted and two families withdrew for logistical or other reasons.</p> <p><b>Data collection</b> All interviews were conducted face-to-face by one researcher (female social scientist with experience interviewing ICU patients/families) in participant's own home or in quiet hospital room. Interviews were 30-90 min and were audio-transcribed verbatim. Topic guides used and participants asked to remember their ICU visit/staff support. Researcher kept contemporaneous notes of interviews and her own reflections, which were also reviewed by other authors.</p> <p><b>Analysis</b> Framework analysis used involving: familiarisation, identifying thematic framework, indexing, charting, mapping and interpretation. Two authors and lead researcher independently generated themes/frameworks and agreed on/refined descriptive headings through iterative</p>	<p>an adolescent ward reviewed it positively, but an adolescent unit was not available in any of the ICUs.</p>	<p><i>Q5: Were the data collected in a way that addressed the research issue? Yes.</i></p> <p><i>Q6: Has the relationship between researcher and participants been adequately considered? Can't tell. Not discussed.</i></p> <p><i>Q7: Have ethical issues been taken into consideration? Yes. Ethical approval granted from South West-Central Bristol ethics committee (Ref 14/SW/1131).</i></p> <p><i>Q8: Was the data analysis sufficiently rigorous? Yes.</i></p> <p><i>Q9: Is there a clear statement of findings? Yes.</i></p> <p><i>Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability) Yes. 1. Yes, contextualises findings in literature, suggests further research. 2. Possibly yes, specific age group and setting make transferability of findings difficult but identified themes plausibly apply in other situations.</i></p>

Study details	Participants	Methods	Themes and findings	Limitations
	<p><b>Exclusion criteria</b> Not reported</p>	<p>process. Data from each transcript entered into framework and key themes extracted and relationships between them were explored. Data and findings also discussed with other team members as well as two ICU nurses not directly involved in project to enhance confirmability and credibility of findings.</p>		<p><i>Overall judgement of quality: No or very minor concerns</i></p>

CASP: Critical Skills Appraisal Programme; N/n: number; NICU: neonatal intensive care unit

## Appendix E – Forest plots

**Forest plots for review question: What features of the environment in which healthcare is provided are important to babies, children and young people to improve their experience of care?**

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

## Appendix F – GRADE-CERQual tables

GRADE-CERQual tables for review question: What features of the environment in which healthcare is provided are important to babies, children and young people to improve their experience of care?

**Table 7: Evidence summary (GRADE-CERQual) for theme 1: Location of care**

Study information		Description of theme or finding	CERQUAL Quality assessment				
No of studies	Design		Methodological Limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
<b>Sub-theme 1.1: Community-based care</b>							
1 (Heath 2015)	Semi-structured interview	Data from 1 study showed that children and young people experience community outpatient clinics and their staff as more a part of their own communities than hospital-based clinics and staff. This sense of belonging may encourage them to experience their own treatment as more personalised to their own situation.  <i>'It's part of my community. It's just around the corner and like when you go to school or something you go past it, you see it and I'm used to it being there.'</i> (Heath 2015, page 50)	No or very minor concerns	Moderate concerns <sup>1</sup>	Minor concerns <sup>2</sup>	Minor concerns <sup>3</sup>	MODERATE

<sup>1</sup> Evidence was downgraded for coherence because only one study contributed to the review finding

<sup>2</sup> Evidence was downgraded for relevance because study was conducted only in the West Midlands, UK

<sup>3</sup> Evidence downgraded for adequacy because study offered some rich data

**Table 8: Evidence summary (GRADE-CERQual) for theme 2: Physical healthcare environment**

Study information		Description of theme or finding	CERQUAL Quality assessment				
No of studies	Design		Methodological Limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
<b>Sub-theme 2.1: Age-appropriateness</b>							
4 (Heath 2015, Hunt 2015, McKenzie)	Semi-structured interview	Data from 4 studies showed that children and young people value healthcare environments that are designed with them in mind, although this may be less important depending on their age and	Moderate concerns <sup>1</sup>	Minor concerns <sup>2</sup>	Moderate concerns <sup>3</sup>	Minor concerns <sup>4</sup>	MODERATE

Study information		Description of theme or finding	CERQUAL Quality assessment				
No of studies	Design		Methodological Limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
2010, Wood 2018)		<p>reason for treatment. Younger children generally liked decorated, open environments in which they can play or in which their interests are catered for. However, older children and young people are conscious of their difference to their younger peers and generally feel that there is nothing for them to do. Children and young people may also find the layout of large healthcare environments, such as hospitals, and associated signposting confusing or difficult to understand.</p> <p><i>'I wouldn't mind if people were like fourteen, fifteen, because like, that's close enough to my age for me to deal with, but if everyone's like eight, nine, ten, that's quite young. That's a lot different than my age. That would be weird' ( Wood 2018, page 749)</i></p>					
<b>Sub-theme 2.2: Privacy and an area for friends and family</b>							
4 (Boyden 2009, Brown 2012, Dean 2015, Flacking 2013)	Semi-structured interview	<p>Data from 4 studies showed that children and young people value having a space that affords privacy and does not curtail their opportunities to be more than a patient. The intense activity and noise, and the various equipment associated with a particular healthcare environment, such as an adult in-patient ward or the A&amp;E department, can make a strong impression on them, especially when they are in close proximity to adult patients who may make them worry or feel uncomfortable. Restrictions on their opportunities to see friends and family, or to have them present for their care, are not liked. For parents of babies in a neonatal intensive care unit, decorated rooms with available everyday amenities (e.g. showers, television, and kettles) were felt to be 'homely' and provided a barrier between them and the outside world, maximising time with their babies and family. However, some recognised the potential for isolation.</p>	Moderate concerns <sup>1</sup>	Moderate concerns <sup>5</sup>	Minor concerns <sup>6</sup>	Minor concerns <sup>7</sup>	MODERATE



Study information		Description of theme or finding	CERQUAL Quality assessment				
No of studies	Design		Methodological Limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
		<i>“It was so noisy—I was near the nurses’ desk and they talked all night. The other patients just kept moaning and crying and calling out but no one seemed to go to them ... it was very scary.” (Dean 2015, page 233)</i>					

*1 Evidence was downgraded for methodological limitations as per CASP qualitative checklist*

*2 Evidence was downgraded for coherence as evidence supporting review finding was reasonably compelling*

*3 Evidence was downgraded for relevance because studies were conducted in various settings and populations/age groups*

*4 Evidence was downgraded for adequacy because studies offered some moderately rich data*

*5 Evidence was downgraded for coherence because evidence supporting review finding was only moderately compelling*

*6 Evidence was downgraded for relevance because studies were conducted in various settings and populations/age groups*

*7 Evidence was downgraded for adequacy because studies offered some moderately rich data*

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

**Economic evidence study selection for review question: What features of the environment in which healthcare is provided are important to babies, children and young people to improve their experience of care?**

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

## **Appendix H – Economic evidence tables**

**Economic evidence tables for review question: What features of the environment in which healthcare is provided are important to babies, children and young people to improve their experience of care?**

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

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

**Economic evidence profiles for review question: What features of the environment in which healthcare is provided are important to babies, children and young people to improve their experience of care?**

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

## **Appendix J – Economic analysis**

**Economic evidence analysis for review question: What features of the environment in which healthcare is provided are important to babies, children and young people to improve their experience of care?**

No economic analysis was conducted for this review question.

## Appendix K – Excluded studies

**Excluded studies for review question: What features of the environment in which healthcare is provided are important to babies, children and young people to improve their experience of care?**

### Clinical studies

**Table 9: Excluded studies and reasons for their exclusion**

Study	Reason for Exclusion
Palatability of hypoallergenic formulas for cow's milk allergy and healthcare professional recommendation, <i>Pediatric allergy and immunology</i> , 29, 857-862, 2018	Not related to features of physical environment in healthcare settings
Home interventions and light therapy for the treatment of vitiligo (HI-Light Vitiligo Trial): study protocol for a randomised controlled trial, <i>BMJ open</i> , 8, 2018	Not a qualitative study
Abdelrahim, Z., Dooley, A., Khan, A., Development of a paediatric specialist multidisciplinary down syndrome clinic, <i>Archives of disease in childhood</i> , 103 (Supplement 1), A162-A163, 2018	Conference Abstract
Abid, S., Greenshields, N., Lowe, J., Survey of stakeholders of a paediatric anaesthetic room, <i>Archives of disease in childhood</i> , 103 (Supplement 1), A163-A164, 2018	Conference abstract
Aceijas, C., Waldhausl, S., Lambert, N., Cassar, S., Bello-Corassa, R., Determinants of health-related lifestyles among university students, <i>Perspectives in Public Health</i> , 137, 227-236, 2017	Not related to features of physical environment in healthcare settings
Ahmed, M., Boyd, C., Vavilikolanu, R., Rafique, B., Visual symptoms and childhood migraine: Qualitative analysis of duration, location, spread, mobility, colour and pattern, <i>Cephalalgia</i> , 38, 2017-2025, 2018	Not related to features of physical environment in healthcare settings
Ahmed, S. A., Arasu, A., Ethical dilemma in neonatology, <i>Archives of Disease in Childhood</i> , 97, A300, 2012	Conference abstract
Ahmed, S. A., Arasu, A., Another ethical dilemma in neonatology, <i>Archives of Disease in Childhood</i> , 96, A72, 2011	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, <i>International journal of obesity</i> , 35, 53-515, 2011	Not a qualitative study
Alexander, S., Bath, L., McDonald, M., Adolescent diabetic outpatient clinics-more than just an HbA1c, <i>Archives of disease in childhood</i> , 101 (Supplement 1), A275-A277, 2016	Conference abstract
Allen, Kate, Marlow, Ruth, Edwards, Vanessa, Parker, Claire, Rodgers, Lauren, Ukoumunne, Obioha C., Seem, Edward Chan, Hayes, Rachel, Price, Anna, Ford, Tamsin, 'How I Feel About My School': The construction and validation of a measure of wellbeing at school for primary school children, <i>Clinical child psychology and psychiatry</i> , 23, 25-41, 2018	Not related to features of physical environment in healthcare settings
Al-Taei, M., Abood, S., Garrett, C., Choudhary, P., Kapoor, R. R., Feasibility and acceptability of robot assistant in self-management of type 1 diabetes in children, <i>Hormone Research in Paediatrics</i> , 1), 104-105, 2014	Conference abstract

Study	Reason for Exclusion
Armstrong, V. G., Howatson, R., Parent-infant art psychotherapy: A creative dyadic approach to early intervention, <i>Infant mental health journal</i> , 36, 213-222, 2015	Not related to features of physical environment 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, <i>Health and Place</i> , 23, 138-147, 2013	Not related to features of physical environment in healthcare settings
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, <i>JMIR Mental Health</i> , 5, e10067, 2018	Not related to features of physical environment 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, <i>Photochemistry and photobiology</i> , 92, 193-200, 2016	Not related to features of physical environment in healthcare settings
Bailey, S., Taylor, A., Kent, A., More space, Better quality care? Parents' perception of quality of care prior to and after neonatal unit relocation, <i>Intensive Care Medicine</i> , 37, S428-S429, 2011	Conference abstract
Biddiss, E., Knibbe, T. J., McPherson, A., The effectiveness of interventions aimed at reducing anxiety in health care waiting spaces: A systematic review of randomized and nonrandomized trials, <i>Anesthesia and Analgesia</i> , 119, 433-448, 2014	Not a qualitative study
Datt, C., Travers, M., Odell, C., Improving the hospital experience for young people (YP) with autism, <i>Archives of disease in childhood</i> , 102 (Supplement 1), A20, 2017	Conference abstract
Dean, L. A., An exploration of the experiences of young people who have been nursed on adult wards, <i>Archives of disease in childhood</i> , 1), A76, 2012	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, <i>Educational and Child Psychology</i> , 29, 86-100, 2012	Population not in protocol - 13-21 with not identification of years in text.
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, <i>Archives of disease in childhood</i> , 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, <i>Archives of Disease in Childhood</i> , 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, <i>Bone Marrow Transplantation</i> , 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!, <i>Clinical Medicine, Journal of the Royal College of Physicians of London</i> , 16, 146-151, 2016	Age group >17 years
Farrugia, E., Edwards, K., Art therapy in hospital waiting rooms, <i>Rheumatology (United Kingdom)</i> , 57 (Supplement 8), viii8, 2018	Conference abstract

Study	Reason for Exclusion
Fawcett, R., Porritt, K., Stern, C., Carson-Chahhoud, K., Experiences of parents and carers in managing asthma in children: A qualitative systematic review, JBI Database of Systematic Reviews and Implementation Reports, 17, 793-984, 2019	Systematic review. References checked for possible included studies - none were identified.
Fenton, K., Larkin, M., Boden, Z. V. R., Thompson, J., Hickman, G., Newton, E., The experiential impact of hospitalisation in early psychosis: Service-user accounts of inpatient environments, Health and Place, 30, 234-241, 2014	Study participants >17 years age
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	Relates to experiences as a parent rather than as a proxy for baby
Finlay, Fiona, Baverstock, Anna, Lenton, Simon, Therapeutic clowning in paediatric practice, Clinical child psychology and psychiatry, 19, 596-605, 2014	Not a systematic review (narrative literature review)
Flacking, R., Dykes, F., Creating a positive place and space in NICUs, The practising midwife, 17, 18-20, 2014	Not a qualitative study
Fletcher, T., Glasper, A., Prudhoe, G., Battrick, C., Coles, L., Weaver, K., Ireland, L., Building the future: Children's views on nurses and hospital care, British Journal of Nursing, 20, 39-45, 2011	Included in 5.1. Not related to features of physical environment in healthcare settings
Foster, M. J., Whitehead, L., Maybee, P., Cullens, V., The parents', hospitalized child's, and health care providers' perceptions and experiences of family centered care within a pediatric critical care setting: a metasynthesis of qualitative research, Journal of Family Nursing, 19, 431-468, 2013	Not a UK study
Hassall, L., Lynch, J., Swan-Merrison, J., Manchanda, R., Norman, R., Make it fun and they will come: Creating a youth friendly culture in a first episode psychosis clinic, Early intervention in psychiatry, 1), 63, 2010	Conference abstract
Hodkinson, S., Bunt, L., Daykin, N., Music therapy in children's hospices: An evaluative survey of provision, Arts in Psychotherapy, 41, 570-576, 2014	Survey of music therapists and staff experiences
Hope, G., Haake, A., Hilliard, C., The bare necessities of life: An evaluation of a live-music programme in a children's hospital, Psycho-Oncology, 25 (Supplement 3), 72, 2016	Conference abstract
James, J., Children as service users of a children's centre, Community practitioner : the journal of the Community Practitioners' & Health Visitors' Association, 89, 42-45, 2016	Study about experiences of children as users of preschool/nursery at children's centre. Not related to healthcare settings.
Kean, S., Children and young people visiting an adult intensive care unit, Journal of advanced nursing, 66, 868-877, 2010	Related to CYP's experience as visitors rather than users of healthcare
Kerri, O., Byron, P., Improving strategies to better support adolescents with cancer: The creation of an "adolescent-friendly oncology ward", Pediatric Blood and Cancer, 53 (5), 751-752, 2009	Conference abstract
Kim, J., Stegemann, T., Music listening for children and adolescents in health care contexts: A systematic review, Arts in Psychotherapy, 51, 72-85, 2016	Not a qualitative study



Study	Reason for Exclusion
Kingsnorth, S., Treurnicht Naylor, K., Lamont, A., McKeever, P., MacArthur, C., The effectiveness of music in pediatric healthcare: A systematic review of randomized controlled trials, Evidence-based Complementary and Alternative Medicine, 2011, 2011	Not a qualitative study
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
Lambert, Veronica, Coad, Jane, Hicks, Paula, Glacken, Michele, Young children's perspectives of ideal physical design features for hospital-built environments, Journal of child health care, 18, 57-71, 2014	Study conducted in Ireland
Larkin, M., Boden, Z. V., Newton, E., On the Brink of Genuinely Collaborative Care: Experience-Based Co-Design in Mental Health, Qualitative health research, 25, 1463-1476, 2015	Age group unclear; only describes as young adults with psychosis
Lee, Soeun, Narendran, Gaya, Tomfohr-Madsen, Lianne, Schulte, Fiona, A systematic review of sleep in hospitalized pediatric cancer patients, Psycho-Oncology, 26, 1059-1069, 2017	Not a qualitative study
Livesley, J., Long, T., Children's experiences as hospital in-patients: Voice, competence and work. Messages for nursing from a critical ethnographic study, International journal of nursing studies, 50, 1292-1303, 2013	Study reports children's experiences as hospital in-patients. Does not report on features of physical environment.
Longhi, Elena, Pickett, Nick, Hargreaves, David J., Wellbeing and hospitalized children: Can music help?, Psychology of Music, 43, 188-196, 2015	Not a qualitative study
Loyland, B., Angelhoff, C., Kristjansdottir, G., Sjolie, H., A systematic integrative review of parents' experience and perception of sleep when they stay overnight in the hospital together with their sick children, Journal of Clinical Nursing, 29, 706-719, 2020	Systematic review. References checked for possible included studies - none were identified.
McMaster, C., Gow, M., Cohen, J., Neal, R., Alexander, S., Baur, L., Patient and parent satisfaction with hospital-based paediatric weight management services and reasons for attrition: a mixed methods systematic review, Obesity Research and Clinical Practice, 13 (3), 311, 2019	Conference abstract
Nichols, Andy, The impact of the clinical environment on family centred care in the neonatal unit: A qualitative investigation, Journal of Neonatal Nursing, 20, 230-235, 2014	Participants are healthcare staff members
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 features of physical environment 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
Norton-Westwood, D., Pearson, A., Robertson-Malt, S., The ability of environmental healthcare design strategies To impact event related anxiety in paediatric patients: A comprehensive systematic review, JBI Library of Systematic Reviews, 9, 1828-1882, 2011	Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion.
O'Reilly, M., Dogra, N., Hughes, J., Reilly, P., George, R., Whiteman, N., Potential of social media in promoting mental health in adolescents, Health promotion international, 30, 30, 2018	Not related to features of physical environment in healthcare settings

Study	Reason for Exclusion
Panda, A., Garg, I., Bhobe, A. P., Children's perspective on the dentist's attire, International journal of paediatric dentistry / the British Paedodontic Society [and] the International Association of Dentistry for Children, 24, 98-103, 2014	Study conducted in India
Peng, M., Lovett, S., Damda, F., The treatment room on children's ward-a quality improvement project, Archives of Disease in Childhood, 1), A93, 2014	Conference abstract
Petrie, K., McArdle, A., Cookson, J., Powell, E., Poblete, X., 'Let us speak'-children's opinions of doctors, Archives of Disease in Childhood, 102 (Supplement 1), A200-A201, 2017	Conference abstract
Pineda, R., Raney, M., Smith, J., Supporting and enhancing NICU sensory experiences (SENSE): Defining developmentally-appropriate sensory exposures for high-risk infants, Early Human Development, 133, 29-35, 2019	Country not in protocol: USA
Preti, Costanza, Welch, Graham F., Music in a hospital: The impact of a live music program on pediatric patients and their caregivers, Music and Medicine, 3, 213-223, 2011	Study conducted in Italy
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
Sexton, K., Heinz, P., Lothian, K., Young people get active! focus group involvement to improve the experience of adolescent paediatric patients in emergency departments, Archives of Disease in Childhood: Education and Practice Edition, 1), A109, 2013	Conference abstract
Shahheidari, Marzieh, Homer, Caroline, Impact of the design of neonatal intensive care units on neonates, staff, and families: A systematic literature review, The Journal of Perinatal & Neonatal Nursing, 26, 260-266, 2012	Only one included study from this systematic review is relevant(Beck 2009)which was conducted in Denmark
Sisson, Helen, Jones, Catriona, Williams, Rhona, Lachanudis, Lisa, Metaethnographic synthesis of fathers' experiences of the neonatal intensive care unit environment during hospitalization of their premature infants, Journal of Obstetric, Gynecologic, & Neonatal Nursing: Clinical Scholarship for the Care of Women, Childbearing Families, & Newborns, 44, 471-480, 2015	Related to fathers' experiences in the NICU, rather than fathers' acting as proxies for babies' experiences
Smith, L., Medves, J., Harrison, M. B., Tranmer, J., Waytuck, B., The Impact of Hospital Visiting Hour Policies on Pediatric and Adult Patients and their Visitors, JBI Library of Systematic ReviewsJBI Libr Syst Rev, 7, 38-79, 2009	Not a qualitative study
Stickland, A. E. J., Clayton, E. K., Hill, C. M., Children's sleep quality in hospital, Archives of disease in childhood, 1), A65, 2012	Conference abstract
Stickland, A., Clayton, E., Sankey, R., Hill, C. M., A qualitative study of sleep quality in children and their resident parents when in hospital, Archives of disease in childhood, 101, 546-551, 2016	Population not in protocol - parental views only. Mean age = 7, only 2 children under 5.
Stuart, M., Melling, S., Understanding nurses' and parents' perceptions of family-centred care, Nursing children and young people, 26, 16-21, 2014	Not related to features of physical environment in healthcare settings
van Veenendaal, N. R., van Kempen, A. A. M. W., Franck, L. S., O'Brien, K., Limpens, J., van der Lee, J. H., van Goudoever, J. B., van der Schoor, S. R. D., Hospitalising preterm infants in single family rooms versus open bay units: A systematic review and meta-analysis of impact on parents, EClinicalMedicine, 23, 100388, 2020	Systematic review. Included studies checked for relevance.

Study	Reason for Exclusion
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, <i>Neuromuscular Disorders</i> , 29, 221-230, 2019	Specific to DMD; Not related to features of physical environment in healthcare settings
Walsh, L., Play in the children's hospital; discreet activity or way of life?, <i>Archives of disease in childhood</i> , 103 (Supplement 2), A46, 2018	Conference abstract
Watts, R., Wilson, S., Impact of the physical environment in paediatric hospitals on health outcomes: a systematic review, <i>Journal of Evidence-Based Healthcare</i> , 7, 908-941, 2009	Systematic review - references checked for possible included studies. None were identified.
Wensley, C., Botti, M., McKillop, A., Merry, A. F., A framework of comfort for practice: An integrative review identifying the multiple influences on patients' experience of comfort in healthcare settings, <i>International journal for quality in health care</i> , 29, 151-162, 2017	Systematic review looking at patient experience in general, with no segregated data for BCYP
Whale, K., Cramer, H., Joinson, C., Left behind and left out: The impact of the school environment on young people with continence problems, <i>British journal of health psychology</i> , 23, 253-277, 2018	Not related to features of physical environment in healthcare settings
Winner-Stoltz, R., Lengerich, A., Hench, A. J., O'Malley, J., Kjelland, K., Teal, M., Staff Nurse Perceptions of Open-Pod and Single Family Room NICU Designs on Work Environment and Patient Care, <i>Advances in Neonatal Care</i> , 18, 189-198, 2018	Cohort study including perceptions of healthcare staff

### Economic studies

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

## **Appendix L – Research recommendations**

**Research recommendations for review question: What features of the environment in which healthcare is provided are important to babies, children and young people to improve their experience of care?**

No research recommendations were made for this review question.

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

### Reference group and focus group evidence for review question: What features of the environment in which healthcare is provided are important to babies, children and young people to improve their experience of care?

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

**Table 10: Evidence from reference groups and focus groups**

Age < 7 years	Age 7-11 Years	Age 11-14 years	Overall quality of the evidence
<p>There was no evidence from this group for this question.</p>	<ul style="list-style-type: none"> <li>• Room to watch movies</li> <li>• Replace curtains – I don't like hearing noises</li> <li>• More than 1 play area</li> <li>• Have a bell for people who can't walk</li> <li>• Have a calm waiting room</li> <li>• Spilt the waiting room in half or have different waiting rooms for play and calm</li> <li>• No bad smells</li> <li>• Clean rooms/chairs</li> <li>• Colourful – rainbows, multicolour</li> <li>• Climbing frame (to keep me busy whilst waiting)</li> <li>• Characters to paint on the walls:                             <ul style="list-style-type: none"> <li>• Mr Bean</li> <li>• Horrid henry</li> <li>• Superman</li> <li>• Gumball and Aryn</li> <li>• Spiderman</li> <li>• Ironman</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Nightlight</li> <li>• Soft beds x2</li> <li>• Tool (panic button) to use when you want procedure/treatment to stop</li> <li>• Big rooms, not cramped x2</li> <li>• Furnished</li> <li>• Comfy</li> <li>• Clean/hygienic x 4</li> <li>• Countryside (MH services)</li> <li>• Automated reception area – to do on phone/tablets</li> <li>• Fish + music etc in waiting room, toys, tv with kids shows, box of books</li> <li>• Not cheap seats – comfortable</li> <li>• Not too busy</li> <li>• Not too claustrophobic</li> </ul>	<ul style="list-style-type: none"> <li>• Low</li> </ul>

Age < 7 years	Age 7-11 Years	Age 11-14 years	Overall quality of the evidence
	<ul style="list-style-type: none"> <li>• Corrie [Coronation Street]</li> <li>• I'm a celeb [Ant and Dec]</li> <li>• Sensory room, inc. slime</li> <li>• Builder to build new rooms for different activities</li> <li>• A window so you can talk to your friends – window clean so you can see out</li> <li>• I really want the comfy chairs... the electric chairs that recline</li> </ul>		

## Appendix N – Evidence from national surveys

### Evidence from national surveys for review question: What features of the environment in which healthcare is provided are important to babies, children and young people to improve their experience of care?

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 11: Evidence from national surveys**

Survey	Findings	Overall quality of the evidence
Association for Young People's Health. Young people's views on involvement and feedback in healthcare 2014	<ul style="list-style-type: none"> <li>No relevant findings were identified for this question</li> </ul>	<ul style="list-style-type: none"> <li>N/A</li> </ul>
Care Quality Commission. Children and young people's inpatient and day case survey 2018	<p><b>WARD SUITABLE:</b></p> <ul style="list-style-type: none"> <li>70% of 12-15 year olds said ward was suitable for someone their age</li> <li>Of those who stayed on a teenage or adolescent ward this rose to 80%</li> <li>Of those who stayed on a children's or adult ward this fell to 66%</li> </ul> <p><b>EQUIPMENT:</b></p> <ul style="list-style-type: none"> <li>73% 0-15 year olds had appropriate equipment or adaptations to meet their needs</li> <li>Poorer experience was reported by parents of children with developmental disability, mental health conditions, neurological conditions or other long term condition</li> </ul> <p><b>SLEEP:</b></p> <ul style="list-style-type: none"> <li>40% 8-15 year olds said it was quiet enough to sleep</li> </ul>	<ul style="list-style-type: none"> <li>Low</li> </ul>

Survey	Findings	Overall quality of the evidence
	<p>CLEANLINESS:</p> <ul style="list-style-type: none"> <li>• 67% parents reported that hospital room or ward was very clean</li> </ul>	
Child Outcomes Research Consortium. Child- and Parent-reported Outcomes and Experience from Child and Young People's Mental Health Services 2011-2015	<p>FACILITIES /WAITING AREA:</p> <ul style="list-style-type: none"> <li>• 63.5% of children and young people said the facilities were comfortable</li> </ul>	<ul style="list-style-type: none"> <li>• Moderate</li> </ul>
Health and Social Care Information Centre. Children's Dental Health Survey 2013. (Country specific report for England, published 2015)	<ul style="list-style-type: none"> <li>• No relevant findings were identified for this question</li> </ul>	<ul style="list-style-type: none"> <li>• N/A</li> </ul>
HM Inspectorate of Prisons. Children in Custody 2016-2017	<ul style="list-style-type: none"> <li>• No relevant findings were identified for this question</li> </ul>	<ul style="list-style-type: none"> <li>• N/A</li> </ul>
Opinion Matters. Declare your care survey 2018	<ul style="list-style-type: none"> <li>• No relevant findings were identified for this question</li> </ul>	<ul style="list-style-type: none"> <li>• N/A</li> </ul>
National Children's Bureau. Listening to children's views on health provision 2012	<p>HOSPITAL ENVIRONMENT:</p> <ul style="list-style-type: none"> <li>• Children and young people aged 12-19 reported: 'Depressing and boring because you have to wait long hours and there's nothing to do.'</li> <li>'Horrible, the smell makes you nervous.'</li> <li>'The beds are old and uncomfortable, toys don't work and parts are missing.'</li> </ul>	<ul style="list-style-type: none"> <li>• Moderate</li> </ul>
Picker Institute. Children and Young People's Patient Experience Survey 2018.	<ul style="list-style-type: none"> <li>• No relevant findings were identified for this question</li> </ul>	<ul style="list-style-type: none"> <li>• N/A</li> </ul>



Survey	Findings	Overall quality of the evidence
<p>Picker Institute. Paediatric Emergency Department Survey 2015 and Children and Young People's Outpatient Survey 2015</p>	<ul style="list-style-type: none"> <li>• No relevant findings were identified for this question</li> </ul>	<ul style="list-style-type: none"> <li>• N/A</li> </ul>
<p>Picker Institute/NHS England/Bliss. Neonatal Survey 2014</p> <p><i>Results for individual questions were converted into scores on a scale of 1 to 100, with 100 representing the best possible outcome (the scores are not percentages).</i></p>	<p>WARD FACILITIES:</p> <ul style="list-style-type: none"> <li>• Was there enough space for you to sit alongside your baby's cot in the unit? Score = 82</li> <li>• In your opinion was there adequate security on the neonatal unit? Score = 88</li> </ul> <p>OVERNIGHT STAYS:</p> <ul style="list-style-type: none"> <li>• If you wanted to stay overnight to be close to your baby, did the hospital offer you accommodation? Score = 70</li> </ul>	<ul style="list-style-type: none"> <li>• Moderate</li> </ul>
<p>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</p>	<ul style="list-style-type: none"> <li>• No relevant findings were identified for this question</li> </ul>	<ul style="list-style-type: none"> <li>• N/A</li> </ul>

N/A: not applicable