Babies, children and young people's experience of healthcare

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Association for Young People's Health	General	General	Age range: We feel very strongly that the guidelines should include 18-24 year olds. This is in line with Children's Commissioner guidance, Lancet views on age of adolescence, new 10-year NHS plan, WHO definition of 'young people' et al. In terms of the age range, it is also a bit misleading even to include 'young people' in the title if the intention is not to go up to age 24. If the age stops at 17, this should be infants and children.	Thank you for your comment. As there is already a NICE guideline on patient experience of adult NHS services, and a NICE guideline on transition from children's to adults' services, it has not been possible to extend the age limit for this guideline above 17 years, as this may lead to uncertainty about which guideline applies to individuals aged between 18 and 24. However, we recognise that some young people may continue using paediatric or young people's services up to the age of 24 and so we have indicated in the 'Who the guideline is for' section that it may also be relevant to 18 to 24 year olds.
Association for Young People's Health	General	General	Exclusion of transition: We can see that the Committee feels that transition is well covered in other documents, but at least mentioning it in this document offers a chance for more of a link-up between different sets of recommendations.	Thank you for your comment. If the guideline committee feels it is appropriate it will be possible to cross-link to the existing NICE guidelines on transition and this will help provide a more coordinated approach across the two different guidelines.
Association for Young People's Health	General	General	Need to broaden the definition of relevant healthcare professionals. There is a general move in the NHS 10 year plan for example, to including pharmacists, and we would also argue youth workers (as in Redthread and the Well Centre in Streatham). This is a critical part of improving the experiences of young people in healthcare.	Thank you for your comment. The scope has been amended to specify that it is aimed at all practitioners providing NHS- or local-authority commissioned services, so this will include groups such as pharmacists and youth workers.
Association for Young People's Health	General	General	The role of youth voice and participation is rather underplayed – for the first ¾ of the document all references to young people's views relate to their own care, rather than to improving services generally. Yet we know that participation in planning and service design will lead to better satisfaction among young patients as a whole. This is acknowledged later in the 'key issues' section but could be flagged earlier. It may also be useful to include 'praticipation' in the search terms (3.5).	Thank you for your comment. We agree that involvement of children and young people in planning services is important and, as you have noted, we have a review question about the involvement of children and young people in service design. Thank you for your suggestion to include 'participation' in the search terms.
Association for Young People's Health	General	General	'You're Welcome' criteria are mentioned, and it is great that this is so – the refresh has been undertaken, and any encouragement for roll-out is most welcome in terms of improving young people's experiences. It is also important that overall messages line up across this consultation and You're Welcome. However You're Welcome does cover a different age range.	Thank you for your comment. We agree that the 'You're Welcome' criteria are important and were useful for us when considering areas for inclusion in the scope.

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Association of Child Psychotherapists	General	General	We welcome the development of guidelines on babies, children and young people's experience of healthcare. However, we note that the draft scope document does not include the experience of emotional and psychological support/care provided to babies, children, young people and families in healthcare settings including what is sometimes called paediatric liaison or psychiatric liaison. Although some Nice guidelines do recommend emotional and psychological support/care in relation to physical healthcare services the provision is patchy across the country and it would be helpful to include this in the consultation on experience – i.e. what is the experience of psychological/emotional support, or indeed the lack of it. There is considerable evidence* for the need for emotional and psychological support for children suffering health conditions, acute or chronic, in hospital and other healthcare settings. We would recommend that the experience of healthcare should address all areas of development which would include, social, educational, physical and emotional/ psychological support. The many areas where this approach is essential include: children and young people with medically unexplained symptoms; general paediatric and adolescent medicine including somatising illness; chronic conditions such as asthma, dermatology, rheumatology, diabetes, HIV, Sickle Cell Disorder; Thalassaemia, Crohns disease, endocrine and urology problems; surgery; neonates; children's and young people's cancer, including radiotherapy; intensive care; as well as accident and emergency services including deliberate self-harm and acute psychiatric presentations. A guideline that considered the experience of the 'whole child', including the emotional and psychological support provided to them and their	Thank you for your comment and for sharing details of this work with us. We have a draft review question that asks, 'How do children and young people want healthcare staff to support them?' which is likely to include reviewing the evidence for emotional and psychological support.

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			families whilst receiving healthcare, would be in line with a range of national policy documents including No Health Without Mental Health which states that, "High quality liaison psychiatry services … have been shown to save money for the NHS by reducing hospital admissions and lengths of stay. Collaborative care arrangements outside hospital can also improve people's ability to manage their own health and offer a cost-effective way of joining up mental and physical healthcare for people with long term conditions." *for example, Hysing M, Elgen I, Gillberg C, Lie SA, Lundervold AJ. (2007). Chronic physical illness and mental health in children. Results from a large-scale population study, J Child Psychol Psychiatry. 48(8):785-92. ** https://www.gov.uk/government/publications/mental-health-implementation-framework	
Better Start Bradford	General	General	We welcome all examples throughout this scope document which recognise that babies and children of pre-school age can express the ways they directly expereince healthcare. From birth babies use communication cues to express comfort, pain, fear, and a desire for closeness with caregivers. Individual babies are born 'ready to relate' with individual preferences and responses to care. Babies' communications and cues can be reliably interpreted by healthcare practitioners after basic training. Even when a baby is premature or very unwell their expereince of care can be inferred from signs such as heart rate and oxygen saturations. We advocate that the emerging science about early infant and child development be applied within healthcare settings to truly see babies and very young children as service users, in their own right, throughout all healthcare settings. We believe that overall the scoping document	Thank you for your comment. The guideline committee will be reviewing the evidence for the experience of babies and pre-school children, and where appropriate will be making recommendations specific to this group. We have now clarified this in the 'Groups that will be covered' section of the scope.

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			now reflects this and therefore gives a sound basis for enquiry into how this should be done in practice. We hope that this will be interpreted to also include inquiry into parent/infant dyad healthcare settings – most notably postnatal maternity care.	
British Youth Council	General	General	My comment is in relation to the main outcomes section. I am reading these guidelines to try and further explain, how to work with young people improve their care. Should one of the main outcomes not be some kind of guideline around how to train staff to work with young people. Building on an understanding of where staff feel like they could need more support?	Thank you for your comment. The list of outcomes refers to the outcomes for existing research that we will review as part of our evidence, and not the outputs of the guideline development process itself. However, although it is possible that the recommendations may require training of staff to ensure they are implemented, NICE guidelines do not usually provide specific details of what that training should involve and how it should be carried out.
British Youth Council	General	General	I feel that one of the key issues that I could not find on the draft was the distinction in care given between children and young people. For example whilst talking to one of my peers who is going through the diagnosis of ADHD, according to the NICE guidelines she would have to wait 10 weeks until she could get diagnosed. This may be an issue as she wouldn't have a sufficient amount of time to arrange extra support during her A Levels examinations. Also SENCO has stated that in order to get extra support during the A Level examination period she would have to had extra support previously in tests, which is difficult to conduct due to the long waiting period. So something I suggest is that the guidelines should take into consideration the young persons age/circumstances, and that fact that young people have more capacity to make decisions about their treatment, when applying the guidelines to them.	Thank you for your comment. We are aware that there will be different considerations for children and young people and we have clarified this in the scope (in 'Groups that will be covered'). We have included a draft review question about how children and young people can be empowered to advocate for themselves, which we hope will address the fact that many young people do have capacity to make decisions about their treatment.
Children's Law Centre	General	General	Dear Sirs The Children's Law Centre is an independent charitable organisation established in September 1997 which works towards a society where all	Thank you for your comment and for your interest in this guideline. Thank you for telling us about the 'Elephant in the Room' report which may be considered by the guideline committee in their review of the evidence if appropriate. NICE guidelines cover health and care in England. Decisions

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			children can participate, are valued, have their rights respected and guaranteed without discrimination and where every child can achieve their full potential. Our organisation is founded on the principles enshrined in The United Nations Convention on the Rights of the Child. From its perspective as an organisation, which works with and on behalf of children in NI, both directly and indirectly, the Children's Law Centre is grateful for the opportunity to comment upon the NICE draft scope consultation: infant, children and young people's experience of healthcare. We generally welcome the creation of this draft scope consultation, but as NICE Guidelines are often adopted in Northern Ireland without being amended there are a number of matters in relation to the Northern Ireland context of young people's experience of healthcare, specifically in relation to access to mental health services that we wish to bring to the attention of NICE to help inform the development of this scoping exercise. We would welcome these been included in the scoping exercise. The Children's Law Centre has been working in the field of child and adolescent mental health since 1997. Research has shown that there has been a significant increase in the number of children and young people with mental health needs in Northern Ireland in recent years.[1] It was recognised by the Chief Medical Officer as far back as 1999 that approximately 20% of children and young people in Northern Ireland will suffer significant mental health issues before their 18th birthday.[2] Northern Ireland has a unique situation regarding the mental health needs of its young people due to the history of the conflict and trans-	on how they apply in other UK countries are made by ministers in the Northern Ireland Executive. We will therefore not be able to make specific recommendations in the guideline relating to service in Northern Ireland.

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[1] A Vision for a Comprehensive Child and Adolescent Mental Health Service – The Bamford Review, November 2005.

[2] Chief Medical Officer (1999), Health of the public in NI: report of the Chief Medical Officer 1999: Taking care of the next generation. Belfast: DHSSPS.

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			generational mental health needs. It is recognised that the incidence of mental health needs among vulnerable groups of children and young people is disproportionately high, including children and young people with disabilities and those living in poverty[3] as well as children in conflict with the law[4] and care experienced children or those in need of safe and secure accommodation. A recent study found linkages between long term unemployment and mental health needs in young people with a third of long term unemployed young people having contemplated taking their own lives. The research found that long term unemployed young people were more than twice as likely as their peers to have been prescribed anti-depressants. One in three (32%) had contemplated suicide, while one in four (24%) had self-harmed. The report found that 40% of jobless young people had faced symptoms of mental illness, including suicidal thoughts, feelings of self-loathing and panic attacks, as a direct result of unemployment.[5] Despite this Child and Adolescent Mental Health Services have been chronically underfunded for decades with the current CAMHS budget being 8% of the Adult Mental Health budget. It is CLC's views that this constitutes age discrimination and budget allocation is not in the best interests of children. The UNCRC guarantees children the right to the highest attainable standards of health and health care (Article 24): *"State Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. State Parties shall strive to ensure*	

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[3] Miller et al., 2003; O'Reilly and Stevenson, 2003; Muldoon et al., 2005.

[4] Northern Ireland Human Rights Commission (NIHRC) 'In Our Care', March 2002, p.91; Criminal Justice Inspectorate Northern Ireland (CJINI) 'Inspection of the Juvenile Justice Centre', October 2004, p.115 - 117; Department of Health, Social Services and Public Safety (DHSSPS) 'Young People in Regional Care Centres and Youth Justice', October 2004, p.24.

[5] The Prince's Trust Macquarie Youth Index, January 2014.

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			that no child is deprived of his or her right of access to such health care facilities" There are only limited inpatient beds for young people with mental health needs in Northern Ireland. The Beechcroft Unit, which is based in Belfast, has a maximum capacity for 33 young people. This is the regional inpatient unit. CLC works with and on behalf of many of the young people who have been detained in this hospital under the terms of the Mental Health (NI) Order 1986. In our experience many young people have experienced difficulties in accessing mental health services both prior to their admission to the unit and upon discharge. CLC through our casework are also aware of a number of young people who experience delayed discharge from mental health hospital as a result of there being no suitable community placement available for them. This has a detrimental effect on the young person, their family and upon staff who are caring for them during the delayed discharge period and is in our view in breach of UK and NI domestic and international human rights obligations. Significantly delayed discharge also causes bed blocking; where young people who need to be admitted to the service cannot be due to beds being unnecessarily occupied by delayed discharge patients. CLC have also worked on behalf of a number of young people who have had to leave Northern Ireland to access care and treatment under the "ECR" process due to the unavailability of the services with Northern Ireland. Whilst the young person is gaining access to the appropriate treatment being out of the jurisdiction impacts upon the young person's right to family life. The availability of ECRs in respect of children placed in the South of Ireland post Brexit remains unclear at the time of writing but must be considered in any consultation.	

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			There is not a robust system of data collection in relation to child and adolescent mental health in Northern Ireland despite this having been a specific recommendation of the Bamford Review of Mental Health in 2007. Attached to this letter is a copy of the report entitled "Elephant in the Room: Exploring young people's awareness of mental health in Northern Ireland" which was published in October 2018. This report was prepared by Dr Jonny Byrne in collaboration with the Youth Mental Health Committee, representing Children's Law Centre's youth advisory panel youth@clc, Belfast Youth Forum and NI Youth Forum. This report was based upon work carried out by the "NI Young People's Report to the UN Committee on the Rights of the Child – Our Lives in Our Words"[6] which represented the views of 900 children and young people who participated in research to inform the report. The Elephant in the Room campaign was youth led and attempted to give young people across Northern Ireland a say, to let their voices be heard and help shape the future of mental health education and support services, as well as challenging the culture of silence and pushing for change from decision makers. The report found that young people had very negative experiences of existing mental health provision. There was dissatisfaction with the level, type and form of provision with many contending that there was not enough support, tailored to meet the very specific needs of young people and that as a consequence of these experiences young people's understanding and knowledge about mental health and personal wellbeing was limited.	

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[6] June 2015

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			The “Elephant in the Room: Exploring young people’s awareness of mental health in Northern Ireland” made a number of recommendations: - **Decision makers should engage with young people to create and fund safe digital solutions to receive mental health support and information**. - **The creation of a compulsory curriculum programme for all schools and colleges on mental health and wellbeing that helps to raise awareness and challenge stigma and also allows young people to access consistent mental health information. Furthermore, the curriculum programme should be long term and embedded in schools as one off workshops will not be effective.** - **There is also a need to ensure mental health and well-being training for all teachers, school support workers and youth workers so that this programme can be delivered effectively**. - **Decision makers should support the creation of a youth-led, government backed, mental health campaign challenging the culture of silence and negative stigma and that there is a need to engage with young people to develop a new and positive language around mental health by creating a ‘mental health dictionary.’ This could be used as part of a potential mental health curriculum programme**. A copy of the report is attached at Appendix A and it provides an up to date views from NI young people relevant to this draft scoping exercise. At every stage of the policy development process consultation should be carried out with affected individuals and representative groups as	

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			early as possible (this includes with children and young people), affected individuals and representative groups should be consulted and consideration should be given as to how best to consult or engage with them. The accessibility of the language and the format of information should be considered to ensure that there are no barriers to the consultation process, information should be made available on request in accessible formats and systems should be in place in order that information can be made available in accessible formats in a timely fashion. CLC would submit that this includes the production of a child accessible version of the consultation document when it is produced. This is required by legislation in NI under the equality duty provided for under s75 NI Act 1998. The Children's Law Centre is grateful for the opportunity to make this submission to NICE; we hope that our comments have been constructive and useful. We wish to be kept fully informed of the progress in the development of these proposals.	
Faculty of Dental Surgery (Royal College of Surgeons)	7	5	This guideline is very much welcomed, but it is imperative that all health care settings are considered, including children's experiences and engagement in primary and secondary **dental** settings. The respondent, acting on behalf of the RCS, works within an existing and internationally recognised research group, and would be keen to collaborate in this guideline. The group (Children's ORal HEAlTh REsearch 'CREATE') aims to improve the oral health and treatment experiences of children and young people through a combination of clinical and social scientific research strategies that: • Give children an active voice in relation to their oral health.	Thank you for your comment. Dental settings are not excluded from this guideline so will be covered, and the draft guideline committee composition includes a co-opted dentist. Thank you for sharing your work with us. The evidence reviews that will be used to write guideline recommendations will provide a detailed analysis of the evidence and this may be included, if appropriate

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			• Explore and evaluate the impact of oral health on the daily lives of children and their families. • Develop child-centred measures, decision aids and resources. https://www.sheffield.ac.uk/dentalschool/research/create	
Faculty of General Dental Practice	5	7	The draft scope envisages covering a suitably wide range of healthcare practitioners, patients and aspects of patient experience. However, while babies clearly have an experience of healthcare and can be communicated with, stating that the guideline is intended to be used by babies clearly does not make sense. Similarly remarkable language is used elsewhere in the draft to refer to babies' 'views', 'perspectives' and 'access to healthcare information'.	Thank you for your comment. We have amended the scope as in some cases it is appropriate to refer to babies' experiences directly, but in other instances it is more logical to refer to their parents/carers. For example, we have removed the reference to babies accessing information and clarified that it is their parents or carers.
Faculty of General Dental Practice	General	General	The Faculty of General Dental Practice (UK) is the only professional membership body in the UK specifically for general dental practice. Based at Royal College of Surgeons of England, our mission is to positively influence oral health through education of the dental profession and the provision of evidence-based guidance. We welcome the development of this guidance and the opportunity to comment.	Thank you for your comment. As you will have seen from the proposed guideline committee composition we plan to involve a co-opted dentist in the development of this guideline and welcome the involvement of the Faculty of General Dental Practice in the consultation on the scope, and in future the draft guideline.
Faculty of General Dental Practice	General	General	At present, the draft is very secondary care-specific, and it should not be assumed that recommendations considered with the hospital environment in mind will be necessarily transferrable to other environments with very different contexts without informed consideration. Nor will it be sufficient for those developing the guideline to imagine these other settings in the absence of first-hand experience; representatives covering the full spectrum of the professional groups to	Thank you for your comment. The guideline will cover all healthcare settings and we have clarified this in key area 6 of the scope. We have also removed the reference to 'in hospital' from draft question 7.1. The guideline committee will include people from both secondary care, primary care and also other areas where healthcare may be delivered.

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			whom NICE wishes the guidance to be applicable should be involved in its development.	
Faculty of General Dental Practice	General	General	A separate section on personal health responsibility would be a useful addition – that is, on the experiences and preferences of children and young people of receiving advice from practitioners which is aimed at empowering them to self-care and help avoid preventable illness in future. Understanding these experiences and preferences is key to engendering positive habits and lifestyle changes which can improve health outcomes.	Thank you for your comment. The scope of the guideline covers all aspects of healthcare experience for babies, children and young people including advice and support and making shared decisions about their health. However, we prefer to address personal health responsibility within the existing proposed structure, rather than adding a separate section on this.
Genetic Alliance UK	General	General	Genetic Alliance UK welcomes the development of a guideline on infant, children and young people's experience of healthcare. This is an important topic which has in the past been neglected. To date, research has traditionally relied on the views of those involved in their care − such as their carers, parents and healthcare professionals − to provide such insight. However whilst these individuals are often very knowledgeable about children and young people's healthcare experience,' having been on much of the journey with them, their perspective is likely to differ from that of children and young people. For this reason, in 2017 Rare Disease UK (a campaign run by Genetic Alliance UK) carried out an exploratory project to understand what it is like to be a child or young person affected by a rare disease through listening to children tell their stories, in their own words. We found that although children and young people are able to adapt to many of the challenges that living with a rare disease can bring, the findings of this report also highlight that there are improvements that could be made to their care and treatment, and lessons that can be learned from the experiences that the children and young people had to	Many thanks for your comment. We agree that it is important to obtain the views of children and young people and have addressed this through the composition of our guideline committee, and we are also investigating other ways to obtain the views of children and young people in the guideline development process. Thank you for sharing the work you have undertaken. We hope to be able to use the results of research like this to inform our recommendations, if appropriate. Thank you for highlighting the specific needs of children with rare diseases. We are aware that there will be different considerations for children and young people and we have clarified this in the scope (in 'Groups that will be covered').

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			share. A number of examples of best practice were also identified and described. The findings of these workshops highlighted that as children get older − and particularly as they progress through the education system and move to adult services − their needs, and the issues that they face, change. This means that the experiences of young people affected by rare disease are usually very different to those of children. The report produced as a result of this piece of work (Understanding Children and Young People's Experiences, 2018) can be found at https://www.raredisease.org.uk/our-work/understanding-children-and-young-peoples-experiences/. Rare Disease UK has also published an earlier report (The Rare Reality, 2016) examining the patient and family experience of rare disease, which while not specifically focussing on the perspectives of children and young people, expands on many of the themes identified. This can be found at: https://www.raredisease.org.uk/our-work/the-rare-reality-2016/ While brief, the key issues and draft questions in section 3.4 of the draft scope appear to have the potential to cover all the major issues identified in 'Understanding Children and Young People's Experiences'. The key challenge will be how the committee expands on these to develop more detailed review questions which do not exclude any of the areas for improvement we have identified in these two reports. It will also be important for the committee to recognise that although disease-specific issues are outside the scope of this guideline, many of the challenges to delivering positive experiences of healthcare for children and young people are exacerbated if the child or young person	

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			is affected by a rare disease, such as issues relating to coordination of care and information provision in the context of a scarcity of expertise.	
Great Ormond Street Hospital – Patient Experience Team	General	General	Overall, this document covers the vast majority of the topic and the approach seems comprehensive. Great care will be needed to differentiate ways of collecting and improving experience of children/young people with additional needs and/or children/young people of different ages. At GOSH we use: under 7s, 8 – 11 yrs, 12+ as our standard age groups for different approaches.	Thank you for your comment. We agree that recommendations may need to be different for different ages and have clarified this in the scope (in ‘Groups that will be covered’). It is useful to know the age bands that GOSH uses for different approaches.
Great Ormond Street Hospital – Patient Experience Team	7	11	The experience of siblings should be considered as well as primary patient and parents.	Thank you for your comment. We agree that siblings may be important when babies, children or young people are receiving healthcare, and we have added specific reference to siblings into draft review question 7.1 ‘How can health services support engagement in usual activities (for example sibling relationships, other family relationships, schooling, friendships, social activities) for babies, children and young people?’ However, it is not in the scope of this guideline to consider the experiences of siblings directly.
Great Ormond Street Hospital – Patient Experience Team	7	15	Information should also be available to siblings.	Thank you for your comment. We agree that siblings may be important when babies, children or young people are receiving healthcare, and we have added specific reference to siblings into draft review question 7.1 ‘How can health services support engagement in usual activities (for example sibling relationships, other family relationships, schooling, friendships, social activities) for babies, children and young people?’ However, it is not in the scope of this guideline to consider the experiences of siblings directly.
Great Ormond Street Hospital – Patient Experience Team	7	17	Siblings should also be able to access advocacy and support (separately to primary patient).	Thank you for your comment. We agree that siblings may be important when babies, children or young people are receiving healthcare, and we have added specific reference to siblings into draft review question 7.1 ‘How can health services support engagement in usual activities (for example sibling relationships, other family relationships, schooling, friendships, social activities) for babies, children and young people?’

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				However, it is not in the scope of this guideline to consider the experiences of siblings directly.
Great Ormond Street Hospital – Patient Experience Team	7	19	Siblings should also be involved in improving healthcare – they add a unique perspective.	Thank you for your comment. We agree that siblings may be important when babies, children or young people are receiving healthcare, and we have added specific reference to siblings into draft review question 7.1 'How can health services support engagement in usual activities (for example sibling relationships, other family relationships, schooling, friendships, social activities) for babies, children and young people?' However, it is not in the scope of this guideline to consider the experiences of siblings directly.
Great Ormond Street Hospital – Patient Experience Team	7	21	Siblings should also have the option to be involved in planning environments.	Thank you for your comment. We agree that siblings may be important when babies, children or young people are receiving healthcare, and we have added specific reference to siblings into draft review question 7.1 'How can health services support engagement in usual activities (for example sibling relationships, other family relationships, schooling, friendships, social activities) for babies, children and young people?' However, it is not in the scope of this guideline to consider the experiences of siblings directly.
Great Ormond Street Hospital – Patient Experience Team	7	23	Encouraging sibling involvement is also key, especially if families are separated when the patient is in hospital.	Thank you for your comment. We agree that siblings may be important when babies, children or young people are receiving healthcare, and we have added specific reference to siblings into draft review question 7.1 'How can health services support engagement in usual activities (for example sibling relationships, other family relationships, schooling, friendships, social activities) for babies, children and young people?'
Great Ormond Street Hospital – Patient Experience Team	7	28	While we understand that transition is covered in a separate guideline, this can have such a huge impact on experience that it should be cross referenced. This is particularly true of specialist providers such as GOSH.	Thank you for your comment. If the committee feels it is appropriate, it will be possible to cross-link to the existing NICE guideline on transition and this will help provide a more coordinated approach across the two guidelines.
Great Ormond Street Hospital – Patient Experience Team	10	10	How will measures be developed? A simple net promoter score is conceptually difficult for CYP to understand and they don't want a friend to go through what they are going through.	Thank you for your comment. The evidence review for this question will aim to address the most appropriate types of measurement tools.

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Great Ormond Street Hospital – Patient Experience Team	10	16	Ditto comments above about sibling involvement.	Thank you for your comment. We agree that siblings may be important when babies, children or young people are receiving healthcare, and we have added specific reference to siblings into the draft review question 7.1 'How can health services support engagement in usual activities (for example sibling relationships, other family relationships, schooling, friendships, social activities) for babies, children and young people?' However, it is not in the scope of this guideline to consider the experiences of siblings directly.
Healthwatch Essex	General	General	The priorities of this draft scope closely reflect the lived experience of healthcare that Healthwatch Essex has gathered from over 2,000 young people in the past 4 years, such as communication, environment, access to healthcare information, etcetera. That seldom-heard groups of young people such as asylum seekers, LGBT+ and young carers is important, as these young people tend to have poorer experience of healthcare.	Thank you for your comment. We are pleased that the priorities we have identified match those you have identified in your work. We have identified in our draft Equality Impact Assessment that the groups you have listed may require special consideration.
Healthwatch Essex	1	27-28	Where quantitative statistics form the evidence basis in this scope, it might be beneficial to also consult qualitative evidence that could explain some of these findings, e.g. *why* it is that young people feel less positive about their experiences than their parents.	Thank you for your comment. This introductory section is only meant to provide a brief overview of some facts and figures and the evidence reviews that will be used to write guideline recommendations will cover both quantitative and qualitative evidence.
Healthwatch Essex	5	10-11	Based on the statement that the guideline may also be relevant for commissioners and providers of social care services for babies, children and young people, this guideline may also be relevant for: Babies, children and young people using social care services, their families and carers, and the public	Thank you for your comment. This guideline may be relevant to providers of social care as, for example, it may be social workers who are involved in taking children in care to appointments. However, it will not necessarily be relevant to babies, children and young people if they are only accessing social care and not healthcare.
Healthwatch Essex	5	15	We would advocate for the consideration of children and young people not attending mainstream education to this list, such as 'school refusers,' children and young people who have been absent for large parts of their schooling, children and young people who are home-schooled and so on. As many young people from our studies have cited school as their primary source of public health information (such as sexual health, drugs and alcohol information, etc), or say their teachers	Thank you for your comment. We have amended the list of potential inequalities and grouped them together and now have a group that covers all babies, children and young people who may have difficulties in accessing healthcare, which would include this group that you have mentioned.

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			play a role in their pastoral care (including the reporting of safeguarding concerns) this might contribute to health inequalities in the population of young people not attending mainstream education.	
Healthwatch Essex	6	12	It might be beneficial to consider 'children of prisoners' in general, as again this demographic sees some of the poorest outcomes.	Thank you for your comment. We have amended the list of potential inequalities and grouped them together and now have a group that covers all babies, children and young people who come from a social or family background that may affect their experience of healthcare, and this includes the group you have mentioned.
Healthwatch Essex	6	2	The choice of the word 'different' might be confusing. It could be replaced by another word such as 'minority,' if this is the intention.	Thank you for your comment. We have amended the list of potential inequalities and grouped them together and now have a group that covers all babies, children and young people who have protected characteristics and this includes race. We have removed the word 'different'.
Healthwatch Essex	7	1-3	Some mental health or learning disability services extend their services to young people in their twenties. Furthermore, The Children (Leaving Care) Act 2000 extends duties to some care-leavers into their twenties. As those leaving care are cited among the equality considerations in this document (p. 6, l.9) for the sake of preventing fragmentation, the draft scope could include those young people eighteen or over who are still accessing such young people's services as these.	Thank you for your comment. As there is already a NICE guideline on patient experience of adult NHS services, and a NICE guideline on transition from children's to adults' services,, it has not been possible to extend the age limit for this guideline above 17 years, as this may lead to uncertainty about which guideline applies to individuals aged between 18 and 24. However, we recognise that some young people may continue using paediatric or young people's services up to the age of 24 and so we have indicated in the 'Who the guideline is for' section that it may also be relevant to 18 to 24 year olds.
Healthwatch Essex	7	15	We hope that this access to information will include the ability to understand what is being communicated, and information on their entitlement to factors such as confidentiality, making appointments for themselves, requesting an appointment with a specific doctor, etcetera.	Thank you for your comment. This key area is meant to provide an overview of the topics that will be covered. The recommendations that are developed for this key area will provide more detail on the nature of the information that should be provided. However, we have added a new review question in the information section, 2.2 which asks 'How can children and young people and the parents or carers of babies and young children be supported to make informed decisions, including about risks

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				and benefits?' We also have other questions which will address issues of confidentiality.
Healthwatch Essex	7	28	Transition between child and adult services consistently comes up in our engagement with young people. We hope that if not addressed in this scope it will be considered in other updated guidelines.	Thank you for your comment. Transition will not be covered in this guideline because there is already a NICE guideline on transition from children's to adults' services. If the committee feels it is appropriate it will be possible to cross-link to the existing NICE guideline on transition and this will help provide a more coordinated approach across the two guidelines.
Metabolic Support UK	1	10-11	Metabolic Support UK supports the development of a guideline that BCYP's experience on healthcare. Our charity supports a lot of patients with chronic conditions and as such we strongly feel this guideline will help maintain good practice in healthcare settings.	Thank you for your comment.
Metabolic Support UK	5	15	We welcome the new additions in taking account of potential inequalities	Thank you for your comment.
Metabolic Support UK	6	19-22	While we understand that the guideline is focusing on BCYP's experience we welcome the recognition of the views of parents and carers in guideline developing process.	Thank you for your comment.
NIHR CLAHRC North Thames	General	General	1. Are there any cost saving interventions or examples of innovative approaches that should be considered for inclusion in this guideline? ***Name of intervention*** Young commissioners model: Funded by the NHIR North Thames CLAHRC and work undertaken by the Institute for Health and Human Development at the University of East London. They have co-designed service enhancement. ***Age group for the intervention***: 16-21 years ***Description of the intervention***:	Thank you for your comment and thank you for the examples of innovative approaches to involving children and young people in commissioning and in social prescribing. We hope to be able to use the results of research like this to inform our recommendations, if appropriate.

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			This project was identified has best practice by the NIHR Central Commissioning Facility (2017) and NHS England Patient and Public Participation Team (2016) for its novel way of working with young patients and producing tangible and meaningful outcomes/impact in the field of health service design. This study trained young people to work with NIHR CLAHRC North Thames researchers - to systematically collect and assess the views and experiences of disengaged children and young people living with diabetes, and then feed this information back to service providers and commissioners leading on service improvements and transformation. The development of the Diabetes Youth Commissioners model is a practical example of how a study can involve young people in commissioning and decommissioning services in the NHS and Public Health. Involving patients and service users in commissioning and designing services makes for more appropriate care, which is more likely to be taken up by those who need it. In addition, the model succeeds in simultaneously addressing service quality and wastage whilst building resilience and self-management amongst patients/service users. ***Cost effectiveness*:** Further funding is required to evaluate and determine the cost-effectiveness of the enhanced commissioning function. ***Link to further information about the intervention* (website or publication);** https://www.uel.ac.uk/research/ihhd/research-programmes-and-projects http://clahrc-norththames.nihr.ac.uk/child_and_adolescent_health_theme/	

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NIHR CLAHRC North Thames	General	General	1. Are there any cost saving interventions or examples of innovative approaches that should be considered for inclusion in this guideline? ***Name of intervention***: Evaluation of young people social prescribing in four English sites: Funded by NHS England and the evaluation is undertaken by the Institute For Health and Human Development in partnership with StreetGAmes ***Description of the intervention***: The Department of Health is funding this project through their Health and Wellbeing Fund for social prescribing. The funding for this project was awarded in July 2018, but agreement on evaluation with collaborators did not take place until recently due to issues of data collection with four different partners. In order to inform investment decisions of local co-funders (Clinical Commissioning Groups etc.) in year two, we need to speed up data collection as much as possible in order to provide sufficient evaluation evidence for decision making. ***Age group for the intervention*:** 10-24 years ***Cost effectiveness:*** Cost-effectiveness measures are built into the evaluation framework in order to support the commissioning of future services in the four test sites. ***Link to further information about the intervention (website or publication);*** https://www.uel.ac.uk/research/ihhd/research-programmes-and-projects	Thank you for your comment and thank you for the examples of innovative approaches to involving children and young people in commissioning and in social prescribing. We hope to be able to use the results of research like this to inform our recommendations, if appropriate

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NHS England	General	General	It is important that the guidance is co-produced along with Young People and their parents/carers so that the guidelines will be realistic, adherable and help capture patient experience successfully and consistently.	Thank you for your comment. There will be involvement of 4 young people and 2 parents/carers on the guideline committee, and we are planning other ways to involve children in the guideline development process. The draft guideline will then undergo a period of public consultation and organisations representing young people can register to become stakeholders so they can comment on the draft guideline
NHS England	General	General	Following the CYP MH Green Paper, Mental Health Support Teams [MHSTs] are being set up to work in schools and colleges. Following the first wave of these being set up, the ambition is that by 2023/24 between one-fifth and a quarter of the country will have NHS-funded MHSTs working in schools and colleges. With the above in mind, it is important that the guidelines consider the patient experience in these settings and that they are applicable to both these and more traditional settings.	Thank you for your comment. The guideline will include experience of mental health as well as physical healthcare services, and in all settings where these services are delivered, and we have clarified this by amending the statement on 'who is the focus of this guideline' and the wording of key area 6.
NHS England	2	11-14	With regards to children with mental health [MH] needs, hospital staff in acute settings report a lack of confidence and competency in caring for them. Programmes like We Can Talk aim to improve this (https://wecantalk.online/).	Thank you for your comment and for telling us about the We Can Talk programme, although we notice this is a programme for staff training. It is possible that the recommendations may require training of staff to ensure they are implemented, however, NICE guidelines do not usually provide specific details of what that training should involve and how it should be carried out.
NHS England	2	16-17	Again, with regards to children and young people's mental health [CYPMH], this fact is generally in keeping with anecdotal evidence about children and young people being treated as their diagnosis/symptoms and not as individuals – a shift towards the latter could remedy some of these findings.	Thank you for your comment. We hope that the guideline that is produced on the basis of this scope will encourage individualised care for children and young people.
NHS England	3	2-8	Although this may be labelled as 'current practice', is there a high respondent rate to this and is it therefore seen as a successful method?	Thank you for your comment. This introductory section is only meant to provide a brief overview of some facts and figures and the evidence reviews that will be used to write guideline recommendations will provide a much more detailed analysis of the evidence. We have a draft review question that asks: 'How can the experience of babies, children and

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				young people be measured so as to improve their experience of healthcare?' that should help the guideline committee determine if surveys are a successful method for collecting data on their experiences.
NHS England	3	9-11	It would be helpful to understand how widespread this good practice is and whether it is applicable to both children's physical and mental healthcare.	Thank you for your comment. The current practice section of the scope has been shortened as the examples given may not have been representative of services across the country. However, we anticipate that the evidence reviews conducted to answer the draft review questions will provide more detail on good practice to enable the committee to make recommendations.
NHS England	7	11-25	The draft scope does not specifically mention CYP's experience of discharge from services under areas that will be covered. Their experience of leaving a service is important and the guidelines would benefit from their explicit inclusion.	Thank you for your comment. We agree that discharge is important and have revised the key area 8 in the scope to clarify that this includes coordination of care throughout the care pathway, and this will include discharge.
NHS England	7	1-3	YP aged over 18 are cited as not being in scope of this guidance. Will this guidance, therefore, be compatible with guidelines on patient experience in adult NHS services? One of the ambitions for MH in the Long Term Plan is to extend current MH service models to create a comprehensive offer for 0-25 year olds that reaches across MH services for CYP and adults. This aspect of the scope of the guideline and how it is articulated needs to be considered as this could create confusion and ambiguity.	Thank you for your comment. As there is already a NICE guideline on patient experience of adult NHS services, it has not been possible to extend the age limit for this guideline above 17 years, as this may lead to uncertainty about which guideline applies to individuals aged between 18 and 24. However, we recognise that some young people may continue using paediatric or young people's services up to the age of 24 and have indicated in the 'Who the guideline is for' section that it may also be relevant to 18 to 24 year olds. We will make recommendations that are compatible with the adult experience guideline where appropriate, but we envisage that NHS staff and young people aged 18 and above may need to refer to the guideline that is most developmentally appropriate for the young person.
NHS England	7	28	The draft scope says that evidence will not be looked at regarding the transition from children's to adult services. We note that there are Transitions guidelines from NICE and recommend over link to ensure that the experience of those in Transition is also monitored. This can be an important part of a young person's experience of MH services and a lack of clarity on this could see its importance fall between the gaps.	Thank you for your comment. If the committee feels it is appropriate it will be possible to cross-link to the existing NICE guidelines on transition and this will help provide a more coordinated approach across the two guidelines.

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NHS England	9	17-18	This will need to be differentiated for each of the separate groups. Communicating with infants or children and involving them in decisions around their care is a different skill to that with a 17 year old. Staff will need to tailor their approach to take account of the developmental stage	Thank you for your comment. We recognise that communication methods and styles will need to be different for babies, children and young people and will reflect this when searching for the evidence and in the recommendations, and have added information in the 'Groups that will be covered' section to clarify this.
NHS England	10	14-15	There are already NHS services operating in schools and colleges, however with the introduction of Mental Health Support Teams (CYP MH Green Paper), the healthcare environment needs to consider educational settings (see 'General' comment below).	Thank you for your comment. We will be covering the delivery of healthcare in all settings and have amended the wording of key area 6 to clarify this, but have not named schools or colleges specifically.
NHS England – South West (South) Nursing and Quality Team	5	15	The guide line scope talks about focus on the inequalities for babies, children and young peoples in relation to LAC and protection plan. You would also wish to understand the experience of this group when either a LAC or on the protection plan.	Thank you for your comment. We have amended the list of potential inequalities and grouped them together, with some specific examples for each group, but Looked after children or those with a protection plan would be covered in the group who may have difficulty accessing healthcare, and if the evidence review identified evidence specifically for the experience of these children then we will consider it when looking at equality considerations.
NHS England – South West (South) Nursing and Quality Team	7	1	Need to ensure clear connection between the two pieces of guidance. Children and Families Act brings the focus particularly for children with special educational needs or disabilities (SEND) from 0-25	Thank you for your comment. As there is already a NICE guideline on patient experience of adult NHS services, and a guideline on transition from children's to adults' services, it has not been possible to extend the age limit for this guideline above 17 years, as this may lead to uncertainty about which guideline applies to individuals aged between 18 and 24. However, we recognise that some young people may continue using paediatric or young people's services up to the age of 24 and so we have indicated in the 'Who the guideline is for' section that it may also be relevant to 18 to 24 year olds.
NHS England – South West (South) Nursing and Quality Team	7	28	Why is transition particularly excluded? This is a crucial part of the young person's experience and we know it is not always handled terribly well with handovers between young people and adult services not happening smoothly.	Thank you for your comment. Transition will not be covered in this guideline because there is already a NICE guideline on transition from children's to adults' services. If the committee feels it is appropriate it will be possible to cross-link to the existing NICE guideline on transition and this will help provide a more coordinated approach across the two guidelines.

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Northern Care Alliance	General	General	There needs to be some questions that capture how CYP and families attend hospital / health - access, parking, transport , opening times etc	Thank you for your comment. We have draft review questions relating to the environment and accessibility of care and it is likely these issues will be considered as part of these questions
Northern Care Alliance	General	General	Some consideration needs to be given to the type of clinical setting: children's hospital , specialist hospital, large acute with paediatric inpatient facilities , local provider of ambulatory services, community and primary care, socio economic profile of the area	Thank you for your comment. The recommendations will cover all environments that provide NHS services, including those you have listed, and the guideline committee will ensure that they do not disadvantage any socio-economic groups. We have amended Key area 6 to clarify that all settings in which healthcare is delivered will be covered.
Northern Care Alliance	General	General	Need to consider: consent / understanding – how this is assessed and integrated within the standards	Thank you for your comment. We have a draft review question about issues of consent so this will be addressed within the recommendations.
Northern Care Alliance	General	General	The scoping has a focus on the experience – need to consider how it can include – how CYP want to share their experiences when experience not so positive , how they would want to raise a concern, complaint - how they might seek advice and support if the need ,expectation of the CYP is different to parent / carer	Thank you for your comment. We recognise that complaints systems are not generally child-friendly and we have included draft questions on how their experience can be measured so as to improve care. We anticipate that the guideline committee will cover the use of complaints and feedback mechanisms as part of this review. We also have draft questions about communication, access to healthcare information, support for informed decision-making and involvement of parents or carers in decision-making, which will address the advice, support and different expectations issues that you have raised.
Northern Care Alliance	General	General	The scoping should enable recommendations on minimum data sets so that pt experience can be "compared", local, regional, national	Thank you for your comment. There is a draft question in the scope that will review the evidence for measuring experience of healthcare and which may include methods of collecting data, but it will not be within the scope of the guideline to make recommendations on minimum data sets. However, the guideline will be used to develop the NICE Quality Standard for babies, children and young people's experience of healthcare.
Northern Care Alliance	General	General	How will CYP parents /carers be selected to participate in the consultation? Can organisations volunteer to support the process	Thank you for your comment. There will be involvement of 4 young people and 2 parents/carers on the guideline committee, and we are planning other ways to involve children in the guideline development process. Organisations interested in the guideline can register as stakeholders (via the NICE website). When the draft guideline is

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				completed it will then undergo a period of public consultation and stakeholders can comment on the draft guideline.
Northern Care Alliance	General	General	There is an opportunity to look at pt experience along the whole pathway , therefore guidance / standards need to consider this	Thank you for your comment. The guideline will look at experience throughout the whole care pathway and we have clarified key area 8 to state this.
Northern Care Alliance	General	General	Education is mentioned – however health is not responsible for this therefore if this is part of the scope then DoE / Local Education need to be sighted – would be great to have education part of core offer as it once was.	Thank you for your comment. As you have noted, it is outside the scope of NICE guidelines to comment directly about education, but the evidence review will consider how healthcare services can support 'normal' life for children and young people which will include their access to schooling and education
Northern Care Alliance	General	General	Is this guidance really needed? The aim is develop quality standards on experience– however there are already many other documents / guidance that also detail / aspire to this- what will be the added value o Professional standards o 6 C's or equivalent o Locality plans : which are far more realistic to plan and develop care for communities o GMCA : CYP plan o Action for sick children : childrens charter o Patient experience network report o BLISS o Neonatal peer review o National surveys : CYP, A+E	Thank you for your comment. We agree that there are already a number of other documents and we may be referring to some of these as part of our evidence review, where appropriate, but a NICE guideline will ensure that all healthcare services for babies, children and young people have a common set of core recommendations on which to base local provision. It is likely that quality standards will be produced based on this guideline.
Northern Care Alliance	6	17	Need some honesty until a baby/child is able to communicate then parents / carers will always be the source of information – perhaps the age range should be 4 – 17 years	Thank you for your comment. Babies can experience healthcare and so we think it is important that the guideline covers them from birth, although we have acknowledged in "Groups that will be covered" that parents and carers play a key role.
Northern Care Alliance	6	23	Exclusion groups : is there a need for a different set of principles / standards for standards for end of life / chronic health etc ; I would expect/hope that the aim at each point of contact would be to ensure its meaningful, appropriate, thoughtful compassionate etc having different	Thank you for your comment. We are not proposing different standards but different groups of children and young people have different needs, and the specific needs of babies, children and young people with life-limiting conditions are already covered in the NICE guideline on End of

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			standards for different patient groups has the potential to set either services to fail, tiered system of care and inability to manage expectations. Are neonates an exclusion group ? not clear and with the National aspiration to implement FiCare this should be the focus for this patient group Are CYP with CAMHS concerns included or excluded?	life care There are also a number of condition-specific guidelines relating to children and we will not therefore be duplicating more specific recommendations in these guidelines.. The guideline covers from birth up to and including 17 years so neonates are not excluded. **Mental health is not excluded from this guideline and we have clarified this in the 'Groups that will be covered' section of the scope.**
Patient Experience Library	1	18-20	We agree that the ideal approach for treating children cannot be extrapolated from adult evidence and services, and we welcome the development of more specific guidelines for children and young people.	Thank you for your comment.
Patient Experience Library	2	23-30	The Children's Commissioner and PEN reports that are cited are good. But as we move into 2019, they are seven and six years old respectively. The guidance could perhaps reference more recent reports - the following list (in no particular order) offers some examples: • World Health Organization, Health of refugee and migrant children, technical guidance, 2018 • Children's Commissioner, Children's mental healthcare in England, October 2017 • National Audit Office, Improving children and young people's mental health services, 9th October 2018 • Care Quality Commission, Review of children and young people's mental health services, October 2017 • Healthwatch England, Children and young people with autism, Findings from the Healthwatch network, March 2017 • NHS, We Can Talk, Children and Young People's Mental Health (CYP MH), 2017	Thank you for your comment and for telling us about these references. This introductory section is only meant to provide a brief overview of some facts and figures and the evidence reviews that will be used to write guideline recommendations will provide a much more detailed analysis of the evidence, but we may evaluate these documents for inclusion if appropriate.

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			• Nuffield Trust, Admissions of inequality, emergency hospital use for children and young people, December 2017 • Peninsula Cerebra Research Unit - PenCRU, In hospital and out of reach - the perceptions of disabled children, 2017 • Healthcare Play Specialist Education Trust, Exploring the impact environments have on children and young people's experience of healthcare, a review of the literature, Children's Environments of Care Report, May 2015 • National Voices, My Life, My Support, My Choice, A narrative for person-centred coordinated care and support for children with complex lives, 2015	
Patient Experience Library	3	9-24	The good practice examples could perhaps make reference to: NHS England, The Fifteen Steps Challenge, Quality from a patient's perspective; A children and young people's toolkit, 2017	Thank you for your comment and for telling us about this toolkit. The current practice section of the scope has been shortened as the examples given may not have been representative of services across the country. However, the evidence reviews that will be used to write guideline recommendations will provide a much more detailed analysis of the evidence, and we will evaluate this toolkit for inclusion if appropriate.
Patient Experience Library	4	16	Our understanding is that the 2011 framework has been superseded by the NHS Improvement Patient Experience Improvement Framework, June 2018.	Thank you for your comment. Our understanding is that these are 2 separate documents and the 2018 NHS Improvement Patient Experience Improvement Framework provided advice for boards and senior teams in the NHS to continuously improve healthcare, while the 2011 NHS Patient Experience Framework list the specific elements which are crucial to a patient's good experience of healthcare.
PIP UK	General	General	All children and young people, not only babies, in hospital need as much contact with their family as possible. This includes brothers and sisters and close relatives such as grandparents. Speaking from the viewpoint of a child and adolescent psychotherapist I would hope to see this point emphasised throughout as basic good practice. I do not think this is something anyone questions, it is more a matter of facilitating the	Thank you for your comment. We agree that family involvement and contact is important while babies, children and young people are in hospital and have a draft review question in the scope which will aim to identify how health services can support the continuation of family relationships for babies, children and young people.

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			necessary arrangements. This might be quite practical, like helping to arrange transport or even finding a free parking space.	
PIP UK	General	General	Although discharge has not been mentioned, I would like to add that sometimes the experience post-discharge is quite different for parents taking a baby home. Their anxiety level will be very high, especially if their baby has been looked after by 'experts' for an extended period. Some form of follow up in the home may be necessary. This is especially so if the baby's hospitalisation was due to a congenital problem. If parents become stressed this can affect the baby and set up a negative feedback which in turn can compromise the attachment relationship. Even if this is only short term, it is upsetting for all and can be avoided.	Thank you for your comment. We agree that care after discharge is important and have revised the key area 8 in the scope to clarify that this includes coordination of care throughout the care pathway, and this will include on discharge.
PIP UK	2	11	Babies cannot verbally comment on their experiences. However, they can communicate what they are thinking and feeling by their behaviour and responses. But for this to be appreciated the ward may need access to someone familiar with working with parents and infants who can become the baby's advocate. This would also be a source of information on the experiences of babies in hospital if it was collected in some way.	Thank you for your comment. We will be including evidence on the experiences of babies, however collected or reported, in the evidence reviews and also have a draft review question relating to advocacy so will be including both the experience of babies, and advocacy for babies in the development of the guideline.
PIP UK	3	12	Babies are as different from children as children are from young people. They and their parents need the provision of suitable space where they will be protected from seeing or hearing things that they will not have the capacity to understand, and which may provoke anxiety.	Thank you for your comment. We have a draft review question that asks 'What features of the healthcare environment are important to babies, children and young people to improve their experience of care?' that we hope will allow us to make recommendations on what aspects these age groups believe are important in a healthcare environment.
PIP UK	5	20	All the inequalities subsequently listed are a potential source of stress for a parent. Parents who are stressed may find it hard to hold their baby in mind. Staff should be aware that these groups are likely to contain dyads where the baby's attachment relationship may be at risk of being extremely insecure. This is separate from medical considerations. In which instances other services (such as an infant	Thank you for your comment. We have amended the list of potential inequalities and grouped them together and now have a group that covers all babies, children and young people who may come from a social or family background that may affect their experience of healthcare, which would include this group that you have mentioned.

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			mental health team or specialist health visitor) will be needed in addition to the medical provision.	
PIP UK	6	12	Babies in prison with their mothers as a very special case. Firstly it is important to bear in mind that it is the mother who is being punished, not the baby. Separating a baby from her mother is a form of punishment. So it should be standard practice within a prison setting, as elsewhere, that the separation between a baby and mother should be minimised if it cannot be non-existent. If the baby in prison needs healthcare then everything in this guideline should apply. In addition, by the fact of imprisonment it is likely that the mother has come from a difficult background and that she will also need specialised help in order to form the best possible relationship with her baby. This should be enabled. This relates to future mental health, and so comes under the remit of healthcare.	Thank you for your comment. We have included 'babies who are in prison with their mothers' in the list of potential inequalities and recognise that these babies should receive the same level and experience of healthcare as other babies.
PIP UK	6	19	The experience of a baby can never be taken out of the context of the relationship with the mother (sometimes father if he is prime caregiver). If the experience of the baby is to be assessed or considered both baby and mother need to be thought about together. Research has shown that a secure baby in the presence of their mother shows reduced distress in reaction to painful procedures than an insecure one, and both show more distress if the mother is not present.	Thank you for your comment. We have acknowledged that 'parents or carers play a key role and the views of parents or carers will be taken into consideration when developing this guideline.' There will be 2 parents or carers on the guideline committee. We also recognise that a baby's best experience of healthcare may be with their primary carer and this may be reflected in the recommendations.
PIP UK	7	11	Sometimes it needs someone with specialist knowledge to unravel the communication of babies; and this will be different depending on whether or not their mother is present.	Thank you for your comment. We have a draft review question that asks 'How should healthcare staff communicate with babies, children, young people and their parents or carers?' to address the best way to communicate with babies.
PIP UK	7	21	As in comment number 3. The healthcare environment for a baby has specific demands in line with their stage of development. It should whenever possible have the parent as part of that environment; and staff should have a prime responsibility for facilitating this.	Thank you for your comment. We recognise the importance of the primary carer's presence for babies and will review the evidence for the best possible environment for all groups of children.

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Royal College of General Practitioners	1	24	A limitation should be noted on the survey discussed. Although the document refers to young people up to the age of 17, the survey demographic was limited to 8-15 year olds As a definition of a young person, the WHO and other experts now consider the 10-25 range as being developmentally appropriate one. This narrowing of the age range may limit the impact and implementation of this work. In general practice children only really begin to consult alone at an average age of 15-16.	Thank you for your comment. We are aware that the CQC survey only covered children of a certain age range, but it was a large survey and provided some useful insights into the views of children of this age. This introductory section is only meant to provide a brief overview of some facts and figures and the evidence reviews that will be used to write guideline recommendations will cover the age range specified (0 to 17 years). As there is already a NICE guideline on patient experience of adult NHS services, and a NICE guideline on transition from children's to adults' services, it has not been possible to extend the age limit for this guideline above 17 years, as this may lead to uncertainty about which guideline applies to individuals aged between 18 and 24. However, we recognise that some young people may continue using paediatric or young people's services up to the age of 24 and so we have indicated in the 'Who the guideline is for' section that it may also be relevant to 18 to 24 year olds.
Royal College of General Practitioners	2	7	A useful measure here would be to mention the number of patients (12-15year olds) who wanted to discuss their care with health staff without parents rather than simply the percentage who did.	Thank you for your comment. This introductory section is only meant to provide a brief overview of some facts and figures and the evidence reviews that will be used to write guideline recommendations will provide a much more detailed analysis of the evidence as you suggest is necessary. We have a specific review question (3.1) about how children and young people want their parents/carers involved in decisions about their care.
Royal College of General Practitioners	2-3	General	General practice and primary care provide significant care for infants, children and young people. There is however, limited mention of primary care or the role it plays within this scope.	Thank you for your comment and for highlighting the importance of primary care. The guideline will cover all settings where healthcare is delivered and this will include primary care. We have amended key area 6 to clarify this.
Royal College of General Practitioners	8	7	The NICE transition document referenced only covers transition between paediatric and adult services – not within primary care or between paediatric care and primary care. There would be value in further exploring these additional transfers and their potential to impact on provision of quality care.	Thank you for your comment. We recognise that the transition guideline only covers transition between children's and adults' services but the issue of transfer to and from primary care (for those aged under 18) will be covered under key area 8 which relates to continuity and coordination

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				of care across the whole care pathway, and we have modified the wording to clarify this.
Royal College of General Practitioners	8-10	18-28	RCGP identifies the differing care needs of infants, children and young people. Current guidelines do not fully account for these needs as age groups are frequently merged. For example, NG 86, CG 138 and CG 136 group young people >18 with adults. Equally inclusion of young people with infants and children in this current scope, risks omission of key health needs for this group. For this reason consideration should be given to Children and young people need to be considered as distinct groups	Thank you for your comment. We recognise that young people may have specific needs but in order to prevent overlap between guidelines it has been necessary to use an upper age limit of 17 years for this guideline. However, we plan to consider the needs of children and young people as separate groups where applicable, and have added information in the 'Groups that will be covered' section to clarify this.
Royal College of General Practitioners	9-10	General	Other key issues to consider include primary care specific barriers: • difficulties of access, • negotiating appointment making, • difficulties of parental access to notes, problems of referral thresholds and waiting times (e.g. of CAMHS)	Thank you for your comments and bringing these potential barriers to our attention. We have a draft review question (8.1) that asks: 'What are the facilitators and barriers for babies, children and young people in accessing healthcare services?' and this will include barriers in all care settings, including primary care.
Royal College of General Practitioners	9-10	General	If the age range was determined by what id developmentally appropriate i.e. up to 25 it would enable experience of health care after leaving home, going to university to be considered – one issue that could be explored would be dual registration	Thank you for your comment. As there is already a NICE guideline on patient experience of adult NHS services, and a NICE guideline on transition from children's to adults' services,, it has not been possible to extend the age limit for this guideline above 17 years, as this may lead to uncertainty about which guideline applies to individuals aged between 18 and 24. However, we recognise that some young people may continue using paediatric or young people's services up to the age of 24 and so we have indicated in the 'Who the guideline is for' section that it may also be relevant to 18 to 24 year olds.
Royal College of General Practitioners	9-10	General	We recommend consideration be given specifically around what this guideline will add to drive improvements in primary care. A significant number of infants, children and young people are seen in the primary care setting and there is some evidence and understanding on desired experiences of care. The value of a guideline could be in identifying improvements that could be made without adding significant burden– however there is limited quality evidence available on this topic.	Thank you for your comment. The guideline will cover all healthcare settings, and we recognise that many babies, children and young people access healthcare through primary care.

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Royal College of Midwives	General	General	RCM suggests that the guideline may benefit from the use of more specific distinguishing language when describing the age of the "user"; neonate, infant and child may be helpful.	Thank you for your comment. When making recommendations, the guideline committee will consider whether to define the age groups more specifically.
Royal College of Nursing	General	General	This is just to inform you that the feedback I have received from nurses working in this area of health suggests that there are no comments to submit on behalf of Royal College of Nursing to inform on the consultation of the draft scope of Infant, children and young people's experience of healthcare. Thank you for the opportunity to participate. We look forward to participating at the next stage.	Thank you for your comment.
Royal College of Paediatrics and Child Heath	General	General	This guideline is well written	Thank you for your comment.
Royal College of Paediatrics and Child Heath	General	General	This guideline is welcomed and the YPHSIG are supportive of the ambition to improve the experience of babies, children and young people in health care. The inclusion and focus on young people is particularly welcomed. Overall the draft covers key areas and asks pertinent questions.	Thank you for your comment.
Royal College of Paediatrics and Child Heath	General	General	For the age range of this document to be valid in referring to young people it should be in line with the currently acknowledged definition of young people, WHO recommends definition of 10 - 24 years (http://www.searo.who.int/entity/child_adolescent/topics/adolescent_health/en/). Youth is defined by the United Nations as 15 – 24 years (https://www.un.org/development/desa/youth/what-we-do/faq.html). Many members see young people, or run services, that span to 24 years and there is a move for services to consider beyond previous definitions of 16 or 18 years old and transition, including in the recently published NHS Long Term Plan. It is acknowledged that there is a NICE guideline for over 18s, and the work from that could be incorporated into this guideline. Therefore, if this planned document is not using WHO or United Nations definitions, then in our opinion the guidance should cover up to a	Thank you for your comment. As there is already a NICE guideline on patient experience of adult NHS services, and a NICE guideline on transition from children's to adults' services, it has not been possible to extend the age limit for this guideline above 17 years, as this may lead to uncertainty about which guideline applies to individuals aged between 18 and 24. However, we recognise that some young people may continue using paediatric or young people's services up to the age of 24 and so we have indicated in the 'Who the guideline is for' section that it may also be relevant to 18 to 24 year olds.

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			minimum 19 years. There is evidence that 16-19-year olds are experiencing gaps in service provision that is leading to poor outcomes and dissatisfaction. The poor levels of care for this group are likely being missed in the analysis of adult surveys (because they are a small number within in the adult survey). There are discussions about whether this age group should be seen by specialist paediatricians or young adult physicians hence, we feel it is imperative that they are heard in this guideline.	
Royal College of Paediatrics and Child Heath	General	General	Transition of care – it is acknowledged that there is a separate guideline for transition and not a need to duplicate scope of this guideline however, given the importance of this aspect of care in the experience particularly of young people signposting to the appropriate guidance points should be clearly included. It would be remiss to not utilise this opportunity to aid those accessing the guideline to be introduced to new ideas and concepts.	Thank you for your comment. If the guideline committee feels it is appropriate it will be possible to cross-link to the existing NICE guidelines on transition and this will help provide a more coordinated approach across the two different guidelines.
Royal College of Paediatrics and Child Heath	General	General	There is a missed opportunity within the current draft to highlight planning services as part of the experience of good health care.	Thank you for your comment. There is a draft review question which asks 'How can the perspective of children and young people, and of the parents or carers of babies inform the design of healthcare services?' and we will be including involvement in planning services as part of the experience of good healthcare.
Royal College of Paediatrics and Child Heath	General	General	Missed appointments and did not attend (DNAs) are not mentioned in the guidance which is an important consideration for improving experience of healthcare and also safeguarding in babies, children and especially young people.	Thank you for your comment. We have noted the importance of missed appointments and the link to experience and safeguarding, and the guideline committee may decide to include these as outcome measures. We have now also included in the scope reference to the NICE guideline on child abuse and neglect, which the committee may choose to cross-refer to if appropriate.
Royal College of Paediatrics and Child Heath	5	25	To include potential inequalities relating to babies, children and young people whose parents or carers may be unable to advocate for them in light of their own learning difficulties.	Thank you for your comment. We have amended the list of potential inequalities and grouped them together and now have a group that covers all babies, children and young people who do not have parents or carers who can advocate for them, and this will include the groups you have mentioned.

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Royal College of Paediatrics and Child Heath	7	13	Where this says involved, there should be more emphasis on active involvement of young people in planning their care, and also in co-creating and planning services. Acknowledgement of the importance of offering time alone to young people for communication and psychosocial screening would be welcomed.	Thank you for your comment. The review question for key area 1 (1.1) asks: 'How do children and young people like to be involved in planning their healthcare and making shared decisions about their health?' and there is a separate question on planning services (key area 5) which asks: 'How can the perspective of children and young people and of the parents or carers of babies inform the design of healthcare services?' We believe that the question on consent, privacy and confidentiality will address issues around consultation without parents/carers being present.
Royal College of Paediatrics and Child Heath	7	15	Emphasis should be on access to developmentally appropriate information (not always age related, but developmental stage).	Thank you for your comment. This key area is meant to provide an overview of the topics that will be covered. The recommendations that are developed for this key area will provide more detail on the nature of the information that should be provided, and this is likely to include making sure it is developmentally appropriate.
Royal College of Paediatrics and Child Heath	7 9	11-16 11-22	Communication - consider whether letters and summaries should be addressed to the young person or their parents, rather than to the GP (Academy of Medical Royal Colleges Guidance 2018) Provision of a quiet private room adjacent to the clinical area, to have confidential conversations with children and families is important.	Thank you for your comment and for your suggestions. We have draft review questions about the best methods of communication, privacy and confidentiality and so the committee will be reviewing evidence to make recommendations in all these areas.
Royal College of Paediatrics and Child Heath	7 9	15 21-22	Ensure that all information leaflets and consent forms used are age-appropriate for the children and young people who use them.	Thank you for your comment. This key area is meant to provide an overview of the topics that will be covered. The recommendations that are developed for this key area will provide more detail on the nature of the information that should be provided, and this is likely to include age appropriateness.
Royal College of Paediatrics and Child Heath	7 10	19-22 6-15	Facilities - consider whether it is appropriate to have single-sex inpatient bays (4-6 beds) and single-sex bathroom and toilet facilities for young people of secondary school age? This may be desirable for privacy and safety, but can be difficult to guarantee, when all the beds are full most of the time. The issue of how to accommodate LGBT+ children also needs to be addressed.	Thank you for your comment and for your suggestions. The draft review question 'What features of the healthcare environment are important to babies, children and young people to improve their experience of care?' will review the evidence for the best possible environment for all groups of children. We have also identified in our Equalities Impact Assessment that recommendations will need to take into account the needs of children of different sexual orientation (for example LGBT+) and gender.

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Royal College of Paediatrics and Child Heath	7 10	21-22 12-16	Mental health – safety considerations may require the use of single rooms for these patients, with no objects that might be used in self harm or suicide attempts. Toileting may need supervision. Young people with severe mental health problems may need to be nursed separately from babies and younger children, and may also require separation in the schoolroom and play/recreation areas.	Thank you for your comment and for highlighting the fact that we may need to consider making recommendations specifically to address the environmental needs of children or young people with mental illness, or those sharing space with them in a healthcare setting.
Royal College of Paediatrics and Child Heath	7 10	21-24 12-17	Child-friendly staff, play equipment and nappy changing facilities should be available in all outpatient facilities where children are seen, including fracture clinics, general surgical clinics, dermatology, A&E, ENT and ophthalmology, as well as in paediatric clinics and wards. The hospital should have a designated person on the management board who is responsible for maintaining these standards across all departments.	Thank you for your comment. We will be covering the delivery of healthcare in all settings and have amended the wording of key area 6 to clarify this, but have not named individual wards or departments.
Royal College of Paediatrics and Child Heath	9	21	In the draft the focus is on how to access information, but it would also be important to include who information is accessed from, and where.	Thank you for your comment. We recognise that accessing information will need to include from whom and where and this detail is likely to be reflected in the recommendations.
Royal College of Paediatrics and Child Heath	10	18	There should be focus not only on engagement with usual activities while in hospital, as mentioned, but also at any time when babies, children and young people are interacting with health care (often outpatient burden or time spent self-managing between admissions is equally challenging).	Thank you for your comment and for highlighting the importance of primary care. The guideline will cover all settings where healthcare is delivered and this will include primary care. We have amended key area 6 and question 7.1 to clarify this.
Royal College of Physicians	General	General	The RCP is grateful for the opportunity to respond to the above consultation. We have liaised with our Young Adults and Adolescents Steering Group (YAASG) and would like to make the following comments.	Thank you for liaising with your steering group. Please see the responses to your comments below.
Royal College of Physicians	General	General	We welcome this consultation as it recognises from work done with the AYPH that young people have a poor experience of health care which can impact on future health care decision making.	Thank you for your comment.

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Royal College of Physicians	6	17	Line 17 – The group would like the age covered to be clearer currently it reads 0-17 years, yet later in the paragraph under 'groups that will not be covered' young people aged 18 and over are not covered. We would prefer the age covered to be 0-18, (Or 0-17 years 364 days) with patients 18+ not covered – as potentially young people aged 17-18 would fall between both documents.	Thank you for your comment. Until young people reach their 18th birthday they are still 17 years old so we think it is clear to say this guideline covers babies, children and young people aged 17 years and under.
Royal College of Physicians	7	21	Line 21, item 6 – Healthcare environment – including facilities and equipment appropriate to age and needs of the target group We would like to see training of staff included, suggest, 'Healthcare environment – including facilities, equipment, and evidence of staff training appropriate to age needs of the target group'. This is because many young people aged 16-18 are admitted onto adult wards where staff may feel under confident in dealing with young people and where, RCP survey data has shown, that training in Adolescent and young people's needs may be minimal at best.	Thank you for your comment. Although it is possible that the recommendations may require training of staff to ensure they are implemented, NICE guidelines do not usually provide specific details of what that training should involve and how it should be carried out.
Royal College of Psychiatrists	General	General	**Infants:** Ensure staff have training and experience in understanding infant behaviour as communication, and knowledge of infant attachment and the role of caregiver sensitivity and responsiveness. Health staff require training with respect to the particular communication and attachment needs of babies and infants under 5-year-olds. Understand the need of access to their primary attachment figure throughout any hospital stay or medical assessment/intervention, as well as other important attachment figures such as siblings/grandparents where appropriate. Important to ensure as much continuity as possible of designated key nurse/practitioner to ensure infant's familiarity with practitioner(s) delivering care. In cases where an	Thank you for your comment. Although it is possible that the recommendations may require training of staff to ensure they are implemented, NICE guidelines do not usually provide specific details of what that training should involve and how it should be carried out. Recommendations relating to the experience of babies and pre-school children will be an integral part of the guideline. We will also be considering how children and young people want their parents/carers involved in their care, and maintaining family and peer relationships, as well as continuity of care.

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			infant requires multiple admissions for complex problems, including for safeguarding issues, continuity of medical staff/practitioners should be provided wherever possible to reduce the risk of indiscriminate attachment styles. Staff need to understand the need to work as a team to try to support secure attachment styles and appropriate stranger awareness/anxiety in infant relationships (ie restrict multiple interactions by multiple staff with infant/toddler).	
Royal College of Psychiatrists	General	General	Training in developmental needs of babies and children is key so that staff use age appropriate language and communication style. Important to have knowledge of how to observe and assess an infant's: • Key relationships & ability to use these to get needs met • Developmental profile - physical, cognitive, emotional, social • Individual strengths and difficulties Impact of child's experiences	Thank you for your comment. We have a draft review question that asks, 'How should healthcare staff communicate with babies, children, young people and their parents or carers?' so will be addressing the issues relating to appropriate language and communication that you have raised.
Royal College of Psychiatrists	General	General	Training of staff to improve awareness of how to be attuned to and respond to infants' needs, as well as to support parents in their interactions with their infants. Consideration of training of designated ward staff in a parenting programme that also improves and enhances staff's skills in responding to infants. For example, Circle of Security programme (Circle of Security International - Early Intervention Program for Parents & Children). Refer to THRIVE early years programme.	Thank you for your comment and telling us about the Circle of Security and THRIVE international programme. Although it is possible that the recommendations may require training of staff to ensure they are implemented, NICE guidelines do not usually provide specific details of what that training should involve and how it should be carried out.
Royal College of Psychiatrists	General	General	Ensure staff elicit the views of under 5-year-olds with respect to their care and ward environment. Training will be required in developmentally appropriate methods of eliciting the views of very young children.	Thank you for your comment. The draft review questions include how healthcare staff should communicate with, and support, babies and children so this will review the evidence for appropriate methods of communication in this age group. Although it is possible that the recommendations may require training of staff to ensure they are implemented, NICE guidelines do not usually provide specific details of what that training should involve and how it should be carried out.
Royal College of Psychiatrists	General	General	Important that infants have safe play environment with clean, good condition age appropriate toys and well-trained playroom staff.	Thank you for your comment. We have a draft review question that asks, 'What features of the healthcare environment are important to babies,

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				children and young people to improve their experience of care?' and so this topic will be covered in the guideline.
Royal College of Psychiatrists	General	General	Ensure staff have training and access to age appropriate tools for the assessment and management of pain and discomfort in babies and young children	Thank you for your comment. Pain is not covered as a separate topic in the guideline but the committee will review what factors are important to improve experience of healthcare, and this may identify pain control. However, pain assessment, including age appropriate tools, and management has been dealt with in other NICE guidelines relating to specific clinical conditions.
Royal College of Speech and Language Therapists	5	15	We appreciate the list of potential inequalities that need to be taken into account in the development of this however we would like to see 'special education needs' taken in to account. This extends beyond learning disabilities or other disabilities. We also consider it would be beneficial to separate 'learning disabilities' with 'communication difficulties' as they may be very different needs and lumping them together carries great risk. The list may read, for example: • Who have special educational needs • With learning disabilities • Who have communication difficulties	Thank you for your comment. We have amended the list of potential inequalities and grouped them together, with some specific examples for each group, and have added special educational needs as one of the examples.
Royal College of Speech and Language Therapists	7	1	We feel there is a fundamental omission of key stages in the area of 'communication' for comprehensive recommendations to be made. We would like to see the following additions (underlined): Communication with babies, children, young people and their parents or carers, including ensuring that children and young people <u>are supported to express their opinion,</u> listened to, <u>understood,</u> and are involved in planning their care and in making decisions about their healthcare	Thank you for your comment. We agree that your suggestions are important for good communication, but the key area is intended to be an overview of the subject, and then the evidence search and guideline committee discussion will provide the detail of the recommendation.

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Royal College of Speech and Language Therapists	7	15	Access to healthcare information is one thing, but we believe this should encompass ‘access to <u>relevant and suitable</u> healthcare information’ to ensure appropriacy of this recommendation.	Thank you for your comment. This key area is meant to provide an overview of the topics that will be covered. The recommendations that are developed for this key area will provide more detail on the nature of the information that should be provided. We have also now added a new review question in the information section, 2.2 which asks ‘How can children and young people and the parents or carers of babies and young children be supported to make informed decisions, including about risks and benefits?’
Royal College of Speech and Language Therapists	7	18	This is very limiting to children are young people in hospital- it does not acknowledge that other uses of healthcare can have substantial impacts on engagement on usual activities (e.g. the need to attend multiple medical points in a week, or being taken out of the classroom for one to one therapy). We strongly recommend that the following is added: 7.1 How can engagement in usual activities (for example family relationships, schooling, peer friendships, social activities) be maintained while children and young people are ~~in hospital?~~ Attending healthcare services.	Thank you for your comment. We agree that this question was too focussed on children in hospital and have amended it to: ‘How can health services support engagement in usual activities (for example sibling relationships, other family relationships, schooling, friendships, social activities) for babies, children and young people?’
Royal College of Speech and Language Therapists	7	21	It would be advantageous for recognition to be placed on education-based healthcare here e.g. therapists working in schools. We would like to see the inclusion of the underlined: • Healthcare environment (including facilities, <u>settings (e.g. school)</u> and equipment) appropriate to the age and needs of babies, children and young people.	Thank you for your comment. We will be covering the delivery of healthcare in all settings and have amended the wording of key area 6 to clarify this, but have not named schools specifically.
Royal College of Speech and Language Therapists	7	25	Monitoring or reassessment of care is a critical to ensure children and young people are able to inform on past, present and future aspects of their care, therefore we recommend adding: Accessibility, continuity, <u>monitoring of</u> and coordination of care	Thank you for your comment. The guideline will look at experience throughout the whole care pathway, including ongoing reassessment of care and we have clarified key area 8 to state this.

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Royal College of Speech and Language Therapists	9	11	We feel there is a fundamental omission of key stages in the area of 'communication' for comprehensive recommendations to be made. We would like to see the following additions (underlined): Communication with babies, children, young people and their parents or carers, including ensuring that children and young people are supported to express their opinion, listened to, understood, and are involved in planning their care and in making decisions about their healthcare	Thank you for your comment. This detail is not necessary to include in the 'key area' as the draft questions ask how communication should happen, and we believe this will address these issues.
Royal College of Speech and Language Therapists	9	17	We are pleased to see the focus on questions around the best way to communicate with children and young people.	Thank you for your comment.
Royal College of Speech and Language Therapists	9	24	The scope for this question seems limited, we would encourage also addressing the following in this section: 2.2. how are parents or carers of babies, and children and young people supported to access healthcare information? 2.3 how are parents or carers of babies, and children and young people supported to understand healthcare information?	Thank you for your comment. We have now added an additional question 2.2 which asks: 'How can children and young people and the parents or carers of babies and young children be supported to make informed decisions, including about risks and benefits?' – this will cover accessing and understanding information.
Royal College of Speech and Language Therapists	9	30	It is important that consideration is taken not only to empowering children and young people to advocate for themselves but also enabling, which has important semantic differences in not assuming all will be able to 'be empowered' by the same means.	Thank you for your comment. We discussed the wording of this question and think that the term empowering will give us enough information to review the evidence about children and young people having the tools to advocate for themselves.
The Brain Tumour Charity	General	General	Consideration should be given to the groups that this guideline should focus upon. Transitions to adulthood can be difficult but this is particularly the case for young people accessing healthcare services. The NHS Long Term Plan detailed how services should essentially be based on need rather than age. It is important that this is considered in more depth to ensure that the guideline mirrors shifts within the NHS towards more person-centred services.	Thank you for your comment. The guideline covers babies, children and young people up to and including the age of 17 but the guideline committee will keep in mind that individuals have different needs that may not be the same for their peers who are the same age, and that some young people may access non-adult services up the age of 24. We have added this consideration to the scope (in the section "Who the guideline is for").
The Brain Tumour Charity	General	General	The draft scope does not focus enough on how shared decision making can be encouraged.	Thank you for your comment. One of the key areas we have identified for inclusion in the guideline is communication, ensuring that children are

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				listened to, and are involved in planning their healthcare and making shared decisions about their health. We have now also added an additional review question in the key area on information, to determine how children and young people can be supported to make informed decisions, which is also part of shared decision-making.
The Brain Tumour Charity	General	General	The draft scope does not provide an adequate consideration of how teenagers can be appropriately supported in healthcare services. The guideline produced should consider the unique challenges associated with accessing healthcare services at this age and suggest ways for healthcare services to better meet their needs. Provision of teenagers' recreation rooms is a useful start but the guideline should clearly outline what teenagers need, how they can be supported and the best ways to involve them in shared decision making.	Thank you for your comment. There are draft review questions which will aim to identify the facilitators and barriers to accessing healthcare, what factors are important to young people to improve their experience of healthcare, and what features of the healthcare environment are important to them. The guideline committee will also look at how young people want to be supported and how they want to be involved in planning their care and making decisions about their care so we anticipate that the topics you have mentioned will be discussed and considered by the committee. We have now also clarified (in the 'Groups that will be covered' section) that we will make separate recommendations for young people if necessary.
The Brain Tumour Charity	3	17-18	More attention should be given as to how to engage and gather feedback from children with visual impairment and learning difficulties ensuring that the feedback accurately represents the views of this group.	Thank you for your comment. The current practice section of the scope has been shortened as the examples given may not have been representative of services across the country. However, the evidence reviews that will be used to write guideline recommendations will provide a much more detailed analysis of the evidence, and the best ways to address the needs of all children and to engage children with different needs in the delivery of healthcare services, including those with visual impairment and learning difficulties.
The Brain Tumour Charity	3	22	It is suggested that year 12 and 13 students acting as ward volunteers is an example of good practice. It is not clear in this draft scope what their role is and how this equates to positive outcomes for infants, children and young people.	Thank you for your comment. The current practice section of the scope has been shortened as the examples given may not have been representative of services across the country. However, the evidence reviews that will be used to write guideline recommendations will provide a much more detailed analysis of the evidence, and the best ways to improve positive outcomes for babies, children and young people.

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Babies, children and young people's experience of healthcare

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The Brain Tumour Charity	3	23	The example of good practice which refers to an electronic tablet-based food ordering system with pictures of the meals available is welcome and is a useful example of good practice. This example should be supplemented with other concrete ideas which would enable all infants, children and young people irrespective of needs to have a more positive experience when accessing children's healthcare services.	Thank you for your comment. The current practice section of the scope has been shortened as the examples given may not have been representative of services across the country. However, the evidence reviews that will be used to write guideline recommendations will provide a much more detailed analysis of the evidence, and the best ways to give babies, children and young people a positive experience.
The Brain Tumour Charity	3	9-24	This section of the draft scope focusing upon examples of good practice is brief and does not encapsulate the needs of all infants, children and young people accessing healthcare. More needs to be included focusing on a range of needs including children with learning difficulties. Innovative ways need to be found, aside from patient experience board games, to really engage these infants, children and young people in the delivery of children's healthcare services.	Thank you for your comment. The current practice section of the scope has been shortened as the examples given may not have been representative of services across the country. However, the evidence reviews that will be used to write guideline recommendations will provide a much more detailed analysis of the evidence, and the best ways to address the needs of all children and to engage children with different needs in the delivery of healthcare services.
The Brain Tumour Charity	4	16-21	The inclusion of the NHS Patient Experience Framework (Department of Health 2011) in the draft scope is appropriate with its focus on patient-centred values in particular. The reference to emotional support is also welcome. More needs to be done to ensure that all children and young people are effectively supported and their emotional needs are met. The guideline should reflect this need.	Thank you for your comment. We agree that this framework provides a useful list of values which the guideline committee may take into consideration when making specific recommendations for babies, children and young people.
The Brain Tumour Charity	4	22-28	It is positive that the World Health Organisation (WHO) standards for improving the quality of care for children and young adolescents in health facilities (WHO 2018) has been incorporated into the draft scope. The emphasis on appropriate care for age and stage of development is welcome and the standards must be considered.	Thank you for your comment. We agree that this document provides useful standards. The evidence reviews that will be used to write guideline recommendations will provide a much more detailed analysis of the evidence, and the best ways to give babies, children and young people a positive experience of healthcare.
The Brain Tumour Charity	5	27	Equality considerations should also be made for infants, children and young people with visual impairments and learning difficulties.	Thank you for your comment. We have amended the list of potential inequalities and grouped them together and now have a group that covers all babies, children and young people who have communication difficulties, and this will include the groups you have mentioned.

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The Brain Tumour Charity	7	3	More detail should be provided in relation to the advocacy and support available for children and young people. It is crucial that if necessary advocates are professional trained and able to speak on behalf of children and young people if they are unable to do so themselves.	Thank you for your comment. More detail about the advocacy and support reviews is included in the 4 draft questions in section 3.4 of the scope. The questions are: 3.1 How do children and young people want their parents or carers to be involved in their care and decisions about their care? 3.2 How do children and young people want healthcare staff to support them? 3.3 How can children and young people be empowered to advocate for themselves? 3.4 How can parents or carers, healthcare staff and independent advocates represent the views of babies, children and young people? The guideline committee will review evidence to answer these questions and use that to make their recommendations, including evidence that is available on the use of independent advocates.
The Brain Tumour Charity	9	11-14	It is unclear what approach will be taken to communicate with babies and involve them in planning their care and making decisions about their healthcare. It might be more appropriate for it to be considered how babies can be advocated for and ensure their needs are met with parents properly supported and informed.	Thank you for your comment. We have amended the scope as in some cases it is appropriate to refer to babies' experiences directly, but that in other instances it is more logical to refer to their parents/carers. For example, we have removed the reference to babies accessing information and clarified that it is their parents or carers, and included babies in the questions on advocacy.
The Brain Tumour Charity	9	30-31	It is really positive to see the inclusion of how children and young people can be empowered to advocate for themselves but it needs to be backed up with clear ways in which these groups can be supported effectively to ensure that informed decisions are made.	Thank you for your comment. We have now added an additional question 2.2 which asks: 'How can children and young people and the parents or carers of babies and young children be supported to make informed decisions, including about risks and benefits?' which will address the issue you have raised.
Young Minds	General	General	YoungMinds is the UK's leading charity championing the mental health and wellbeing of children and young people. At YoungMinds we are in a	Thank you for your comment and for sharing with us the results of the 'Your Voices Amplified' which provides useful information about the areas

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			unique position as our insights and solutions are informed by the experiences of children, young people, parents and professionals, as well as evidence and data we have collected. At YoungMinds, we are delighted that you are developing guidance on children and young people's experiences of healthcare. This email outlines some of the work and insights that we have gained by supporting and building participation into the children and young people's mental health system through the NHS England funded Amplified project. As part of the Amplified project, we have gained insights that may assist with the development of the draft guidance. Notably, in 2018 we published 'Your Voices Amplified' which includes the insights of 1498 young people, 658 parents and carers, and 414 professionals on their experiences of and attitudes towards participation in mental health services. Through this, children and young people told us that they: • Want to be actively involved in looking after their own wellbeing, but to do this they feel that they need more information about mental health. They feel that there is already information out there, but it isn't always created with the needs of young people in mind. • Want to be more involved in the decisions made about their mental health care, and better informed about who might be able to find out what they say at appointments. • Feel that getting help from trained professionals when we need it is really important, but it's also important to feel that those professionals respect their views and experiences.	that are important for children and young people, and which correlate well with the key issues that have been included in the scope.

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			• Can improve the services they use by getting involved in planning and designing processes. They want more chances take part in these decisions, and to get clear feedback on how their input has made a difference. • Want every young person to have an equally good experience of services and want to have a role in making that happen. I hope that this information will be useful when developing the draft guidance and if you would like any further information then do not hesitate to get in touch.	