Babies, children and young people's experience of healthcare

Consultation on draft guideline - Stakeholder comments table
05 March 2021 - 16 April 2021

Stakeholder	Document	Page No	Line No	Comments	Developer's response
Allergy UK	Guideline	007	010	Having communication resources and information that is pitched to the appropriate health literacy of the intended audience is important to ensure understanding and informed decisions can be made upon the information. Avoidance of medical jargon, with explanations and definitions provided with examples to support their relevance to everyday life. For example anaphylaxis pronounced ana-fil-lax-is is a word used to describe the most severe form of an allergic reaction.	Thank you for your comment. The detailed recommendations in section 1.2 of the guideline on providing information state that information should be presented in a language that can be understood, avoids jargon and explains terms, as you have suggested. We have now also added that simple and clear language should be used.
Allergy UK	Guideline	009	005	It is not uncommon that parents of children who use the services of our charity report to the helpline staff or clinical team that they have not felt listened to or understood by their Health Care Professional. Communication is well reported in research to be a cornerstone of an effective patient/HCP relationship. It is important that parents feel that there concerns and anxieties around their baby or child's health and well being are being heard. Having strategies for encouraging parents and children (age appropriate) to contribute to the decision-making processes will lead to improved health outcomes as this will drive compliance with treatment and care.	Thank you for your comment. We hope the guideline will improve healthcare experience relating to communication and shared decision-making as we agree these are very important aspects of the healthcare experience and may impact on health outcomes.
Allergy UK	Guideline	011	004	Be aware of the potential impact that the condition or disease that the family are dealing may not always be evident during consultations or visits to healthcare services. Children and families living with food allergy often experience anxiety of varying degrees due to the perceived fear of a severe allergic reaction or even death as a result of accidental exposure to an allergen. Social exclusion can be a real problem for children living with allergy especially those with severe expressions of	Thank you for your comment. The committee are aware that illness can have an impact on the child or young person's usual activities, and this is addressed in section 1.9 of the guideline, with recommendations on how healthcare providers can support participation in usual activities, including education.

				allergy which can result in an inability to participate in school activities (exclusion from school holidays/day trips and sports, they can also be bullied and feel left out.	
Allergy UK	Guideline	012	020	It is key to consider the individual when providing health information. Parents want information that they can trust and that is presented in a clear and concise manner and that is evidence based which in turn is translated into meaningful data not baffling science. All to often discrepancies exist where those in lower socio economic groups aren't able to access information in the same ways as those with access to the internet, newspapers etc. Consistency is important when sharing information, it is a common cause of confusion and a lack of trust or confidence where a lack of consistency exists.	Thank you for your comment and for your support for our recommendations on the provision of information, which cover the points, you have raised about clear, concise, trusted, consistent and evidence-based information. We note your concern that those in lower socioeconomic groups may not access healthcare information particularly via the internet. We recognise there may be differences in access to digital information and have included a new over-arching recommendation at the beginning of the guideline about digital access and the need to offer alternative sources of information.
Allergy UK	Guideline	014	002	It is key to consider the individual when providing health information. Parents want information that they can trust and that is presented in a clear and concise manner and that is evidence based which in turn is translated into meaningful data not baffling science. Patient organisations like Allergy UK provide a suite of resources on different allergies that have been through the information standard as part of their development and a robust internal compliance to ensure they are written by experts in their field and peer reviewed as well as user tested by members of the public. Charities have an important role to play in the information they provide as Health Care Professionals are commonly time poor and may not always provide families with information to take away or signpost to useful support services. Include the contact details for relevant charities in supporting information given to patients. Their role is vital in supporting patients and provide information and advice that compliments care.	Thank you for your comment and for your support of our recommendations on information, which include all the factors, you have mentioned. Thank you for telling us about the resources produced by Allergy UK and the rigorous development process you use. We appreciate the importance of the role of charities such as yours and have already included a recommendation advising signposting to charities and support groups as credible sources of additional information.

Allergy UK	Guideline	015	019	Engagement with families is key to fostering good relationship and compliance with care and treatment and achieves the best health outcomes for babies and children. Research has shown that families from a low socioeconomic background are much less likely than families from a higher socioeconomic background to have used health services for their children. Some parents will actively seek this whilst for others they will need to be taken on the journey.	Thank you for your comment. We agree that engagement with families is important and that families from certain groups may face barriers accessing healthcare services for their children. In the recommendations on access (section 1.10), we have amended our recommendation on supporting access for parents and carers to highlight that certain groups may require additional support and encouragement to access healthcare services.
Allergy UK	Guideline	25	004	Accessible allergen free meals and drinks should be available. Patients may have one or more food allergies that require a diet free from these foods and any risk of cross contamination with e.g. buffet style/meal trolley contamination. Communication with parents on what the baby or child can eat and those foods they need to avoid can help achieve positive allergy management as the patient and their family feel catered for and can have safe nutrition whilst in health care settings . Catering staff need to be trained in allergen management and strict protocols in place to ensure allergen management policies and procedures are in place and complied with.	Thank you for your comment. The committee agreed that 'dietetically appropriate' would include the need for allergen free food. It was not within the scope of the guideline to consider specific clinical conditions and so the committee agreed that the other information on allergen management was too specific to be included in this guideline.
Allergy UK	Guideline	033	011	The change in how health care is delivered in the past year during the COVID-19 pandemic has shaped how services best manage their caseloads and patient needs. Telephone and video calls can be an effective use of time for both HCP's and parents as the time and expense of travel is not required. It also makes healthcare accessible to those who may be limited by their geographical location and services available in that region. This is particularly true for the allergic community we support as allergy services in some regions are non existent. Our experience of delivering clinical services at Allergy UK to provide dietetic and skin allergy consultations and advice	Thank you for your comment, support of the recommendations on virtual consultations and for sharing how they have been successful. We agree that developments in this area were accelerated by the Covid-19 pandemic and that sharing good practice in this area will be useful.

				allows for maximum engagement across the whole of the UK, reducing barriers with regards to location or geographical area. Collaboration with other agencies and stakeholders involved in service provision for babies, children and young people to share best practice e.g. platforms that have been used, initiatives that have been developed and user experiences of these positive and those suggesting areas of improvement.	
Allergy UK	Guideline	049	General	The recommendations aim to reduce variations in practice across the NHS which is all to common with regards to the postcode lottery concept.	Thank you for your comment. A primary aim of NICE guidelines is to reduce variations in practice across the NHS.
Allergy UK	Question 1	General	General	Resuming to ‘normal’ after COVID-19 and the restrictions this places on Health Care facilities. What roadmaps back to normal service provision will look like. A testimonial from a service user below provides an example of how the unforeseen consequences of the COVID-19 pandemic have impacted on families and children experiences of NHS services. Testimonial ‘Just wanted to say thank you to everyone at the charity who looked into our daughters current condition and offered such great support at such a stressful time. Due to covid and the pressures the NHS have been under we have not had the typical care and thorough assessment since this condition started in October. We are finally starting to get somewhere with it all. Hopefully the dermatology team will assess and determine whether or not allergy testing is the next step and the right ointments to relief her discomfort.	Thank you for your comment. We are interested to hear the impact that Covid-19 has had on NHS services for children and young people but hope that the recommendations in this guideline will help lead to a good healthcare experience.
Allergy UK	Question 2	General	General	The initial setup, training of staff, resources, logistics, development of digital information, investment in IT and digital solutions to support new ways of working. Space and environmental adaptations.	Thank you for your comment. We will pass this consideration onto the NICE team who plan implementation support.
Allergy UK	Question 3	General	General	Having a tool kit to support services to develop and ensure there is consistency so there is not a postcode lottery on service provision and standards of care.	Thank you for your comment. We will pass this consideration onto the NICE team who plan implementation support.
Allergy UK	Question 4	General	General	The changing landscape of how healthcare has had to adapt to the pandemic restrictions	Thank you for your comment. We agree that the Covid-19 pandemic has changed the delivery of healthcare and that

					it would be appropriate to obtain views on this change from children and young people.
Association for Young People's Health (AYPH)	Guideline	General	General	It is noted that this guideline applies to the 0-17 age range and we welcome focus on ensuring that children and young people receive the best quality care from health services. However, the age banding excludes the experiences of all young people in these settings (a young person is defined as aged 10-25). We believe that all young people across all ages should be treated equally and with high-quality care as outlined in this guideline.	Thank you for your comment. This guideline covers children and young people until they reach the age of 18. The NICE guideline on patient experience in adult NHS services (CG138) and the NICE guideline on service user experience in adult mental health (CG136) covers those aged 18 years and above. We appreciate that a young person can be defined as someone aged up to 25 years, but it would be confusing to have overlap between guidelines so a cut-off age of up to18 years was agreed at the scoping stage for this guideline.
Association for Young People's Health (AYPH)	Guideline	General	General	The draft guideline does not reference that young people can attend consultations alongside their friends – suggest this is included.	Thank you for your comment. In the recommendations on support from parents or carers we have added in the suggestion that support can be provided by other family members and that young people can be supported by friends or partners instead.
Association for Young People's Health (AYPH)	Guideline	010	015-027	Suggest including guidance on how to include and involve parents/carers, peers or another trusted adult in scenarios where communication with the child or young person is hard. Parents/carers and peers can provide support for a child or young person who is scared or not engaging with the healthcare professional, though this should not detract from the intention to provide youth-centric care. Children and young people may be more likely to feel safe if their parents/carers or peers feel safe in the healthcare environment too.	Thank you for your comment. The recommendations on what to do if communication difficulties are encountered already include the advice to involve another person and so we have expanded this to give the example of a trusted adult. Children and young people will always have the opportunity to involve their parents or carers in discussions if they wish to, as described in the section on involvement of parents or carers, so we have not included this in this recommendation.
Association for Young People's Health (AYPH)	Guideline	011	023	Suggest adding 'and who else will be involved in the delivery of their care'.	Thank you for your comment. We have amended this recommendation to include details of who will be providing their healthcare.
Association for Young People's Health (AYPH)	Guideline	012	006	Not all children and young people can access digital tools and apps. Other means should also be available. Engagement with young people has found that not all young people have access to devices, phone credit or privacy / safe spaces to access care digitally. During Covid-19, there have been barriers to young people accessing primary care through digital routes (for example, e-consult originally did not let	Thank you for your comment. We appreciate that there may be digital inequalities and have addressed this be adding additional over-arching recommendations to the beginning of the guideline to emphasise that assumptions should not be made about digital access and that alternatives should always be considered if necessary. We also recognise the concerns about possible lack of privacy

				young people request a GP consultation without parental consent, though this has since been reviewed). The UN Convention on the Rights of Child clearly articulate young people's right to accessing health services independently. There is a risk that if young people are unable to access services digitally, then there will likely be delays to care, their health needs may deteriorate and they may be less likely to access services in the future. Furthermore, digital exclusion may exacerbate existing health inequalities.	and we have now also included an additional recommendation in the privacy and confidentiality section of the guideline on ensuring privacy and confidentiality in virtual consultations.
Association for Young People's Health (AYPH)	Guideline	012	006	Any digital tools and apps should be age / developmentally appropriate and designed from the outset with children and young people in mind.	Thank you for your comment. We have an over-arching recommendation that advises that all methods of communication and information should be age and developmentally appropriate, so we have not repeated this again here. We also have a later recommendation in this section that advises that digital (or written) information should be designed in partnership with children and young people, and should be engaging.
Association for Young People's Health (AYPH)	Guideline	013	024	Suggest including information on who young people can discuss their concerns with if they are unsure about information and ways to help them to be more confident in accessing and understanding credible information.	Thank you for your comment. We have added a recommendation to support children and young people to identify reliable sources of information, and to check information with their healthcare professional.
Association for Young People's Health (AYPH)	Guideline	017	016	Suggest changing 'parents and carers' to 'parents or carers'.	Thank you for your comment. We have made this change to 'or' as you suggested.
Association for Young People's Health (AYPH)	Guideline	017	018	Children and young people should be fully supported to be involved in making decisions about their care, including their consent to treatment, when this is age and developmentally appropriate. Suggest that the best practice should link to use of Gillick / Fraser competence, as there is currently a lack of consistency within practice about how to assess and apply these guidelines.	Thank you for your comment. We have now included an additional over-arching recommendation at the beginning of the guideline on competence that clarifies that young people 16 years or older can consent, and that those younger than this can consent if they are deemed to be competent by the healthcare professional.
Association for Young People's Health (AYPH)	Guideline	018	001	The glossary section explains that consent can be verbal or written. Suggest including this within the main body of the text here for clarity.	Thank you for your comment. The committee did not think it was necessary to make this heading more detailed and so did not make this change.
Association for Young People's Health (AYPH)	Guideline	018	013	More information on managing disagreement / conflict between professionals and parents / carers can be found at: https://adc.bmj.com/content/104/5/413	Thank you for your comment. The committee discussed this and it was agreed that it would not be appropriate to link to a single consensus paper, which would not have met the protocol criteria for inclusion in this review..

Association for Young People's Health (AYPH)	Guideline	021	006	Typo – additional comma at the end of the sentence.	Thank you for your comment. We have removed this comma.
Association for Young People's Health (AYPH)	Guideline	026	015	Guidance on healthcare clothing and the use of masks is likely to have been updated under Covid-19 procedures.	Thank you for your comment. This guideline was developed during the Covid-19 pandemic so the recommendations on healthcare clothing took into consideration some of the lessons learnt during the pandemic and where it may impact on experiences of healthcare.
Association for Young People's Health (AYPH)	Guideline	027	003	Children and young people from "under represented groups" are identified as "for example, black, Asian and minority ethnic groups, people with learning disabilities, people from a disadvantaged background, LGBT+ people, people who have not been able to, or have chosen not to, use the service before" Suggest consider also including: homeless young people, Looked After Children / children in care, care leavers, children in institutional care / the justice system, migrant / asylum seeking / refugee young people, young parents, young people affected by sexual violence. Suggest also that there is a recommendation / guidance for health professionals to be alert to health inequalities in all aspects of their care.	Thank you for your comment. The committee wrote the guideline recommendations with the intention that they would apply to all children, and have highlighted in some recommendations (for example, 1.2.6, 1.5.6, 1.7.1, 1.7.6, 1.8.1, 1.10.7, 1.10.13) where they think special consideration needs to be given to certain groups of children and young people. The committee considered whether it was necessary to expand these groups but agreed that it would not be possible to list all potential groups and therefore it was preferable to cite the most common examples of groups who would need special consideration and this is not an exhaustive list.
Association for Young People's Health (AYPH)	Guideline	028	006	The healthcare environment should also support the child or young person's education needs if they need to continue studying.	Thank you for your comment. Education needs and studying are included in the section of the guideline on maintaining usual activities and we have added an additional recommendation about ensuring there is a suitable environment for studying.
Association for Young People's Health (AYPH)	Guideline	029	004	The healthcare environment should be "appropriate for their age and developmental stage". Suggest explicitly referring to the importance of youth friendly services. This should link to the Department of Health and Social Care's 'You're Welcome' standards provide quality criteria for young people friendly health services. AYPH were recently commissioned by PHE to refresh these standards, which are currently awaiting sign off from PHE / NHSE / DHSC. More information available at: https://www.gov.uk/government/publications/quality-criteria-for-young-people-friendly-health-services	Thank you for your comment. The committee were aware of and discussed the 'You're Welcome' standards during development of the guideline but there was no peer-reviewed publication about these standards that met the protocol criteria for inclusion in the evidence review. The recommendations on healthcare environment include the advice the environment should be designed and decorated in a suitable way for the intended age group, and this would include for young people. Thank you for sharing the BMJ link with us. The committee discussed this and it was

				More information on the evidence-base as to the value of providing youth friendly services is available at: https://adc.bmj.com/content/106/1/9	agreed that it would not be appropriate to link to a single consensus paper which would not have met the protocol criteria for inclusion in this review.
Association for Young People's Health (AYPH)	Guideline	032	027	Children and young requiring "additional support" are identified as "for example, looked after children, children in institutional care, care leavers" Suggest consider also including: homeless young people, care leavers, migrant / asylum seeking / refugee young people, young parents, black Asian and minority ethnic groups, people with learning disabilities, people with complex physical / mental health conditions, people from a disadvantaged backgrounds, young people affected by sexual violence, LGBT+ young people, people who have not been able to, or have chosen not to, use the service before. Suggest also that there is a recommendation / guidance for health professionals to be alert to health inequalities in all aspects of their care.	Thank you for your comment. These are some examples of groups of children and young people who may require additional support that had been identified in the evidence review. The committee were aware there would be other groups but this was not meant to be an exhaustive list, as trying to make it so may still likely lead to a group being missed out. As you suggested, we have added an additional recommendation at the beginning of the guideline to raise awareness of the adjustments that may need to be made to services in light of the Equality Act 2010.
Association for Young People's Health (AYPH)	Guideline	033	012	Consultation with young people during Covid-19 has uncovered that not all young people prefer the use of digital / virtual consultations. There are four key issues specific to young people's needs that need to be addressed before 'digital' becomes 'default': equality of access to services, protection of confidentiality, the quality of the consultation and ensuring adequate safeguarding. This is a particularly pertinent issue for certain groups of young people, our work on the We're All Right project highlighted specific concerns for young people affected by sexual violence. More information is available here: https://www.youngpeopleshealth.org.uk/digital-by-default-or-digital-divide-virtual-healthcare-consultations-with-young-people-10-25-years	Thank you for your comment and for sharing this work on digital consultations with us. We appreciate that there may be digital inequalities and have addressed this by adding additional over-arching recommendations to the beginning of the guideline to emphasise that assumptions should not be made about digital access and that alternatives should always be considered if necessary. We also recognise the concerns about possible lack of privacy and we have now included an additional recommendation in the privacy and confidentiality section of the guideline on ensuring privacy and confidentiality in virtual consultations.
Association for Young People's Health (AYPH)	Guideline	034	008	Children and young people requiring "additional support" during the continuation of care are identified as "for example, care leavers, homeless young people, children or young people with complex needs or disabilities"	Thank you for your comment. These are some examples of groups of children and young people who may require additional support that had been identified in the evidence review and is not intended to be an exhaustive list, but we have added children with learning disabilities and looked

				Suggest consider also including: people with learning disabilities, Looked After Children / children in care. Suggest also that there is a recommendation / guidance for health professionals to be alert to health inequalities in all aspects of their care.	after children. The committee were aware there might be other groups but agreed that to try and list them all may still likely lead to a group being missed out. As you suggest, we have added an additional recommendation at the beginning of the guideline to raise awareness of the adjustments that may need to be made to services in light of the Equality Act 2010.
Association for Young People's Health (AYPH)	Guideline	034	015	Digital health records – AYPH has previously conducted research for NHS England on the implementation of their digital strategy. Engagement with young people found that young people believe there is a lack of clarity and awareness about where healthcare information is stored and what is shared between healthcare professionals. 87% believed having access to their own medical record would be a good thing, but only 50% thought that their parents having the same level of access would be positive. Young people expressed concerns around information sharing that should be addressed prior to the sharing of information via digital health records. Notably: what information is shared with what professionals, whether the information is written in youth-friendly language, inappropriate sharing of information / leaking. There are specific concerns relating to privacy for specific groups of young people – for example, young people with HIV do not want all health professionals to be aware of their status if they are seeking medical opinion on an unrelated issue. Concerns around confidentiality are highest for health conditions or issues that may be stigmatised – for example, mental health, sexual health and gender identity. More information is available here: http://www.youngpeopleshealth.org.uk/wp-content/uploads/2016/05/NHS-digital-consultation-April-16-final.pdf	Thank you for your comment and for sharing the results of your work with us. The evidence included in the guideline identified these or similar concerns amongst children and young people. In order to prevent children and young people having to repeat their medical information unnecessarily, the committee were aware that health passports or digital health records could be useful.
Association for Young People's Health (AYPH)	Guideline	034	019	Suggest including a hyperlink to the Act.	Thank you for your comment. This hyperlink has been added.

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Association for Young People's Health (AYPH)	Guideline	036	007	Suggest that the recommendations for research encourages data on health outcomes to record age bands using the quinary age bands where possible, to align with ONS/WHO recommendations, and to capture developmental variation.	Thank you for your comment. We have added the use of ONS/WHO age bands as a suggestion in each of the quantitative research recommendations that the committee has made (in the full evidence reports).
Association for Young People's Health (AYPH)	Guideline	048	021	Typo – full stop missing from the end of the sentence.	Thank you for your comment. We have added this full stop.
Association of Paediatric Emergency Medicine	Guideline	002	NA	In "what settings does this apply to?" we would suggest Emergency Department be added	Thank you for your comment. We have added emergency care to the settings listed, to encompass emergency departments and the ambulance service.
Association of Paediatric Emergency Medicine	Guideline	007	008	We wonder if the Royal College of Paediatrics and Child Health child protection portal should also be referenced RCPCH Child Protection Portal – Child protection and safeguarding in the UK: your essential resource to help inform clinical practice, child protection procedures, and professional and expert opinion in the legal system	Thank you for your comment. The committee discussed whether it would be appropriate to add a link to this document but agreed that the recommendation already states that national and local safeguarding policies and professional guidelines should be adhered to, and it was therefore not appropriate to link to a specific organisation's resource.
Association of Paediatric Emergency Medicine	Guideline	011	008 - 010	We wondered if there could be some clarity on what is meant by "should have skills and competencies in relevant communication skills"	Thank you for your comment. It is not within the remit of NICE guidelines to recommend specific training, although the committee discussed whether any particular standard or level could be defined but agreed this may vary for different groups of staff.
Association of Paediatric Emergency Medicine	Guideline	011	004	A pain response may also be reflected in the absence of movement of the affected part, or to move it in an abnormal manner to avoid pain.	Thank you for your comment. We have amended this recommendation to include physical cues indicating pain as well as behavioural clues.
Association of Paediatric Emergency Medicine	Guideline	016	012	Will guidance be included to help healthcare professions make informed decisions about when they take the lead from the child and when they take the lead from the parent/ carer in respect to how much information it is appropriate to give a child?	Thank you for your comment. The recommendations advise that the child or young person should lead on how much information they wish to know. However, we have amended the recommendations to make it clear that when children or young people are providing informed consent there is a requirement to provide them with information on risks and benefits.
Association of Paediatric Emergency Medicine	Guideline	019	015 - 018	We feel that there should be some reference to ages of children, or at least competence of children to be able to have consultations without parents.	Thank you for your comment. There was evidence that sometimes even children as young as 7 may want to see a healthcare professional by themselves. However, this is a very personal decision and will vary from child to child and

					situation to situation, so it was not possible to set a defined age limit. The section of the guideline on the involvement of parents or carers provides advice on how this should be discussed with individual children and young people.
Association of Paediatric Emergency Medicine	Guideline	021	007	Would this be the right place to confirm how the child/ young person would like to be addressed? Or should it go with their preferred method of communication?	Thank you for your comment. We have included recommendations on finding out how a child or young person would like to be addressed in the recommendations on communication.
Association of Paediatric Emergency Medicine	Guideline	026	015	We feel that this is something which has become an increasing issue with COVID and the need for masks. We do have a duty to support children who lip read. Staff must also be sympathetic to carers not wearing masks, if there is a need to improve communication with children.	Thank you for your comment and your support for this recommendation, which raises awareness of the issues caused by PPE and in particular masks.
Association of Paediatric Emergency Medicine	Guideline	029	006	The current healthcare environment may be affected by COVID-19 adjustments such as one parent and restricted visiting	Thank you for your comment. The guideline was developed during the Covid-19 pandemic but the committee agreed that the recommendations should reflect care in a non-pandemic situation and so did not make Covid-19 specific recommendations relating to restricted visiting.
Association of Paediatric Emergency Medicine	Guideline	032	012 - 014	As above, we feel that some guidance on age or level of competence for making these decisions should be referenced.	Thank you for your comment. We have added an additional recommendation on assessment of competence in the over-arching principles section at the beginning of the guideline, which summarises the right of children of different ages to be involved in decisions about their healthcare without their parents and to give informed consent.
Association of Paediatric Emergency Medicine	Guideline	034	007 - 009	Children in care should also be included here	Thank you for your comment. We have included looked after children (children in care) in this recommendation as you suggest.
Bliss	Guideline	General	General	Bliss welcomes this guideline which champions the rights of babies, children and young people to have a positive experience across different healthcare settings. It is excellent to see a guideline which is so clearly child-centred and takes into account a broad range of issues which affect babies, children and young people who access healthcare services. However, as discussed in our response below there may be opportunities to ensure the needs of babies are more fully	Thank you for your comment and support of this guideline. We have not included a specific section on family-centred care or neonatal care in the guideline but have included recommendations on attendance at ward rounds, parents staying on wards with their babies and children and participating in their usual care and activities. Thank you for comments about the additional issues relating to COVID that have impacted on visitors to

				represented across the recommendations. In particular, a heavier focus on family centred care which champions family partnership in care and decision making could be more fully represented. This is a current national priority for neonatal services in England with the *Implementing the Recommendations of the Neonatal Critical Care Review* (2019) identifying the facilitation of family-centred and family-integrated care practices as an integral part of the review's recommendations. To facilitate this, Family Care-Coordinators are being recruited at Operational Delivery Network Level and services are encouraged to benchmark their practice against recognised audits such as the Bliss Baby Charter and UNICEF BFI. For babies and infants who receive care outside a neonatal setting it is important that these principles of family partnership in care delivery and decision making are also adopted. It is important to note that while this Guideline has been in development COVID-19 has had a significant impact on parental presence within neonatal units, and units continue to restrict parental access at the time of this consultation, with many unable to allow both parents to be with their baby together for any extended time, or for any time at all. Additionally, wider family members such as siblings and grandparents are also not able to be present on units currently. The committee should consider the timing of this publication and whether any additional recommendations can be made to reinforce the importance of parental presence to ensure babies have the best experience of healthcare, and the best outcomes as a result given that there may still be restrictions in place when this is published. Refs: NHS England (2019), Implementing the Recommendations of the Neonatal Critical Care Review Bliss (2021), Bliss Position Statement on Parent Access and Involvement During COVID-19	neonatal units. The recommendations on environment and usual activities already specify, as mentioned above, that babies, children and young people can have parents staying with them, and should be able to maintain other family and social networks. In order to make the guideline future-proof we have not made specific recommendations relating to this in a pandemic, but anticipate that implementation of the recommendations will support family-centred care in the future.

Bliss	Guideline	014 - 015	004 - 023	While it is welcome that recommendation 1.3.4 references that the principles outlined in 1.3.1-1.3.3 should be followed for parents and carers of babies, we would suggest adding ‘’and parents and carers of babies and young children’’ into recommendations 1.3.1-1.3.3 to ensure their role in decision making is given equal weight and does not got overlooked when these recommendations are being applied in practice (e.g. amend 1.3.3 to say ‘’when discussing and making decisions about treatment options with children and young people, or parents and carers of babies and young children’’. 1.3.4 - this recommendation is welcome, but Bliss would suggest this is strengthened further: ‘’Parents and carers of babies and young children are supported to be fully involved in discussions about their baby or young child’s care and are supported to be partners in decision making (for example, for inpatient care, by allowing parents to be present during ward rounds and supporting them to be actively involved in ward round discussions) Bliss (2020) Bliss Baby Charter: Helping to make family-centred care a reality on your neonatal unit, Principle 2.1H	Thank you for your comment. The committee discussed whether to include 'parents or carers of babies and young children' in all the recommendations in this section, but agreed that many of the recommendations were specific to children or young people (for example, including them in decisions where there is no impact on health outcomes, the option to have help from parents or carers, using descriptions of treatment that could be understood by the child). However, the committee agreed that the principles of these recommendations were applicable to the parents or carers of babies and young children and so it would be clearer to state this in a separate recommendation. Recommendation 1.3.4 uses the active verb 'involve in discussions and decisions' and we think this is clearer than using the word 'support' which is open to more interpretation.
Bliss	Guideline	019 - 020	011 - 021	Bliss would strongly recommend a standalone recommendation is included in this section to state that parents and carers of babies must be involved in their baby’s care and decision making, and to recognise that parents and carers are their baby’s principal caregiver and advocate.	Thank you for your comment. We have added another recommendation at the beginning of this section on the involvement of parents or carers as you suggest to state this.
Bliss	Guideline	027 - 028	022 - 007	This recommendation is excellent. Bliss would suggest that the recommendation ‘’actively seek out feedback from children and young people from under-represented groups’’ is extended to include ‘’actively seek out feedback from children and young people, and parents and carers of babies, from under-represented groups.	Thank you for your comment. We have amended these recommendations to include parents and carers as you suggest.
Bliss	Guideline	009 - 010	024 - 004	Suggest amending this recommendation to include reference to the preferred communication method of parents or carers of babies. For babies to have the best experience of healthcare	Thank you for your comment. We have added additional recommendation to include the preferred communication methods and needs of parents or carers as well.

				their parents need to be supported to be fully involved in care and decision making, which relies on clear communication. It's important to consider the communication needs of parents and carers in this instance, including the need for translators, easy-read information and other accessible communication measures that are listed here. It's also important to note that in the context of COVID-19 the ability to ensure parents and carers are fully informed and involved in their baby's care and decision making has been disrupted due to COVID-19 parental access restrictions. A Bliss survey of more than 500 parent experiences (due to publish later in April 2021) has found that parents have found policies where parents are not able to be on the unit together very difficult, with one theme emerging being that the parent on the unit is responsible for sharing complex information about their baby's condition to their partner who is at home. Parents noted that not only was this distressing, they also didn't fully understand what was happening with their baby. For babies, it is vital that *both* parents and carers are supported to be fully involved in their baby's care and decision making and need to be present for these discussions. It's also important to note that as a consequence of COVID-19, wearing face-coverings is common place on the neonatal unit which can be a barrier to communication, particularly for parents with communication needs (Bliss position statement on Parental access and involvement 2021 and BAPM COVID FAQs 2021)	Thank you for telling us how the COVID-19 pandemic has impacted on parents with babies on neonatal units (both in terms of access and the impact of face-masks). We appreciate that this has been a difficult time for parents in this situation, and our recommendations do state that parents and carers of babies and young children should be able to stay with their baby, be involved in ward rounds and be involved in discussions and decisions. However, it was not within the scope of this guideline to make pandemic-specific recommendations. However, we hope the recommendations will serve to improve family-centred care in the future.
Bliss	Guideline	007	010 - 012	Suggest amending this recommendation to reflect that for babies in particular communicating, sharing information and having discussions will be conducted with the baby's parents or carers. For parents and carers to be fully informed and to fully participate in care and decision and making it is equally important that information & discussions are tailored to their needs. It is important that staff can facilitate compassionate discussions which explain jargon and allow time for repetition and questions. It's also important that parents receive	Thank you for your comment. We have included the terminology 'parents or carers of babies and young children' throughout the recommendations on communication and information to emphasise the recognition of their involvement. We have also added an additional recommendation to recognise that the communication preferences and needs of parents or carers should be taken into consideration too.

				information in a format suited most to their needs, for example some parents may need access to translation services to fully engage in their baby's care.	
Bliss	Guideline	008	016 - 017	Suggest removing the brackets around ''and their parents or carers where appropriate''. For babies and infants their parents or carers are a core part of their care team and main advocate and need to have equal weight in this context. It may be worth considering separating some recommendations by 'babies' and 'children and young people' so the different approaches can be more clearly communicated in the guideline?	Thank you for your comment. We have removed the brackets as you suggest and used commas instead. The committee were careful to include parents or carers in recommendations where appropriate, and made some separate recommendations for the parents or carers of babies and young children where they agreed this was necessary, as you suggest.
Bliss	Guideline	009	001 - 003	Suggest separating this bullet point into two to more fully detail the parent or carer role in care and decision making for babies particularly babies who receive neonatal care: - Encouraging and supporting the parents and carers of babies to be partners in discussions and decision making about their babies care, and in care delivery. - Encouraging children, young people and the parents and carers of young children to contribute to and be active participants in discussions and decisions about their care. A family-centred care approach on neonatal units which facilitates parental partnership in care delivery and decision making should be adopted within neonatal settings, and there are national audits, such as the Bliss Baby Charter, and national drivers, such as through Workstream 10 of the Maternity Transformation Programme to improve implementation of this approach. Fully supporting parents to be involved in care and decision making supports the development of babies, promotes secure attachment and improves well-being among parents. Research references to support the positive benefits of parental involvement in neonatal care: O'Brien et al (2018) Effectiveness of Family Integrated Care in neonatal intensive care units on infant and parent outcomes: a multicentre, multinational, cluster-randomised controlled trial, Lancet Child Adolesc Health, 2(4):245-254;	Thank you for your comment. We think that combining the two groups into a single recommendation is less repetitive and does not change the meaning of the recommendation so we have not made this change. We checked the references provided to see if they were suitable for addition into the evidence reviews, but they did not meet our protocol criteria for the following reasons: O'Brien (2018) measured clinical healthcare outcomes rather than experience of healthcare; Pineda (2017) was conducted in the USA which in not included in our list of countries; Flacking (2012) is a narrative review. However, we do believe that active parental involvement within the NICU is adequately covered by recommendations 1.3.4, 1.8.2 and 1.9.7.

				Pineda et al (2017) Parent participation in the neonatal intensive care unit: Predictors and relationships to neurobehavior and developmental outcomes, Early Human Development, 117:32-38. Flacking et al (2012) Closeness and Separation in neonatal intensive care, Acta Paediatr, 101(10): 1032–1037	
Bliss	Guideline	009	009 - 011	Suggest amending this recommendation so it also includes babies, for example: When communicating with children and young people, **and the parents and carers of babies**, particularly those with ongoing health needs, develop an understanding of them as individuals, not only based on their health condition or diagnosis. To ensure babies have the best experience of healthcare they must also be treated as an individual and with dignity, as outlined in Principle 1 of the Bliss Baby Charter. Units can undertake a range of actions to do this including: referring to babies and their parents or carers by their given name, involving families in clothing choice, providing unrestricted access to the neonatal unit [to note: this has been significantly affected by COVID-19] and fostering an environment which responds to each individual babies' cues. Respecting the baby’s individuality (e.g. through using their name) is an important part of respectful care even when parents or carers aren’t present. Bliss (2020) Bliss Baby Charter: Helping to make family-centred care a reality on your neonatal unit	Thank you for your comment, we have amended this recommendation to include babies as you suggest, and have included examples such as the one you have given of using names. We have already included recommendations which support the family-centred care you describe in the sections on environment and usual activities.
Bliss	Guideline	010	018 - 024	Consider including here reference to managing a baby’s discomfort. Steps to mitigate this may include watching and responding to their cues, trying again at a different time, allow parents and carers, as well as staff themselves, to comfort hold and to soothe and reassure during uncomfortable procedures.	Thank you for your comment. An earlier recommendation in this section already refers to using positive touch or containment holding to reassure babies, and a later recommendation covers being alert to behavioural clues, so we have not added these to this recommendation as well.

Bliss	Guideline	011	004 - 007	It is welcome to see behavioural cues of babies, children and young people recognised in this guideline. Consider providing further detail about behavioural cues of babies, and particularly babies who are extremely premature. These babies may not express pain and discomfort in the same way as older gestation babies, or babies born at term. For example, they may not be able to cry to signal discomfort.	Thank you for your comment. We have amended the recommendation to include physical cues, which may indicate pain, as well as behavioural cues.
Bliss	Guideline	012	020 - 029	Suggest extending this recommendation so it applies also to parents and carers of babies.	Thank you for your comment. We have added parents or carers to this recommendation.
Bliss	Guideline	013	011 - 021	Across recommendations 1.2.22 & 1.2.23 amend them to include ‘’parents and carers of babies’’ as these echo best practice for information sharing and ensuring parents and carers are able to make decisions about their babies care and to be fully involved in care delivery (Bliss Baby Charter, Principle 2: Decision Making)	Thank you for your comment. The first of these recommendations already includes parents or carers and we have not added specifically 'of babies or young children' as this recommendation may apply to all parents or carers. We have not added parents or carers to the second of these recommendations as the focus of the guideline is on the healthcare experience of those under 18, not the experience of parents and carers. The committee spent time discussing which recommendations should include parents and carers, but this recommendation on emotional impact was based on evidence for children and young people only, and so the committee limited the advice to that population.
Bliss	Guideline	013	006 - 008	This is an excellent recommendation and we suggest it is made explicit that parents and carers of babies should be present and supported to participate in ward rounds as this practice is still not universal on neonatal units.	Thank you for your comment and for your support of this recommendation. There is already a recommendation in the section of the guideline on shared decision-making that advises that parents or carers of babies or young children should be able to participate in wards rounds, and so we have not repeated that here.
Bliss	Guideline	017	018 - 022	Consider adding the British Association of Perinatal Medicine (BAPM) Enhancing Shared Decision Making in Neonatal Care: A Framework for Practice (2019) to this list.	Thank you for your comment. The committee discussed this and it was agreed that it would not be appropriate to link to this framework from the guideline as it focusses on a specific population.
Bliss	Guideline	021	007	Suggest expanding recommendation 1.5.9 (or adding an additional recommendation) to detail how healthcare professionals can foster a positive relationship with babies to ensure they have the best experience of healthcare (particularly babies receiving neonatal care) by providing cue-	Thank you for your comment. The committee did not find evidence on the specific interventions you have identified such as cue-based care and developmental care and so were unable to make recommendations on this. These have been recommended in other NICE guidelines that were on specific aspects of neonatal care. The scope of

				based cares, modifying the environment (e.g. light and sound) and practicing developmental care. The ''Support from healthcare staff'' section may also benefit from a recommendation outlining the importance of staff building positive, supportive relationships with parents of babies (particularly babies receiving inpatient care, such as in a neonatal setting). Nurses, Doctors and Allied Health Professional staff all play a significant role in encouraging and empowering parents and carers to be partners in care delivery and decision making for their baby.	the guideline was on the healthcare experience of babies, children and young people, and not on the experiences of parents and carers. The committee agreed that it was a difficult distinction between supporting the parents or carers of babies to improve the babies' healthcare experience and recommendations that were directly supporting the healthcare experience of the parents themselves. Throughout the guideline the committee included 'parents or carers of babies and young children' in recommendations where they agreed it was appropriate.
Bliss	Guideline	022	003	The ''Self-advocacy'' section may also benefit from a standalone recommendation recognising the importance role parents and carers play in advocating for their baby and that they too should be supported and encouraged to have views and opinions about their baby's care.	Thank you for your comment. As babies and young children are, by definition, unable to self-advocate for themselves the committee agreed that the focus of this section should be on children and young people only, and that it was not necessary to state that babies and young children would require their parents or carers to advocate for them. However, a recommendation stating this has been added to the beginning of the section on Involvement of parents and carers.
Bliss	Guideline	026	015 - 019	It's important to recognise that due to COVID-19 masks and other PPE are now routinely worn within hospital settings, with many neonatal units also requiring parents to wear masks at all times. Bliss' survey of more than 500 parents (due to publish later in April 2021) has found that parents and carers feel: wearing masks a barrier to caregiving to their baby (particularly during feeding), that they are disruptive to caregiving which can be distressing (e.g. not being able to kiss their baby) and that they have concerns about the impact on bonding and development. These concerns are also reflected in guidance which encourages neonatal units to support parents to remove their masks when cotside with their baby or engaging in skin-to-skin care (BAPM COVID FAQS (2021) Bliss Position Statement on Parental Access and Involvement During COVID-19) These concerns have also been raised in published literature:	Thank you for your comment and for sharing the results of this work with us. We agree that the use of PPE has had an impact on communication and interactions in healthcare, and that this may include an impact on the bonding between a parent and a baby. We appreciate the references that you have highlighted. Unfortunately, neither are suitable for inclusion. Green (2021) is a discussion paper, and presents no original research. Muniraman (2020) includes a mixed population in their survey respondents, and data for parents (within protocol population) is not presented separately for analysis (as it is only in scope to include evidence of parents' views with children aged 5 or younger).

				The Implications of face masks for babies and families during the COVID-19 pandemic: A discussion paper (2021), Journal of Neonatal Nursing, Vol 27 Issue 1 Parental Perceptions of the impact of neonatal unit visitation policies during COVID-19 pandemic (2020) BMJ Paediatrics Open, Vol 4 Issue 1	
Bliss	Guideline	027	001 - 007	This recommendation is excellent. Bliss would suggest that the recommendation ‘’actively seek out children and young people from under-represented groups’’ is extended to include ‘’actively seek out children and young people, and parents and carers of babies, from under-represented groups.	Thank you for your comment. We have added 'parents or carers of babies or young children' to this recommendation as you suggest.
Bliss	Guideline	030	018 - 022	Suggest extending this recommendation to include that inpatient settings for babies have free internet access over wifi and that parents and carers of babies have access to this. Internet connection on neonatal units is patchy, however parents and carers often rely on online communications to access support and information.	Thank you for your comment. As with other areas of the guideline, the focus was on the healthcare experience of babies, children and young people and not parents or carers. The committee spent time discussing which recommendations should include parents and carers, but this recommendation on access to WiFi was based on evidence for children and young people only, and so the committee limited the advice to that population.
British Pregnancy Advisory Service	Guideline	General	General	Although the scope of the guideline includes young people up to age 18, the recommendations are focused almost exclusively on children and infants who are unable to consent to or direct their healthcare provision. As an abortion provider, we treat thousands of young people under the age of 18 a year who are competent to give consent to care, some of whom have parents who disagree with their decision to access abortion care. The perspective of competent young people seems to be neglected in the guideline, and risks treating all people under the age of 18 as unable to direct their care and make clinical decisions – despite the statutory presumption of competence for medical care being at 16, and the routine use of Gillick competence/Fraser Guidelines. We hope that the Committee could revisit the full guideline and make additions to recognise the differing powers of competent young people, and their relationship to care and care providers – as well as the importance of Montgomery-compliant informed consent which means that competent young people are not able to opt	Thank you for your comment. The section of the guideline on consent recommends that children and young people should be supported to make informed decisions about their healthcare, taking into account their capacity. This is reinforced in many other sections that encourage children to be involved in decision-making and to self-advocate. The guideline also recommends that healthcare professionals should make the children and young people the focus of discussions, offer to see them without their parents, and support them to make their own decisions. However, we have now also added an additional over-arching recommendation that clarifies that young people 16 years or older can consent if they have capacity, and that those younger than this can consent if they are deemed to be competent by the healthcare professional. We have also amended the recommendations on risks and benefits to clarify that children and young people may need to be informed of the risks for the purposes of obtaining informed consent.

				out of receiving information in the same way as younger children.	
British Pregnancy Advisory Service	Guideline	General	General	We hope the committee may consider including recommendations in the guideline about young people accessing care where they either have not informed their parents, or their parents are not supportive of or actively opposed to care. As an abortion provider, this is something we do encounter – and these young people have a very different set of needs to those who attend with supportive parents. This is not, however, only an issue in abortion care (although 7500 people under 18 access abortion care every year) – it also extends to sexual healthcare, contraception, and – increasingly – gender services. Although Fraser Guidelines include a requirement to encourage young people under 16 to inform and engage their parents, this is not the case for young people aged 16 and 17. We believe the guideline would be improved by including some specific recommendations for young people where they do not wish their parents/carers to be involved with or informed of their care.	Thank you for your comment. The section of the guideline on consent recommends that children and young people should be supported to make informed decisions about their healthcare, taking into account their capacity. This is reinforced in many other sections that encourage children to be involved in decision-making and to self-advocate. The guideline also recommends that healthcare professionals should make the children and young people the focus of discussions, offer to see them without their parents, and support them to make their own decisions. However, we have now also added an additional over-arching recommendation that clarifies that young people 16 years or older can consent, and that those younger than this can consent if they are deemed to be competent by the healthcare professional. The guideline is therefore clear that children and young people under the age of 16 who are deemed competent may see a healthcare professional on their own and without their parents' knowledge.
British Pregnancy Advisory Service	Guideline	007	009	The section on age and developmentally appropriate care would be improved by including a paragraph on Gillick competence and statutory presumption of ability to consent – that all young people 16 and over, and competent young people under the age of 16 are legally able to consent to care and that this should be recognised by staff and used as part of the care pathway for young people.	Thank you for your comment. We have added a new section to the over-arching principles section on competence, which outlines that children aged 16 or over can consent, and that those under 16 can consent if they are competent, as you have suggested.
British Pregnancy Advisory Service	Guideline	011	012	As per our general suggestion, this particular suggestion treats young people as if they are not making decisions about their own healthcare. Failing to provide some of the information in this list to the person consenting to care would be considered falling short of informed consent as laid out in Montgomery. We would suggest an additional recommendation on how best to provide information for competent young people where they do not have the ability to opt out of receiving information on their condition, treatment etc.	Thank you for your comment. We have not edited this recommendation in light of your comments as this list just provides a guide to the type of information that should be discussed. The details about the information to be supplied to obtain consent are included in the section of the guideline on consent. However, we have also edited the recommendations on risks and benefits to clarify that children and young people giving informed consent will need to be informed of the risks and benefits in enough

					detail to allow informed consent (as laid out in the Montgomery ruling).
British Pregnancy Advisory Service	Guideline	012	003	We support this recommendation and the aim to normalise a variety of different communication methods. As with many providers, during the pandemic we have shifted to telemedical provision of care, and it is our experience that many young people find telephone and video calls easier to engage with than face-to-face appointments in clinic settings.	Thank you for your comment. The committee agreed that the pandemic had increased the adoption of telephone and video consultations and that used appropriately these could improve the healthcare experience of children and young people, and they have been included as options in the recommendations
British Pregnancy Advisory Service	Guideline	012	012	We wholeheartedly support the ability of young people to access care without their parents or carers present. This forms a key part of the care we provide, to ensure that young people feel able to share their feelings without feeling under pressure.	Thank you for your comment and support of this recommendation.
British Pregnancy Advisory Service	Guideline	012	016	We support the ability of young people to determine if and what about their condition and care their parents and guardians are told	Thank you for your comment and for your support for this recommendation.
British Pregnancy Advisory Service	Guideline	013	022	We wholeheartedly support this recommendation – in the field of abortion care, misleading and non-evidence-based information is a serious issue that can damage clients' health.	Thank you for your comment and support of this recommendation.
British Pregnancy Advisory Service	Guideline	014	005	As per our general recommendation on competency, we suggest another recommendation that makes clear that those aged 16 and 17, and competent people under 16, not only have a right to be 'involved' in care, but to provide consent and make decisions about their own healthcare. This should recognise that they are not 'included in decisions' but legally able to make these decisions for themselves.	Thank you for your comment. The committee agreed that all children and young people should be involved in shared decision-making as much as possible, as defined in the recommendations made in this section of the guideline. We have also added a new section to the over-arching principles section on competence, which provides additional guidance on involvement in decision-making and consent for those aged 16 or over, or for those under 16 years.
British Pregnancy Advisory Service	Guideline	014	022	This recommendation must make clear that for those over the age of 16 and competent people under 16, only they are able to give consent and therefore they are not able to opt out of shared decision-making without posing serious risks to the principles of informed consent	Thank you for your comment. The provision of information to obtain informed consent is covered in the section of the guideline on consent. We have not amended this recommendation but instead have addressed your comment by amending the recommendations on risks and benefits to make it clear that children and young people giving informed consent must be informed of the risks and benefits.
British Pregnancy Advisory Service	Guideline	018	009	This recommendation needs to include a differentiation between competent young people and children and young	Thank you for your comment. We have added additional information into this recommendation to state that the

				people who are unable to provide consent – particularly with regard to the inclusion or relevance of the views of their parent or carer). The phrasing of this recommendation currently comes across as if the aim in a difference of opinion is to convince the child or young person that they should change their mind – rather than respecting their position. We would suggest including a recommendation on how to manage parents and carers of competent young people where views differ (bearing in mind the young person's views are the only ones that legally matter).	primary focus of the discussions should be on what is in the best interests of the baby, child or young person. We have also added a new recommendation in the over-arching principles section at the beginning of the guideline to clarify that young people aged 16 or over or under 16 but deemed competent can consent. However, there may still be situations where there is disagreement over decisions and where extra support will be required and this situation would still be covered by the advice in this recommendation.
British Pregnancy Advisory Service	Guideline	019	013	We support this provision.	Thank you for your comment and support for this recommendation.
British Pregnancy Advisory Service	Guideline	025	012	We wholeheartedly support this provision – recognising that particularly in relation to maternity care or hospital care for babies, bottle feeding facilities are sometimes unavailable.	Thank you for your comment and support for this recommendation.
British Pregnancy Advisory Service	Guideline	033	011	We wholeheartedly support this provision and hope it will be retained in full in the final guideline. During the pandemic our service has shifted to a primarily telemedical provision in the first instance, with in-person attendance being only clinically indicated or on request. This has enabled us to provide much more accessible and confidential care for young people who may otherwise have had to rely on parents, carers, or adult friends to attend care. There is a sizeable amount of evidence that where young people are unable to access abortion care, they may either opt to try and end their pregnancy alone outside formal healthcare (putting their own health at serious risk),or conceal their pregnancy until they ultimately deliver a child without medical intervention. It is our opinion that these instances are the worst possible outcomes for young people – and that they are easily addressed by improving the responsiveness of services in how we engage with young people and enable them to access care. Telephone and video calls are a fundamental part of how access can be improved – and essential to enable young people to exercise their rights to access healthcare.	Thank you for your comment, support of the recommendations on virtual consultations and for sharing how they have been successful. We agree that developments in this area were accelerated by the Covid-19 pandemic and that there may be many benefits relating to the use of virtual consultations.

British Psychological Society	Guideline	General	General	Could add discussion on what should happen if there is a disagreement between CYP/family and medical team.	Thank you for your comment. The guideline provides recommendations on what should happen if there is a disagreement in the section on consent.
British Psychological Society	Guideline	025	1.6/general	Could explicitly talk about attachment/psychological safety/psychological needs of the child and what considerations should be given There is no mention of trauma nor the need to understand the impact of past traumas (medical trauma and non-medical trauma) and how this can influence current presentation of child and parents/caregivers. It is essential to understand the context of presenting behaviours. There is limited mention of how to prevent trauma –e.g limited tries with IV insertion, blood draws etc but we welcome the references to psychoeducation and sharing of information plus checking understanding There should be reference to different types of development - emotional, physical, cognitive and what can impact on these (e.g. McCusker et al 2006) There is for also significant impact on maternal mental health of parenting a child with a life-limiting condition (e.g Fraser et al 2021) and on parents of children with congenital heart defects (Doherty et al 2009). This level of impact is avoidable with the right support (e.g. Doherty & McCusker 2016). McCusker, C.G., Doherty, N N Molloy, B., Casey, F., Rooney,N., Mulholland, C., Sands, A., Craig B., and Stewart, M. Determinants of neuropsychological and behavioural outcomes in early childhood survivors of congenital heart disease. Arch Dis Child. 2007 Feb; 92(2): 137–14 Fraser, L.K. , Murtagh, F.E.M, Aldrigo, J., Sheldon, T., Gilbody, S. & Hewitt, C. (2021) Health of mothers of children	Thank you for your comment. Recommendations have been crafted with psychological needs of babies, children and young people in mind where applicable. However, as the guideline is concerned with the overall healthcare experiences of children, specific psychological interventions to decrease trauma were outside the scope of this guideline. Similarly, while we appreciate that parental mental health is an important area of concern, this is also out of scope for this guideline. Thank you for providing the references, which we have checked and found that none of them meet our protocol criteria for inclusion: McCusker (2007) does not relate to babies, children or young people's experience of healthcare; Fraser (2021) only measures outcomes relating to maternal mental health; Doherty (2009) only measures outcomes relating to parental mental health; Doherty & McCusker is a book chapter (2016).

				with a life-limiting condition: a comparative cohort study. *Archives of Disease in Children Epub ahead of print. March 2nd* 2021. DOI:10.1136/archdischild-2020-32065 Doherty, N. N., McCusker, C.G., Molloy, B., Mulholland, H. C., Rooney, N., Craig, B., Sands, A., Stewart, M. & Casey, F. (2009). Predictors of psychological functioning in mothers and fathers of infants born with severe congenital heart disease. *Journal of Reproductive and Infant Psychology, 27(4)*, 390-400. Doherty,N.N**.** & McCusker, C.G. 'The Congenital Heart Disease Intervention Programme & Interventions in Infancy' Chapter *in Congenital Heart Disease and Neurodevelopment, 1st edition*. Edited by Christopher McCusker and Frank Casey Elsevier 2016	
British Psychological Society	Guideline	005	4-5	We believe that parents should be involved in the guideline to represent the children who may have been too young (e.g. babies) at the point of care. It is a strength of the document to have CYP views at the forefront.	Thank you for your comment. As well as involving children and young people in the development of the guideline there were lay parent members on the committee with experience of children with neonatal and childhood healthcare needs. The evidence reviews also included parental views of healthcare experience for babies and children under 5.
British Psychological Society	Guideline	005	Section: Context	There could be more focus on the rationale behind why improving experiences is important. On a general level, it is of course essential to ensure services meet the needs of the CYP and that a positive experience is received. It could highlight that there is a raft of evidence to support this actually being a core component of adjustment to condition, and health-related behaviours such as adherence. So a positive experience can have wide reaching impacts on physical and psychological outcomes for that child, which will in the long term potentially reduce healthcare usage and health-related complications. Could link here to the Faculty Review 2015 what good looks like doc – physical health paper	Thank you for your comment. We appreciate that improving healthcare experience may have the added advantage of improving physical and mental health, but it was not within the scope of this guideline to include health-related outcomes and so no evidence for such outcomes was reviewed as part of the guideline development process, and so this has not been included in the context section.

British Psychological Society	Guideline	007	1.1.2	Clinicians are rarely given ongoing training on adapting communication for developmental stage. This is a significant area of need to ensure that communication is appropriate	Thank you for your comment and for highlighting this potential training need. It is outside the scope of NICE guidelines to make specific recommendations on training that may be necessary to assist implementation and training is the responsibility of the employing NHS organisations.
British Psychological Society	Guideline	007	1.1.3	This is a key point. Many young people may choose not to receive information about their healthcare, or want to limit information. So it is essential that this is a collaborative discussion	Thank you for your comment and support for this recommendation.
British Psychological Society	Guideline	011	1.2.14	What are the skills and competencies and how will they be measured? Ref: 'What good looks like in psychological services for children, young people and their families?' The Child & Family Clinical Psychology Review (3) 2015	Thank you for your comment. It is not within the remit of NICE guidelines to recommend specific training, although the committee discussed whether any particular standard or level could be defined but agreed this may vary for different groups of staff.
British Psychological Society	Guideline	013	1.2.21	Place is important – many rooms are unsuitable for disseminating health-related information but owing to space demands (especially due to the pandemic) are used – environment is key in disseminating news, especially "bad news". Could also comment on information giving via remote means	Thank you for your comment. Privacy and confidentiality for discussions is already covered in two sections of the guideline: in the section on privacy and confidentiality and in the section on environment, so we have not repeated it again here. The provision of information via remote means is covered in an earlier recommendation about using preferred methods to provide information, but we have added an additional recommendation to the section on privacy and confidentiality to reinforce the privacy issue that may arise with virtual consultations.
British Psychological Society	Guideline		Section 1.2	These recommendations in section 1.2 are positive but it needs to be made clear how will training be provided and how needs will be met.	Thank you for your comment and your support for the recommendations in section 1.2. We appreciate that there may be training needs arising from recommendations and have advised this in the final recommendation. However, training is the responsibility of the employing NHS organisations and so the details of training are not included in NICE guidelines.

Babies, children and young people's experience of healthcare

Consultation on draft guideline - Stakeholder comments table
05 March 2021 - 16 April 2021

British Psychological Society	Guideline	019	1.4.11	Should add in "within the limits of confidentiality as explained to the CYP"	Thank you for your comment. The following recommendation (now number 1.4.14) includes explaining to the child or young person when confidentiality may need to be broken.
British Psychological Society	Guideline	019	1.5.1	Need more to support parents being seen as advocates for their babies. Need to enable them as active care partners not the parent/child system as passive recipients of care. One cannot be separated from the other. There can be significant impact on parental health and wellbeing (Doherty & Utens 2016). Pscyhological support for parents, babies and children should always be considerd Doherty N.N. & Utens, E. 'A Family Affair', Chapter in Congenital Heart Disease and Neurodevelopment, 1st edition. Edited by Christopher McCusker and Frank Casey Elsevier 2016	Thank you for your comment. The scope of this guideline is on the healthcare experience of babies, children and young people, and recommendations on advocacy were developed using evidence on how children and young people would like their parents or carers to advocate for them. Although views of parents and carers were taken into consideration, making recommendations to improve parents' or carers' healthcare experiences or outcomes by providing psychological support is not within the guideline scope.
British Psychological Society	Guideline	025	1.6.1	Food – need consideration of parents too especially breast feeding mothers. Also consider available accommodation and beds for parents	Thank you for your comment. The recommendation already includes advice to ensure that facilities are available for breast and bottle-fed babies. There are recommendations in the section of the guideline on the healthcare environment about facilities for parents to stay and sleep in the hospital with their baby or child.
British Psychological Society	Guideline	025	1.6.2	Don't say won't hurt. We can never anticipate how anyone else will experience pain. There needs to be greater education of the factors that can increase perception of pain and management of anxiety (within whole system – parent's child and healthcare professional). Also need specific mention of the factors that can help babies especially parental involvement including holding and skin to skin. Parents are most effective pain relievers during procedures. See 'Be Sweet to Babies' @kidsinpain https://itdoesnthavetohurt.ca/ Chambers, C.T., Dol, J., Parker, J.A., Caes, L., Birnie, K.A., Taddio, A., Campbell-Yeo, M., Halperin, S.A., & Langille, J.	Thank you for your comment. The guideline makes recommendations on upholding and believing a baby, child or young person's experiences of pain and we have edited these to make it clear that healthcare professionals should believe experiences of pain and avoid language that minimises pain. It was not within the scope of the guideline to consider specific clinical conditions and so the committee agreed that information on methods of pain relief was out of scope for this guideline. Thank you for sharing the Chambers et al. references. However, as per the population stated in our protocols, the study is not suitable for inclusion because it includes only parent and healthcare professional opinions. Where parent views are presented, there is no separation of views of parents of

				(2020). Implementation effectiveness of a parent-directed YouTube video (“It Doesn’t Have To Hurt”) on evidence-based strategies to manage needle pain: Descriptive survey study. *JMIR Pediatrics and Parenting, 3*(1), e13552. doi:10.2196/13552 Chambers, C.T. (2018). From evidence to influence: Dissemination and implementation of scientific knowledge for improved pain research and management. *PAIN, 159*(Suppl. 1), S56-S64. doi: 10.1097/j.pain.0000000000001327	children under 5 years old (in scope for this guideline’s population) and views of parents of children over 5 years old (outside scope for this guideline’s population).
British Psychological Society	Guideline	030	1.9.3	For babies the means active parental involvement. See FICare model and family centred care Franck, L.S., Waddington , C., O'Brien, K. (2020) - Family Integrated Care for Preterm Infants Crit Care Nurs Clin North Am . 2020 Jun;32(2):149-165 Church, PT., Grunau, RE., Mirea, L., Petrie, J. (2020) Family Integrated Care: FiCAre. The positive impact on behavioural outcomes at 18 mths. Early Human Development 151 (4) 105196	Thank you for your comment. We have included recommendations in the sections on environment and maintaining usual activities that relate to parents of babies being able to stay at the hospital with their baby, and to participate in their usual care, both of which are key components of family integrated care. Thank you for listing these references, which we have checked, and neither are suitable for inclusion as per our review protocol. Franck (2020) is a narrative review. Church (2020) reports only quantitative results and does not investigate any of the interventions noted in our quantitative evidence review.
British Society of Gastroenterology	Guideline	general	general	Most recommendations indicated that extra time is needed to deliver the guidelines. Within the current constraints on the health service guidance on duration of consultation should be offered as a minimum standard.	Thank you for your comment. The duration of a consultation will vary depending on local issues, the clinical situation and the purpose of the consultation so it is not possible for the committee to recommend a minimum standard time.
British Society of Gastroenterology	Guideline	012	003 - 010	Communication with careers and Children and young person younger than 16 will have different legal framework than with those older than 16. Can communication with a younger than 16 be done directly without involving parents?	Thank you for your comment. We have added an additional recommendation in the over-arching principles section at the beginning of the guideline, which summarises the right of children and young people to be involved in discussions and decisions about their healthcare without their parents, clarifies the role of competence and highlights the

					difference between those younger than 16 and those 16 or above.
British Society of Gastroenterology	Guideline	019	005	Same question with page 19	Thank you for your comment. We have added an additional recommendation in the over-arching principles section at the beginning of the guideline, which summarises the right of children and young people to be involved in discussions and decisions about their healthcare without their parents, clarifies the role of competence and highlights the difference between those younger than 16 and those 16 or above.
British Society of Gastroenterology	Rationale And Impact	038	004	It's unclear what tools/methods should be adopted to determine whether needs and preferences may have changed	Thank you for your comment. The committee did not suggest that a specific tool could be used to measure changes in needs and preferences, but that this would be determined by discussions with the child or young person.
British Society of Gastroenterology	Rationale And Impact	038	018	This recommendation needs to consider methods of communication during Covid or for remote consultations as will likely be the norm in the future.	Thank you for your comment. The guideline includes recommendations on the use of virtual consultations which have become used more frequently due to the pandemic.
British Society of Gastroenterology	Rationale And Impact	040	024	This recommendation will be a challenging change in practice because of limited time during busy clinics and should identify the HCP best suited to this process	Thank you for your comment. We appreciate that time in consultations may be limited. It was not possible in the recommendations to specify which healthcare professional should be involved in the shared decision-making process as this may vary between different settings, specialities and individuals.
British Society of Paediatric Dentistry	Guideline	006	016	Attendance at a dentist should not be occasional. Please reword to emphasise that CYP should be accessing dental care regularly as soon as their first tooth comes through, or by their first birthday. Please see www.dentalcheckbyone.co.uk.	Thank you for your comment. We have amended this text to remove the word occasional.
British Society of Paediatric Dentistry	Guideline	009	028	Please use the term "reasonable adjustments" here and expand this section to include specific mention of CYP with learning disabilities and/or autism.	Thank you for your comment. We have not included the use of the term reasonable adjustments here, as we have included a new over-arching recommendation at the beginning of the guideline, which provided guidance on the

					use of reasonable adjustments where necessary in accordance with the requirements of the Equality Act 2010.
British Society of Paediatric Dentistry	Guideline	017	020	Please include reference to the General Dental Council's guidance on consent.	Thank you for your comment. We have now included a link to this document.
British Society of Paediatric Dentistry	Guideline	026	015	Mention of social stories might be useful here. We have received very positive feedback for our social stories available here: https://www.bspd.co.uk/Professionals/Resources/COVID-19/COVID-19-Dental-Resources-for-Children	Thank you for your comment and telling us about this resource. We will pass this information onto the NICE team who plan implementation support.
British Society of Paediatric Dentistry	Guideline	027	001	There needs to be greater emphasis on the health inequalities agenda throughout this document – equitable access, excellent experience and optimal outcomes.	Thank you for your comment. The committee wrote the guideline recommendations with the intention that they would apply to all babies, children and young people, and have highlighted in some recommendations (for example, 1.2.6, 1.5.6, 1.7.1, 1.7.6, 1.8.1, 1.10.7, 1.10.13) where they think special consideration needs to be given to certain groups of children and young people to address health inequalities. The committee considered whether it was necessary to expand these groups but agreed that it would not be possible to list all potential groups and therefore it was preferable to cite the most common examples of groups who would need special consideration, and this is not an exhaustive list.
British Society of Paediatric Dentistry	Guideline	033	008	Another example is including oral health clinics at Health Visitor baby weighing sessions, or where possible training for the Health Visitors to 'Lift the Lip', or at best engage with dental care professionals (dental nurse with enhanced skills, hygienist or therapist to be available at baby-weighing sessions for an oral health check.	Thank you for your comment. This recommendation relates to healthcare services being co-located with non-healthcare services so that children and young people may find it easier to access them. This is not the same as offering one healthcare service at the same time as another healthcare service, for which we found no evidence that met our protocol criteria so we have not added this as an example. However, we agree that anything that could contribute to increasing uptake of oral health checks is a good idea.
Central London Community London Healthcare Trust	General	General	General	The overall theme throughout seems to be directed towards the acute and mental health services with little mention of children within the community setting with additional needs. Much of this was not as relevant to community children's	Thank you for your comment. The committee wrote the guideline recommendations to apply, unless otherwise stated, to all healthcare settings and we have now made this clear in the context section at the beginning of the guideline. We have amended some of the

				services. There was very little I terms of parents and children's views around support of health issues within the community	recommendations where we had specifically referred to 'hospital' to make it clearer that they apply to all healthcare settings. However, some of the recommendations do only relate to inpatient care and we have made this clear in the recommendations.
Central London Community London Healthcare Trust	General	General	General	There also needs to be more written as to how we can support staff in dealing with emotional support for a child that is dying are staff comfortable and competent dealing with this. There is much re training staff amid communicating skills to young children but the mental health services and play specialist, the question is are staff comfortable are the comfortable having those very serious conversations with a child re death and dying.	Thank you for your comment. End of life care was excluded from the guideline as this is covered by the separate NICE guideline on End of life care for infants, children and young people (NG61). However, to address your comment we have added a cross-reference and hyperlink to NG61 within the communication section of the guideline. In the recommendations on the emotional impact of information, we have also added further recommendations on the support that should be offered to children and young people. The guideline sets the standard for the healthcare experience that should be provided to children and young people but it is not within the remit of the guideline to make recommendations on the training that staff will need to deliver this experience.
Central London Community London Healthcare Trust	General	General	General	Parents and carers focussed in the paper however LAC children who supports them? This requires expansion in terms of who else can be included.	Thank you for your comment. The committee specifically discussed the needs of those without parents or carers to support them and we have made a recommendation (1.5.6) to ensure these children have alternative support. Looked after children will have a named social worker who will act in lieu of parents. We have also expanded the definition of parents and carers in the section 'Terms used in this guideline' to include those with responsibility for looked after children.
Central London Community London Healthcare Trust	General	General	General	Digital poverty and digital inequalities, does this paper really taken into consideration digital access for all children and those who are neuro diverse or disabled. Use of apps or on line facilities how can we assure that all children have access to digital support? What is the contingency plans for this	Thank you for your comment. We appreciate that there may be digital inequalities and have addressed this by adding additional over-arching recommendations to the beginning of the guideline to emphasise that assumptions should not be made about digital access and that alternatives should always be considered if necessary.
Central London Community London Healthcare Trust	General	General	General	Does this document take into consideration the variations of the population i.e. diversity such as children from working class backgrounds, children form non-white backgrounds, children who have experienced trauma owing to leaving a war torn	Thank you for your comment. The committee wrote the guideline recommendations to apply to all children, and have highlighted in some recommendations (for example, 1.2.6, 1.5.6, 1.7.1, 1.7.6, 1.8.1, 1.10.7, 1.10.13) where they

				environment and the level of support that the child would require	think special consideration needs to be given to certain groups of children and young people. The committee considered whether it was necessary to expand these groups but agreed that it would not be possible to list all potential groups and therefore it was preferable to cite the most common examples of groups who would need special consideration, but that this was not an exhaustive list.
Central London Community London Healthcare Trust	General	General	General	Overall a difficult document to navigate , when clicking on the links often times the link would take one back to the original document or the link would not work	Thank you for your comment. We are sorry that the hyperlinks to the full evidence reports did not work in the consultation version. The hyperlinks to the evidence reports will work in the final published version of the guideline.
Central London Community London Healthcare Trust	General	General	General	Do's and Don'ts and avoid jargon but yet raised points regarding including evidenced based info. Would a young child really understand or care about the evidenced based approach?	Thank you for your comment. The primary audience for the guideline is healthcare professionals and so the recommendation you refer to is to ensure that healthcare professionals provide information that is evidence-based. The committee also felt it was important for children and young people to understand when information is credible and a separate recommendation was made about that.
Central London Community London Healthcare Trust	General	General	General	Not clear in reality as to how some issues are managed	Thank you for your comment. We are not sure what issues this comment relates to so we are unable to respond.
Central London Community London Healthcare Trust	General	General	General	Emotional impact this should be in the leaflet rather than a discussion as a child will not open up initially however the leaflet can afford or assist I fostering a conversation emotional aspects of care required. This process needs authenticity	Thank you for your comment. This recommendation was to alert healthcare professionals that information may have an emotional impact so we do not think this could be addressed in a leaflet. However, we have expanded this recommendation to suggest ways in which children and young people can be supported to help them deal with this emotional impact. There is also another recommendation in this section of the guideline, which advises the use of written information to back up conversations, so leaflets may be provided to back up verbal information if appropriate.
Central London Community London Healthcare Trust	General	General	General	CONSENTING CHILDRNE AND YP this is quite a skill how do we get young people to consent how do we quality assure that their decisions are In their best interest, whilst involving the advocate and not the parents. How do we have those	Thank you for your comment. We think your comment relates to the use of independent advocates helping children to make decisions and consent. It is the responsibility of commissioners to ensure that trained advocates are used who would always be expected to

				conversations with parents regarding the child's rights in decision making.	exercise their professional judgement as to the course of action that was in the best interests of the child. We think the second part of your comment relates to the involvement of parents in decision-making and recommendation 1.5.5 advises that this should be discussed and agreed between the child or young person and their parent or carer.
Central London Community London Healthcare Trust	General	General	General	Whilst the document was generic maybe there needs to be more caveats or more different scenarios if possible	Thank you for your comment. As the guideline is intended to cover babies, children and young people in all healthcare settings it is generic, but the committee have included examples of specific situations or actions where they think this provides additional clarity to the recommendations.
Central London Community London Healthcare Trust	General	General	General	Independent advocates if a child cannot make a decision you would involve a independent advocate. What does it mean for the child to contact the advocate? Would a small chid or a timid teen want to reach out to the advocate. The responsibility should i.e. with the advocate to make initial contact. Will the advocates going to be matched re religion, culture, faith based preferences, age etc.	Thank you for your comment. The recommendations on the use of independent advocates for eligible children have been amended as eligible children or young people should be provided with an advocate and should not have to seek one out or contact them, so this part of the recommendation has been removed. The recommendations state that children can express a preference for an advocate of a particular gender, but it would be unlikely that in practice all eligible children could be provided with an advocate who matches them in religion, culture and faith. However, if children or young people feel they are unable to work with the advocate the recommendations state that they should be able to request a change of advocate.
Children's HIV Association	Guideline	General	General	Comprehensive guidelines with a clear emphasis on viewpoints, perspective of children and young people and easy to read. We are concerned that some recommendations and sentences that refer specifically to parent/carer of babies and young children may be misinterpreted in practice, potentially alienating parents/carers/guardians of older children and young people, with a risk of creating tension and challenges for healthcare professionals. Although we agree with the recommendations, we would suggest including a dedicated section on parents/guardians/ carers with recommendations on effective communication, engaging with parents/carers/guardians in supporting such	Thank you for your comment. NICE recognises that parents and carers have the right to be involved in planning and making decisions about their baby or child's health and care, and to be given information and support to enable them to do this, as set out in the NHS Constitution and summarised in NICE's information on making decisions about your care. This principle is stated at the front of the guideline. However, the scope for this guideline was to develop recommendations that would improve babies, children and young people's experience of healthcare. It was not within the scope to develop recommendations specifically to improve parents' and carers' experiences.

				recommendations, as well as including a sub-section on family-centred care (which is essential to a number of health conditions)	The committee recognised that for babies and young children it was necessary to apply recommendations to parents and carers, as they will act and make decisions on behalf of babies and young children. We have also added an additional recommendation 1.2.7 to recognise that parents and carers may have communication preferences or needs of their own. We have not included a specific section on family-centred care but have included recommendations on attendance at ward rounds, parents staying on wards with their children and participating in their usual care and activities.
Children's HIV Association	Guideline	011	016	We feel the issue of children's rights to health information could be strengthened. We would suggest stressing the fact that children & YP have the right to information about their health condition – perhaps by also considering referring to Gillick Competency	Thank you for your comment. We have added an additional recommendation in the over-arching principles section at the beginning of the guideline, which summarises the right of children and young people to be involved in decisions about their healthcare and to give informed consent if aged 16 or over or if assessed as Gillick competent.
Children's HIV Association	Guideline	013	023	We would suggest broadening access to inaccurate medical information with limited evidence bases beyond just online as some medical information may also be taught, explained by other individuals/professionals outside their level of expertise. It would therefore be good practice to check information with the healthcare team, should parents in general/children/young people think the information is inaccurate or out of date	Thank you for your comment. We have now included information obtained via social media as well as online, as the committee were aware that both these sources could host inaccurate information. We have also added a recommendation to support children and young people to identify reliable sources of information, and to check information with their healthcare professional.
Children's HIV Association	Guideline	014	007	We believe that respecting the Rights of children & YP to be involved in making decisions about their health care ensuring *early* involvement needs to be defined early in the guidelines and be more specific e.g. from diagnosis or in line with developmental capacities for diagnosis from birth	Thank you for your comment. We have added a new section to the over-arching principles section at the beginning of the guideline on competence which provides guidance on involvement in decision-making and consent for those aged 16 or over, or for those under 16 years.
Children's HIV Association	Guideline	016	023	We would suggest early identification of psycho-emotional concerns with appropriate referral to play-specialist, clinical psychologist for instance, for additional support in difficult situations e.g. end of life care, complex treatments or in children and young people where there are concerns about treatment management	Thank you for your comment. The recommendations advise that concerns should be addressed when discussing risks and benefits, but there was no evidence to suggest referral to a particular healthcare professional was required so we have been unable to add this to the recommendation. End of life care was excluded from the guideline as this is covered by the separate NICE guideline on End of life care for infants, children and young people (NG61).

Children's HIV Association	Guideline	018	009	We are concerned that mention of difference in opinions between parents and children and young peoples is limited We would suggest adding a general point about ensuring health care is centred around the best interests of the child principle. Whilst recognising the need for family-based care approaches, and the importance of involving families. However, if conflicting views present e.g. between parents/carers wishes and children and young people's rights /needs - the best interests of the child must be the guiding principle. Especially when relating to information provision which is ongoing in our work	Thank you for your comment. We have added additional information into this recommendation to state that the primary focus of the discussions should be on what is in the best interests of the baby, child or young person.
Children's HIV Association	Guideline	022	001	We would suggest including support from clinical psychologist based on needs of the babies/children/young people if services are available	Thank you for your comment. There was no evidence identified which fitted the protocol criteria that children's experience would be improved by access to a clinical psychologist so we have been unable to recommend this as one of the examples of sources of support.
Children's HIV Association	Guideline	022	020	Although mentioned throughout the guidelines, we would suggest emphasising the need to providing information to a child / young person in line with developmental capacities.	Thank you for your comment. We agree that information provided should be in-line with developmental capacity and so have included this in an over-arching recommendation at the beginning of the guideline, rather than repeating it in multiple recommendations.
Children's HIV Association	Guidelines	General	General	A 2020 survey to assess the provision and delivery of specialist HIV care during COVID-19 Pandemic and the UK Lockdown by the British HIV Association, the Children's HIV Association and Public Health England showed that the pandemic resulted in a significant change in the way consultations were delivered. There was a shift from almost entirely face-to-face appointments to mainly telephone consultations and less than half of the usual routine appointments were provided. There was a reduction in routine monitoring and blood tests, although prescription of medication continued as usual. Issues with remote consultations were frequent with reports of problems with NHS technology and patients having access and technical issues, a reduction in access to mental health services, psychology and support services was also widely reported. The BHIVA/CHIVA/PHE report is being finalised and will be published soon. We would be keen to submit this report and lessons learned to the NICE shared learning database	Thank you for your comment. As part of this consultation, we have received mixed views on the impact of the Covid-19 pandemic with some services reporting that the acceleration of virtual consultations has been beneficial. Thank you for offering to share your report and lessons learnt with NICE and we will pass this on to the NICE team responsible for implementation support.

Communication Matters	Evidence review C	general	general	No overt mention of issues where the child or young person is non verbal/uses AAC and may need communication support, which may then automatically be presumed to be provided by parent/carer. This has huge implications for confidentiality and privacy for the child or young person. This is the case whether or not they have a Learning Disability in addition to a significant physical communication impairment (ie with cerebral palsy) To quote	Thank you for your comment. We have added an additional recommendation in the section on privacy and confidentiality to address the fact that children and young people who have additional communication needs may need additional support to ensure they can have private conversations with healthcare professionals.
Communication Matters	Evidence review H	016	032 - 037	This section clearly outlines the problems that can be caused by “the over involvement of parents….” and re our comment 4, this issue must be addressed for non verbal young people if they are to have the same rights to privacy, confidentiality and self-advocacy as their speaking peers. Simply “identifying the preferred method of communication” does not adequately answer our concerns in these areas.	Thank you for your comment. We have added an additional recommendation in the section on privacy and confidentiality to address the fact that children and young people who have additional communication needs may need additional support to ensure they can have private conversations with healthcare professionals, and have cross-referenced to that recommendation from the section on self-advocacy.
Communication Matters	Guideline	general	general	We are concerned generally that whilst there is very occasional mention in passing (see comment 3 below) of the need to take into account the requirements of children who are non verbal and use alternative methods of communication (AAC), insufficient emphasis and/or explanation of how to mitigate this is provided. It is not nearly enough to simply say “ establish the child’s preferred method of communication” or “more time may be needed”. This is often a highly specialised area and in order for a non verbal child or young person to be able to communicate effectively in a healthcare situation much more support, and knowledge, will almost certainly be needed by the healthcare professional. An additional concern is how to manage “self advocacy” and “consent and confidentiality” where the parent may be being relied on to be the communication interpreter (see comments below)	Thank you for your comment. We have amended the recommendations on identifying preferred methods of communication to state that these methods should be used, and we have added that individuals with additional communication needs might need specialist support, as well as extra time. We have also added an additional recommendation into the section on privacy and confidentiality, and the section on independent advocates, to address how this should be provided for children with additional communication needs, and cross-referred to this from the section on self-advocacy.
Communication Matters	Guideline	008	018	First thing should be to introduce themselves, with full name and role.	Thank you for your comment. We have added this as you suggest.
Communication Matters	Guideline	022	008 – 009 - 010	“establishing the child or young person’s preferred method of communication, paying particular attention to those who do not	Thank you for your comment. We have added more detail into the recommendation in the section of the guideline on

				communicate verbally" It is not enough to "establish"...it must then be possible for the young person to be able to communicate, with assistance if necessary.	communication about establishing and using preferred methods of communication and the use of assistance for communication. We have included a cross-reference to that recommendation from here, instead of repeating the details here.
Faculty of Dental Surgery, Royal College of Surgeons of England	Appendices	general	general	The methodology described for inclusion of publications in the evidence reviews (A-P) indicate that some dental key words were included in the search strategies. However, with the exception of one paper (Marshman et al. Development and evaluation of a patient decision aid for young people and parents considering fixed orthodontic appliances..J Orthod. 2016 Dec;43(4):276-287) there was scant if any inclusion of evidence relating to children's oral/dental healthcare, including their experiences of sedation/general anaesthetic for dental procedure or experiences of children with developmental conditions such as cleft lip and palate. We are aware of several high quality and relevant dental publications which would have undoubtedly have supported the recommendations made. We would like assurances that the dental literature was appropriately reviewed in the development of the evidence for the guideline. Some references that would seem to fit the themes that immediately come to mind include the below, and thus it seems strange that they were not cited, even if they did not meet the subsequent quality criteria: Share Video diaries to capture children's participation in the dental GA pathway. Rodd HD, Hall M, Deery C, Gilchrist F, Gibson B, Marshman Z. Eur Arch Paediatr Dent. 2013 Oct;14(5):325-30. doi: 10.1007/s40368-013-0061-4. Epub 2013 Jun 20. PMID: 23784710 Share	Thank you for your comment. As outlined in the review protocols, studies that focus explicitly on a number of topics, such as oral health, rather than on the views on and experiences of babies, children and young people in healthcare have been excluded as NICE has already produced the 2015 NICE guideline oral health promotion: general dental practice (NG30). However, the dental literature was appropriately considered during the development of the guideline and included in all search strategies. Apart from the study by Marshman 2016, other studies, such as Dickson 2015 (PMID: 26368995) and Barber 2019 (PMID: 31060465) were included and taken into consideration when making recommendations. Furthermore, the Health and Social Care Information Centre. Children's Dental Health Survey 2013. (Country specific report for England, published 2015) has been included as part of the grey literature considered. The committee also included a dentist and lay members with experience of dental services. We have checked the references you have provided to ensure there is nothing we have missed that should have been included, however the studies were not eligible for inclusion as they focus explicitly on oral health rather than on the views and experiences of babies, children and young people in healthcare.

				Development of a decision aid for children faced with the decision to undergo dental treatment with sedation or general anaesthesia. Hulin J, Baker SR, Marshman Z, Albadri S, Rodd HD. Int J Paediatr Dent. 2017 Sep;27(5):344-355. doi: 10.1111/ipd.12267. Epub 2016 Sep 29. PMID: 27684707 Children's experiences of participation in the cleft lip and palate care pathway. Hall M, Gibson B, James A, Rodd HD. Int J Paediatr Dent. 2012 Nov;22(6):442-50. doi: 10.1111/j.1365-263X.2011.01214.x. Epub 2012 Jan 31. PMID: 22292535	
Faculty of Dental Surgery, Royal College of Surgeons of England	Guideline	general	general	The document strives to be comprehensive, but there is definitely a sense of repetition of themes throughout which are counterproductive to giving clear messages to the reader, and engender reader fatigue	Thank you for your comment. We placed some over-arching information to the beginning of the guideline so that common themes such as ensuring approaches are age and developmentally appropriate are not repeated in every recommendation. However, the committee also had to take into consideration that users may not read the guideline from start to finish and may only read specific sections, and so individual sections and recommendations needed to be comprehensive.
Faculty of Dental Surgery, Royal College of Surgeons of England	Guideline	006	016	We are concerned that the document infers that some children's experiences of healthcare recommendation may be limited to 'occasional visits to a dentist of GP.' Whilst this may be true of GP visits it is certainly not true of dental attendances. Children visit the dentist for REGULAR 6-monthly check ups with their family dentist from the age of one. We would request that this statement is rephrased to acknowledge that children and their families are encouraged to attend regular dental visits, not just when they have a problem. The same comment is made on the first page and it is erroneous.	Thank you for your comment. We have amended this text to remove the word occasional.

Faculty of Dental Surgery, Royal College of Surgeons of England	Guideline	031	021 - 022	The 2nd and 3rd bullet points are not grammatically matched with the stem statement and need rewording	Thank you for your comment. We have broken this list into 2 separate recommendations so that it is grammatically correct now.
Faculty of Dental Surgery, Royal College of Surgeons of England	Question 1	General	General	It will be very challenging to implement many of the recommendations relating to child information needs and shared decision-making. The recommendations are rightly under-pinned by involving children as co-creators but this approach has considerable cost, time and training/expertise implications. Development of high quality digital resources have cost implications.	Thank you for your comment. We will pass this consideration onto the NICE team who plan implementation support.
Faculty of Dental Surgery, Royal College of Surgeons of England	Question 2	General	General	As above It will be very challenging to implement many of the recommendations relating to child information needs and shared decision-making. The recommendations are rightly under-pinned by involving children as co-creators but this approach has considerable cost, time and training/expertise implications. Development of high quality digital resources have cost implications.	Thank you for your comment. We will pass this consideration onto the NICE team who plan implementation support.
Faculty of Dental Surgery, Royal College of Surgeons of England	Question 3	General	General	In terms of measuring children’s experiences, it would be helpful and efficient to have a central and generic measure, such as the NHS Children’s Friends and Family Test – rather than 100s of services all developing their own measures.	Thank you for your comment. The research recommendation made about measuring experience is an opportunity for a research project to systematically identify the best methods of measuring healthcare experience. As part of this guideline consultation exercise NHS England and NHS Improvement have shared details of work they are already carrying out in this area. The NHS Children’s Friends and Family Test is extrapolated from adult responses and therefore the committee agreed it may not represent the children and young person voice, and that mixed-methods research into what healthcare factors are

					important to children and young people was an important area to highlight.
Faculty of Dental Surgery, Royal College of Surgeons of England	Question 4	General	General	It might be useful to consider babies, children and young people's experiences of remote (tele) diagnosis in view of the need to rely more on this approach during the pandemic. Invaluable feedback may be now gained on this specific aspect.	Thank you for your comment. We agree that the Covid-19 pandemic has accelerated the adoption of virtual consultations and that it would be appropriate to obtain views on this change from children and young people.
Insight and Feedback team Experience, Participation and Equalities Nursing Directorate NHS England and NHS Improvement	EIA	1.1/ 1.2	002 - 003	In NHS England and NHS Improvement's view, the list of potential equality issues relating to babies, children and young people identified in section 1.1 of the Equality Impact Assessment is comprehensive. We also concur with the preliminary view of NICE's Committee expressed in section 1.2 that '…children who are migrants or whose first language is not English, or whose parents do not speak English may have difficulty accessing healthcare services and may require additional support and advocacy, and alternative methods and types of information and support.' In this context, it is significant that the qualitative research commissioned by the Insight and Feedback team at NHS England from Ipsos MORI to explore children and young people's experience of primary care and to understand more about the most effective methods of seeking feedback about those experiences from children and young people (October 2018) included additional in-depth interviews with children and young people who spoke English as a second language. These additional interviews were carried out to explore the views of a potentially under-represented group and to identify any issues which may affect them specifically. NHS England and NHS Improvement's new National Cancer Patient Experience Survey for under 16s in England will include provision for children and young people who do not speak English to complete the survey over the phone using a translation service.	Thank you for your comment and for informing us about the work on children and young people's experience of primary care and cancer care which has been undertaken or is planned. We are pleased to see this is in-line with the recommendations for measuring healthcare experience in the guideline which state that feedback should be actively sought from under-represented groups.
Insight and Feedback team	Guideline	008	021	The Insight and Feedback team at NHS England commissioned a qualitative research project from the market	Thank you for your comment and for sharing the results of these research projects with us. We have included many of

Experience, Participation and Equalities Nursing Directorate NHS England and NHS Improvement				research agency, Ipsos MORI to explore different options for the wording of the patient Friends and Family Test (FFT) question (February 2019). Quotas for cognitive testing of different question options included a small number of children aged between 7 and 11 and a small number of young people aged between 12 and 15. Results from the cognitive testing suggested that children and young people liked the inclusion of smiley face icons beside closed response scales and thought that this made questions clearer to them. The Insight and Feedback team also commissioned a qualitative research project from Ipsos MORI to explore children and young people's experience of primary care and to understand more about the most effective methods of seeking feedback about those experiences from children and young people (October 2018). The research included six focus groups with children and young people aged between 7 and 15. The groups were split into three age groups – 7-11, 11-13, 14-15. Children in the two younger age groups were assigned to mixed gender groups and in the older age group to single gender groups. The children and young people engaged in the research expressed a preference for providing feedback through paper questionnaires, a preference which Ipsos MORI said highlighted a confusion about how different methods of obtaining feedback work. Children and young people thought that online questionnaires were too restrictive, specifically because they were thought to impose word limits that would prevent children and young people from expressing their views fully. Paper questionnaires were considered more convenient to complete because they could be filled in at the time of primary care appointments and did not require internet access at a later stage. A minority view, expressed by some older children, was that online feedback would be aggregated with the consequence that the views of individual children and young people are lost. Children expressing this view believed that feedback given via paper questionnaires would not be	the options that you identified in these projects in the recommendations - for example using different methods of collecting feedback, at different times and ensuring it is age-appropriate. We hope your results can be published in peer-reviewed literature so that they can inform the wider NHS and be included in future guideline updates.

				aggregated and that individual responses would therefore be given more attention. The research was also consistent with the findings of the Friends and Family Test project in that children and young people thought that feedback methods used should be made as child friendly as possible through the use of elements of ‘gamification’ (the application of game-design elements and game principles to non-game contexts) such as the use of symbols like smiley and sad faces to indicate levels of agreement or disagreement with question statements.	
Insight and Feedback team Experience, Participation and Equalities Nursing Directorate NHS England and NHS Improvement	Guideline	010	019	The research commissioned by the Insight and Feedback team at NHS England from Ipsos MORI to explore children and young people’s experience of primary care and to understand more about the most effective methods of seeking feedback about those experiences from children and young people (October 2018) supports the NICE committee’s view that ‘Time taken to complete the survey was also considered an important outcome…’. Children and young people engaged in the Ipsos MORI research thought that the longer the survey was, the less likely children would be to complete it. Children and young people thought that long surveys reminded them of exams. The research included six focus groups with children and young people aged between 7 and 15. The groups were split into three age groups – 7-11, 11-13, 14-15. Children in the two younger age groups were allocated to mixed gender groups and in the older age group to single gender groups.	Thank you for your comment and for sharing the results of this research project with us. We are pleased that it reflects the evidence we identified and the recommendations the committee made. We hope it can be published in peer-reviewed literature so that they can inform the wider NHS.
Insight and Feedback team Experience, Participation and Equalities Nursing Directorate	Guideline	011	08	The research commissioned by the Insight and Feedback team at NHS England from Ipsos MORI to explore children and young people’s experience of primary care and to understand more about the most effective methods of seeking feedback about those experiences from children and young people (October 2018) does not completely support the NICE reference group’s thinking that ‘… it was best to carry out	Thank you for your comment and for sharing the results of these research projects with us. We have included many of the options that you identified in these projects in the recommendations - for example using different methods of collecting feedback and at different times. We hope your results can be published in peer-reviewed literature so that they can inform the wider NHS and be considered for

NHS England and NHS Improvement				experience surveys while children or young people were still receiving care and not leave it until later'. Some children and young people participating in the Ipsos MORI research said that they would prefer to leave the GP practice as soon as possible, and therefore would be unwilling to remain at the primary care service to complete a questionnaire. Others thought differently and were concerned that they would forget about their experiences if they did not give feedback shortly after their appointment. The research included six focus groups with children and young people aged between 7 and 15. The groups were split into three age groups – 7-11, 11-13, 14-15. Children in the two younger age groups were allocated to mixed gender groups and in the older age group to single gender groups.	inclusion in the evidence reviews in future guideline updates.
Insight and Feedback team Experience, Participation and Equalities Nursing Directorate NHS England and NHS Improvement	Guideline	011	031	The Insight and Feedback team at NHS England and NHS Improvement agrees with the NICE committee's recommendation that 'it was good practice to collect feedback from children and young people, and the parents or carers of babies and young children…'. As an example of its support for this good practice principle, NHS England and NHS Improvement have recently developed the first National Cancer Patient Experience Survey for under 16s in England. The Insight and Feedback team at NHS England and NHS Improvement commissioned Picker to develop a survey programme appropriate for a younger patient population, to be run in children's Principle Treatment Centres across England. Three surveys have been designed: • one for parents/carers of children aged 0-7; • one for children aged 8-11, with a section for parents/carers; and • one for children aged 12-15, also with a section for parents/carers.	Thank you for your comment and for sharing the results of this planned survey with us. We hope it can be published in peer-reviewed literature so that it can inform the wider NHS and potentially inform guidelines such as this.

				The survey is being implemented across England in 2021. Children and young people aged under 16 who have received NHS cancer care during 2020 will be invited to participate. Survey results will be available in summer 2021 and will provide the first national-level insight into the experiences of children with cancer and their parents in England. The feedback will help to create actionable ways to improve aspects of personalised care and children and young people's experience. Commissioners, providers and national policymakers will use the results to assess performance both locally and nationally, to help identify priority areas for enhancing children's cancer services.	
Insight and Feedback team Experience, Participation and Equalities Nursing Directorate NHS England and NHS Improvement	Question 3	General	General	The research commissioned by the Insight and Feedback team at NHS England from Ipsos MORI to explore children and young people's experience of primary care and to understand more about the most effective methods of seeking feedback about those experiences from children and young people (October 2018) concludes with a number of recommendations that may help users overcome any challenges. In order to maximise engagement and impact, Ipsos MORI recommended that: • Feedback mechanisms for children and young people should be as inclusive as possible, incorporating feedback tools that allow young children to express their experiences of using primary care, without limiting the extent to which older children and young people can provide detailed feedback. There should be no lower limit on the age range asked to complete surveys. • Whatever method is used to collect feedback, ease of completion should be maximised and clear messages about confidentiality and how the data will be used provided.	Thank you for your comment and for sharing this work on measuring experience with us. We have included many of the options that you identified in these projects in the recommendations - for example using different methods of collecting feedback, at different times and ensuring it is age-appropriate and reporting back how the feedback has been used. We hope your results can be published in peer-reviewed literature so that they can inform the wider NHS and be included in future guideline updates.

				- Feedback tools should be designed with children and young people in mind. They should contain as few questions as possible, with both questions and any other text written concisely and clearly. - Feedback tools should explain clearly to children and young people that their responses will be kept anonymous, and that any feedback provided will not adversely affect the care that individuals receive. - Feedback tools should present a clear narrative about the long-term and short-term benefits to the health care system of collecting feedback from children and young people. - Aggregated feedback data should be made easily available to children and young people in an accessible format. Clear actions that services are taking as a result of feedback should be identified as part of the feedback. NHS England and NHS Improvement's recently developed first National Cancer Patient Experience Survey for under 16s in England has used colour and images in the children's sections of the survey to make them more appealing to a younger audience. Children and young people will be able to complete a paper questionnaire or an online version of the survey on any device. Those who do not speak English will have the opportunity to complete the survey over the phone using a translation service.	
Manchester Foundation NHS Trust	Guideline	General	General	There may be specific needs relating to LAC in terms of practical implementation that may pose challenges locally around implementation	Thank you for your comment. We agree there may some specific needs for LAC to allow full implementation of this guideline and will pass your comments on to the NICE team who plan implementation support.

Manchester Foundation NHS Trust	Guideline	001	General	It is also not clear why the document is for those 17 years and under should this be up to 18 years. The LTP references up to 25 years in terms of young persons provision	Thank you for your comment. This guideline covers children and young people until they reach the age of 18. The NICE guideline on patient experience in adult NHS services (CG138) and the NICE guideline on service user experience in adult mental health (CG136) covers those aged 18 years and above. We appreciate that a young person can be defined as someone aged up to 25 years, but it would be confusing to have overlap between guidelines so a cut-off age of up to18 years was agreed at the scoping stage for this guideline.
Manchester Foundation NHS Trust	Guideline	014	General	There will need consideration in practice as to how we support staff to achieve it, traditional delivery of care relating to decision making, consent etc is via the parents/carer and the balance of involving the child/young person and offering the opportunity for them to be the decision maker/consultation without parents, is not consistently considered by all members of the MDT. Development of a children's specific training for CYP professionals on these aspects of care may need to be considered to support implementation in practice including clarity on the responsibility of practitioners to achieve this?	Thank you for your comment and for raising these issues relating to the implementation of the shared decision-making recommendations. We will pass your comments on to the NICE team who plan implementation support.
Manchester Foundation NHS Trust	Guideline	017	General	Young people routinely should offered an appointment on their own or with an impartial chaperone instead of parents or carer and that this should be made clear in information about the service – this is not captured in the draft guidance as it stands.	Thank you for your comment. No evidence was found on the experience of children or young people in relation to chaperones, but the committee agreed that chaperones may be used where appropriate in healthcare settings (where they are available), and their use is already highlighted in guidance from the General Medical Council and Nursing and Midwifery Council which has been linked from the guideline. The committee therefore did not make separate recommendations in this guideline. However, the guideline does include recommendations in the section on involvement of parents and carers that children and young people should be seen on their own, if that is what they want, but that they can also choose to have another person (not a parent or carer) with them.

Manchester Foundation NHS Trust	Guideline	019	General	Ensure young people's preference about the consultation itself are considered, including who they prefer to be seen by.	Thank you for your comment. There are already recommendations in the section on accessing healthcare that advise that children and young people may express a preference about the gender of the healthcare professional they see, but in most situations it would not be possible to accommodate preferences about seeing a named individual, so this has not been included in the recommendations.
Manchester Foundation NHS Trust	Guideline	019	General	Consultations should also routinely promote healthy lifestyles in an appropriate way including: Good mental health & emotional wellbeing Healthy eating, weight management and physical activity Smoking cessation Avoiding alcohol and substance misuse As frequently consultation are based on the medical concern.	Thank you for your comment. It was not within the scope of this guideline to include specific health promotion interventions, and no evidence was therefore sought or reviewed on the effectiveness of these interventions, so we are unable to include them.
Manchester Foundation NHS Trust	Guideline	023	General	The use of an advocacy service for CYP is appropriate, however practical application will again require consideration with development of guidance to support conversations, referral processes etc as this is not widely accepted in practice currently	Thank you for your comment. The provision of independent advocates to certain eligible children and young people is already a statutory requirement and so processes will be in place for referral processes. However, we agree that if independent advocate services are expanded to other groups of children and young people there may be the need for the development of additional methods for referral. The recommendations about communication and support from healthcare staff should help to support conversations.
NHS England and NHS Improvement	General	General	General	Is there an opportunity in this document to mention the NHS learning disability improvement standards? https://www.england.nhs.uk/learning-disabilities/about/resources/the-learning-disability-improvement-standards-for-nhs-trusts/ (LDA)	Thank you for your comment. The committee discussed this and it was agreed that it would not be appropriate to link to these standards from the guideline as they focus on a specific population.
NHS England and NHS Improvement	General	General	General	Can this guideline reference the World Health Organisation, European Declaration on the Health and Children and Young People with Intellectual Disabilities and their Families: Better Health, Better Lives: see here: https://apps.who.int/iris/handle/10665/108010. The UK was a signatory to this, and the principles outlines therein. (LDA)	Thank you for your comment. The committee discussed this and it was agreed that it would not be appropriate to link to these standards from the guideline as they focus on a specific population..

NHS England and NHS Improvement	Guideline	General	General	We recommend that learning from LeDeR and the child and young people early preventable death research should be included as well as the need for services to use the digital flag and summary care record for children and young people who are autistic and have a learning disability: https://digital.nhs.uk/services/reasonable-adjustment-flag. (LDA)	Thank you for your comment. The LeDeR is a series of individual reviews and so was not identified as a source of evidence for this guideline and would not have met the inclusion criteria for the review protocols, as it did not relate specifically to the experience of children or young people. Likewise, the use of the digital flag and summary care records had not been identified by the evidence review as improving healthcare experience, and the committee therefore agreed not to make recommendations relating to these. However, the needs of children with learning disabilities was recognised and where appropriate the recommendations take into account their additional needs.
NHS England and NHS Improvement	Guideline	General	General	We recommend the document focuses and makes explicit the needs of disabled children and young people *and* their families, including taking account of the information and communication needs of people with a learning disability and autistic children and young people in particular. Examples of work and resources include: Seldom Heard Voices. (LDA)	Thank you for your comment. While NICE recognises the very important role families play in children and young people's lives, the scope of the guideline was the experience of babies, children and young people receiving healthcare. The recommendations on communication have been expanded to include more details on identifying and using preferred methods of communication and using the correct tools or specialist support to do this. The committee agreed that, as with all health services, those offered to babies, children and young people have a duty to make sure that reasonable adjustments are made to accommodate the needs of those with disabilities, and it was not therefore necessary to specify this separately throughout the guideline. However, they added an additional recommendation to the over-arching principles section of the guideline, which states that the rights of disabled babies, children and young people should be supported as defined in the Equalities Act.
NHS England and NHS Improvement	Guideline	General	General	We recommend the document references the **rights** that carers and parents of children and young people who have a learning disability and who are autistic have. (LDA)	Thank you for your comment. We have added an additional recommendation to the over-arching principles section of the guideline, which states that the rights of disabled babies, children and young people should be supported as defined in the Equalities Act.
NHS England and NHS Improvement	Guideline	General	General	We recommend including the need to inform Education Health and Care Planning and SEN Support planning through the Children and Families Act 2014 and Care Act. (LDA)	Thank you for your comment. The committee agreed that the use of EHC plans was important but the scope of the guideline was the experience of babies, children and young

					people receiving healthcare, and no evidence was identified to show that EHC plans impacted on experience. The committee therefore agreed it was not something that needed to be included in specific recommendations in this guideline.
NHS England and NHS Improvement	Guideline	General	General	We are encouraged to read the reference to Ask Listen Do, as a tool to help organisations understand the need to improve the experiences of children and adults who are autistic and who have a learning disability and their families in all health, education and social care services; and encourage children and adults and their families to have their voices heard. (LDA)	Thank you for your comment. The committee were aware of Ask Listen Do as a simple but effective tool.
NHS England and NHS Improvement	Guideline	General	General	The guideline does not make any reference to the care or experiences of babies, children and young people with terminal illness or at end of life. Perhaps it should be made explicit that end of life care is out of scope and covered by guideline NG61. If this is not the case, the guideline should be updated to include appropriate references to palliative and end of life care. (PC)	Thank you for your comment. End of life care was excluded from the guideline as this is covered by the separate NICE guideline on End of life care for infants, children and young people (NG61). To address your comment we have added a cross-reference and hyperlink to NG61 within the communication section.
NHS England and NHS Improvement	Guideline	General	General	There is no specific reference to screening, immunisations or vaccinations but generally the information is very relevant (PHC OD)	Thank you for your comment. The guideline applies to all settings and situations in which healthcare is delivered and this would include screening, immunisation and vaccinations, but it was not within scope to make specific recommendations related to individual procedures.
NHS England and NHS Improvement	Guideline	General	General	From a primary care perspective (on behalf of NHS England & NHS Improvement), we support the aims of the draft document. The document is inclusive in its language on the needs of children and young people across all healthcare settings including primary care and mental health settings. Children and young people may need particular help with what is contained on their medical records and who has access and why they should have access. (RP-PC)	Thank you for your comment and your support of this guideline. Access to health records must meet the requirements of the Access to Health Records Act 1990, and as such, there is a proscribed mechanism for obtaining access.
NHS England and NHS Improvement	Guideline	General	General	There are no obvious cost implications except to recognise the cost of additional time that can be taken to fully engage children and young people actively in their care. (RP-PC)	Thank you for your comment and the committee agree that the main resource implication for this guideline may be that extra time is needed in consultations.

NHS England and NHS Improvement	Guideline	General	General	The document mentions digital access but should mention explicitly the role of remote and virtual consultations along with their limitations. We may conclude that younger people are more likely to want virtual consultations than older people. An engagement with the national youth forum in 2019 by NHS England found that a surprisingly large proportion of the young delegates desired face to face consultations. We concluded this may be due to younger people being more likely to experience mental health issues rather than physical ill health and long term conditions proportionately. (RP-PC)	Thank you for your comment. The committee discussed at length the advantages and possible pitfalls of remote consultations, particularly as the guideline was developed during the Covid-19 pandemic so this was very topical. The committee has included the use of remote consultations in its recommendations on provision of information and access to healthcare, but only when that method is acceptable to the child or young person and is clinically appropriate. We have now also included an additional recommendation in the privacy and confidentiality section of the guideline on ensuring privacy and confidentiality in virtual consultations.
NHS England and NHS Improvement	Guideline	General	General	COVID has changed the way that all people interact with health services. There may be a group of children and young people with their first conscious episode of ill health during this period who have nothing else to compare their experience with. We should take this into account when considering responses. (RP-PC)	Thank you for your comment. We have consulted with children and young people throughout the development and consultation period of this guideline and so have obtained their views about their healthcare experiences both pre-, during and post-pandemic.
NHS England and NHS Improvement	Guideline	001	2nd para	Recommend replacing the term “individualised” with “personalised” in line with terminology used in the NHS Long Term Plan. (PC)	Thank you for your comment. This change to personalised has been made. We have also changed 3 other occurrences of individualised to personalised.
NHS England and NHS Improvement	Guideline	006	Recommendation	The newly developed NICE guideline for shared decision making should also be referenced here. (PC)	Thank you for your comment. The new NICE guideline on shared decision-making applies to those aged 18 years or over so we have not referenced it here.
NHS England and NHS Improvement	Guideline	006	019	Recommend replacing the term “individualised” with “personalised” in line with terminology used in the NHS Long Term Plan. (PC)	Thank you for your comment. This change to personalise has been made. We have also changed 3 other occurrences of individualised to personalise.
NHS England and NHS Improvement	Guideline	008	017	Suggest including introducing the individual to a named healthcare professional, single point of contact, or keyworker where possible. (PC)	Thank you for your comment. The committee agreed that there would not always be a named professional or key worker, but added to this recommendation that the healthcare professional should introduce themselves, and in the recommendations on information also added that details should be provided on who will be providing care.
NHS England and NHS Improvement	Guideline	09	011	Personalised care conversations and shared decision making focus on what matters to the individual to help understand their needs, preferences, goals. Could this be included here? (PC)	Thank you for your comment. The need to identify individual needs, preferences and goals is included in the recommendations throughout the guideline (for example in

					the sections on communication, information, planning healthcare and advocacy, and support).
NHS England and NHS Improvement	Guideline	011	015	Could add to the list information about additional support to help the person manage their condition such as VCSE organisations, peer support groups, social prescribing schemes, digital support tools such as apps or remote monitoring devices (PC)	Thank you for your comment. We already have later recommendations in the guideline (1.2.27 and 1.5.16) that recommend signposting to NHS resources, charities and support groups, and the use of digital support tools and apps. The committee did not find any evidence for the use of social prescribing schemes for children and young people and so were not able to include these in their recommendations.
NHS England and NHS Improvement	Guideline	011	016	Discussions about treatment options should include discussion about risks and benefits in line with effective shared decision making (PC)	Thank you for your comment. We already have a later section in the guideline (1.3) about planning shared care and discussing risks and benefits so this has not been repeated in this recommendation.
NHS England and NHS Improvement	Guideline	014	005	It would be helpful to define SDM in this document. This would mean that much greater prominence could be afforded to preference based shared decision making which is at the heart of SDM conversations. The definition used by the NICE SDM collaborative is "Shared Decision Making is 'a process in which clinicians and patients work together to select tests, treatments, management or support packages, based on clinical evidence and the patient's informed preferences. It involves the provision of evidence-based information about options, outcomes and uncertainties, together with decision support counselling and a system for recording and implementing patients' informed preferences.'" (PC)	Thank you for your comment. We have included the definition of shared decision-making in the glossary (supplement 1)
NHS England and NHS Improvement	Guideline	014	005	Include reference to Gillick Competency or Parental Responsibility as both these factors may influence when it is appropriate to have an SDM conversation with children and young people.	Thank you for your comment. The committee agreed that all children and young people should be involved in shared decision-making as much as possible, as defined in the recommendations made in this section of the guideline. We have also added a new section to the over-arching principles section on competence, which provides additional guidance on involvement in decision-making and consent for those aged 16 or over, or for those under 16 years.
NHS England and NHS Improvement	Guideline	014	011	Personalised care and support plans, or Education, Health & Care plans provide a way of capturing key information about needs, preferences, goals. They are also useful for supporting	Thank you for your comment. The committee agreed that the use of EHC plans was important but there was no evidence identified that showed the impact directly on

				patients in only having to tell their story once. PCSPs should be developed or referred to where appropriate for babies, children and young people with ongoing health and care needs. (PC)	children and young people's experience of healthcare and therefore it was not something they included in specific recommendations in this guideline
NHS England and NHS Improvement	Guideline	015	010	The NICE shared decision making guideline could again be referenced here. (PC)	Thank you for your comment. The NICE guideline on shared decision-making applies to those aged 18 years or over so we have not referenced it from here.
NHS England and NHS Improvement	Guideline	017	Section 1.4	Would be useful to reference Gillick Competency or Parental Responsibility as both these factors may influence approaches to seeking consent. (PC)	Thank you for your comment. We have now included an additional over-arching recommendation at the beginning of the guideline on competence that clarifies that young people 16 years or older can consent, and that those younger than this can consent if they are deemed to be competent by the healthcare professional.
NHS England and NHS Improvement	Guideline	018	009	It is important that the needs of disabled children and young people and their rights to reasonable adjustments in relation to the environment, sounds, visit preparation and so on are considered and referenced here. Please see the new study from the *Chief Social Workers and the Chief Social Worker for Children and Families to improve the quality of autistic people's lives and social work practice* for *information*:https://www.gov.uk/government/publications/social-work-and-autistic-young-people-an-exploratory-study. (LDA)	Thank you for your comment and making us aware of this study, although we note this relates to social work practice and not healthcare and so we would have been unable to include it as evidence for this guideline. In order to emphasise the need to make reasonable adjustments for children with disabilities we have included a new recommendation in the over-arching principles section at the beginning of the guideline, which states this.
NHS England and NHS Improvement	Guideline	019	005	We welcome the focus on supporting children and young people to advocate on their own behalf. We are aware that such an approach (combined with other components of personalised care) can increase positive outcomes and also confidence, knowledge and inter-personal skills. However, children and young people will still need access to other forms of advocacy (statutory, independent, community, peer-led and so forth) to help them navigate the health and care system. Personalised care interventions which support people to have more choice and control of their care and access to wider resources, such as personal health budgets and social prescribing in particular,are demonstrating positive impact,	Thank you for your comment. We have included recommendations on statutory advocates, and advised that other support (such as social workers, youth workers) be available for children and young people who do not have parents or carers to help them navigate the health system. We have also suggested that the independent advocate availability be extended for children and young people who need additional support but do not currently qualify on statutory grounds. Specific interventions such as social prescribing were not included in the scope of the guideline and so no evidence was therefore sought or reviewed on the effectiveness of

				leading to increased confidence and therefore increased ability to self-advocate. Where possible, it should be considered whether personal health budgets are an option for children and young people with complex needs. (PC)	these interventions, so we are unable to include them. Personal health budgets do not fall within the scope of this guideline but do fall within the scope of the NICE guideline on children with complex needs, which is currently in development.
NHS England and NHS Improvement	Guideline	022	019	Suggest including “taking account of information about needs and preferences that are captured in a personalised care and support plan”. (PC)	Thank you for your comment. The committee were aware that not all children and young people would have a personalised care and support plan so did not add this to their recommendation.
NHS England and NHS Improvement	Guideline	024	029	Commissioners should be encouraged to expand the availability of advocacy for all. The Personalised Care Group at NHS England and NHS Improvement are working with the National Development Team for Inclusion on advocacy and their research has highlighted that health-specific advocacy services for children and young people are patchy at best, non-existent at worst (the research can be shared). (PC)	Thank you for your comment. We agree that there appears to be a need for wider availability of healthcare advocacy services for children and young people and have included a recommendation for commissioners to consider this.
NHS England and NHS Improvement	Guideline	025	Section 1.6.1	This section should include a paragraph on providing appropriate information to support those that are “nil by mouth” or need to be “tube” fed. (PC)	Thank you for your comment. It was not within the scope of the guideline to consider specific clinical conditions and so the committee agreed that information on nil by mouth or tube feeding was too specific to be included in this guideline.
NHS National Services Scotland	Guideline	General		This guideline is stated to apply to the UK. Where there are differences in the developed Nations this would be helpful to acknowledge.	Thank you for your comment. NICE guidelines cover health and care in England. Decisions on how they apply in other UK countries are made by ministers in the Welsh Government, Scottish Government and Northern Ireland Executive.
NHS National Services Scotland	Guideline	029	028-030	For children and Yps with additional needs for mobility or personal care the provision of equipment required should be regarded as reasonable adjustments relating to disability rights	Thank you for your comment. The need to provide an environment that is appropriate, physically accessible and has adaptations available is covered in the recommendations in this section, and an over-arching recommendation has been added to the beginning of the guideline to reinforce the need to make reasonable adjustments.
NHS National Services Scotland	Guideline	006	007	Include information in an accessible form – for children and young people with complex disabilities their passport e.g. PAMIS digital passport will indicate how they wish to communicate and be communicated with, every health facility	Thank you for your comment. The committee were aware that PAMIS passports are used in Scotland and although they may represent good practice they decided not to name specific initiatives. However, the guideline does include

				should have a standard approach to accessing this information before interacting with the person unless there is an urgent clinical need for immediate action	recommendations in the section on continuity and coordination about the use of health passports or digital health records in general.
NHS National Services Scotland	Guideline	033	010	Include mention of pharmacies in this context	Thank you for your comment. This page of the guideline is the contents page so we are not clear where you are suggesting we add pharmacies. However, pharmacies have been included in the examples of healthcare settings to which this guideline applies.
NHS National Services Scotland	Guideline	029	011	Why are mental health wards excluded from children’s choice of resident carer? Resident carer may be essential for young people with disabilities who are admitted to adult wards where this is not routine for inpatients	Thank you for your comment. We have removed the mention of mental health wards as an exclusion, as the committee were aware that policies in different mental health facilities may vary, depending on the type of unit.
NHS National Services Scotland	Guideline	032	013	Include the need for all healthcare practitioners to be aware of the role of Guardianship for young people over age 16	Thank you for your comment. We have added guardians to the definitions of parents or carers used in this guideline, as the committee agreed that all the recommendations relating to parents or carers would be applicable to guardians with parental responsibility.
NHS National Services Scotland	Guideline	033	013	Ensure any video consultation are healthcare secure	Thank you for your comment. The committee were not aware of a nationally required healthcare secure standard for video consultations so were unable to add this to their recommendations.
NHS National Services Scotland	Guideline	034	016	Consider PAMIS digital passport for those with profound and complex disabilities	Thank you for your comment. The committee were aware that PAMIS passports are used in Scotland and although they may represent good practice they decided not to name specific initiatives. However, the guideline does include recommendations in the section on continuity and coordination about the use of health passports or digital health records in general.
NHS National Services Scotland	Guideline	033	019	Consider stating ‘where practical’	Thank you for your comment. The committee added the caveat ‘where clinically appropriate’ to this recommendation but agreed that adding ‘where practical’ as well would not encourage providers to implement this.
NHS National Services Scotland	Guideline	022	022	Consider what health information including mental health is shared with education and social care (GIRFEC) in Scotland and how children and Yps are involved in these decisions	Thank you for your comment. Page 22, line 22 relates to a recommendation on self-advocacy so we are unsure how your comment relates to this recommendation. However, as NICE guidelines are primarily dealing with the health services in England we would not make recommendations

					that are specific to the Scottish government's GIRFEC initiative.
NHS National Services Scotland	Guideline	027	023	Include Primary Care and dental facilities and services as well as pharmacies as health service providers	Thank you for your comment. The recommendations on page 27, line 23 relate to the environment and, as stated at the beginning of the guideline, the recommendations apply to all settings where NHS treatment is received (inpatient, outpatient, GP surgeries, pharmacies, dentists, children's centres, schools, or when healthcare professionals provide care in any other place, including in people's homes) unless otherwise specified. We have not therefore added specific settings into the recommendations on environment.
NHS National Services Scotland	Resources	009	028	Talking Mats, Augmented Aids for Communication, Show Me Where (university of Cardiff)	Thank you for your comment. This recommendation on communication has been edited to include the use of augmentative and alternative communication (AAC) but we have not included any other specific example of tools, as the committee had not found any evidence on these.
NHS National Services Scotland	Guideline	001	007	Using the age of 17 is confusing as UNCRC definition of a child is to age 18 but many children's services handover or refuse admission to children's wards from 16th birthday or even earlier	Thank you for your comment. This guideline covers children and young people until they reach the age of 18. The NICE guideline on patient experience in adult NHS services (CG138) and the NICE guideline on service user experience in adult mental health (CG136) covers those aged 18 years and above. We appreciate that a young person can be defined as someone aged up to 25 years, but it would be confusing to have overlap between guidelines so a cut-off age of up to18 years was agreed at the scoping stage for this guideline. We note your comment that some children's services may have local policies that use different age cut-offs, but the guideline recommends that all care should be provided in an age and developmentally appropriate environment and method.
NHS National Services Scotland	Guideline	005	008	I suggest 'People' is replaced by 'Adults'	Thank you for your comment. We have changed this to 'adults' as you suggest.
NHS National Services Scotland	Guideline	006	008	Surveys are rarely adapted for children (or parents) with communication or learning difficulties	Thank you for your comment. We note that this refers to the surveys mentioned in the context section of the guideline. However, the recommendations in the guideline on design of healthcare and measuring experience do recommend the use of surveys so we have added detail

					here to ensure that methods of gathering feedback take into account communication or learning difficulties.
NHS National Services Scotland	Guideline	007	001	Include information in an accessible form	Thank you for your comment. We have made detailed recommendations on the best way to provide information so that it is in an accessible format and have now added a cross-reference to the NHS Accessible Information Standard in the recommendations on how information should be provided.
NHS National Services Scotland	Guideline	007	010	Suggest a basic level of training and equipment to support communication	Thank you for your comment. The section of the guideline on communication already contains a recommendation that all staff involved in providing healthcare services to babies, children and young people should have skills and competencies in relevant communication skills. The committee discussed whether any particular training standard or level could be defined but agreed this may vary for different groups of staff.
NHS National Services Scotland	Guideline	008	010	Acknowledge the time required to revisit and adpt day to day	Thank you for your comment. The time required to revisit needs and preferences on a regular basis has been acknowledged in the rationale and impact section relating to this recommendation.
NHS National Services Scotland	Guideline	008	019	Acknowledge language needs of staff as well as family especially for locum staff new to UK	Thank you for your comment. The committee agreed that staff providing NHS healthcare would be expected to have a sufficient level of English to carry out their role
NHS National Services Scotland	Guideline	009	007	Action for Sick Children publication ‘Health for All Children’ is a resource based on the views of children from different cultural backgrounds	Thank you for your comment and telling us about this resource. We will pass this information onto the NICE team who plan implementation support.
NHS National Services Scotland	Guideline	010	001	Action for Sick Children Scotland Hospital Playbox, ASC Dental Playbox	Thank you for your comment. We have added the example of augmentative and alternative communication to this recommendation, but have not added details of these specific tools, which may be too specific or only be available in certain areas.
NHS National Services Scotland	Guideline	010	021	Add Health Play Specialists	Thank you for your comment. We have added the example of another healthcare professional, as this could be a number of other professionals.
NHS National Services Scotland	Guideline	011	004	Highlight the needs of children and young people with autism,	Thank you for your comment. This recommendation on behavioural and physical cues may apply to a range of children and not just those with autism, so the recommendation has been left more general.

NHS National Services Scotland	Guideline	011	004	PAMIS digital passport for those with complex disabilities and needs	Thank you for your comment. The committee were aware that PAMIS passports are used in Scotland and although they may represent good practice they decided not to name specific initiatives. However, the guideline does include recommendations in the section on continuity and coordination about the use of health passports or digital health records in general.
NHS National Services Scotland	Guideline	011	008	Include mention of locum staff and the demands on them to communicate when English is not their 1st language	Thank you for your comment. The committee agreed that staff providing NHS healthcare would be expected to have a sufficient level of English to carry out their role
NHS National Services Scotland	Guideline	013	001	For children with Exceptional Healthcare Needs suggest involvement of someone who has experience communicating with the individual child or YP e.g. school nurse	Thank you for your comment. The recommendation this comment relates to is about the development and content of written or digital information so we are not sure how your comment relating to communication with an individual child applies to this recommendation.
NHS National Services Scotland	Guideline	13	019	Specify liaison psychology services	Thank you for your comment. The committee had evidence that information can have an emotional impact on children but did not have any evidence regarding the involvement of any specialist services so we have been unable to make this change.
NHS National Services Scotland	Guideline	014		It may be relevant here to mention the involvement in Anticipatory Care Plans for children or YPs with potentially life limiting or life threatening conditions	Thank you for your comment. Advance care plans are covered in detail in the NICE guideline on End of life care for infants, children and young people with life-limiting conditions: planning and management (NG61), which is now cross-referenced from this guideline, so we have not included them as specific recommendations in this guideline.
NHS National Services Scotland	Guideline	014	015	The wording could be seen as patronising to children and families	Thank you for your comment. The wording used here was suggested by the young people involved in the development of this guideline so the committee were satisfied that this would not be seen as patronising.
NHS National Services Scotland	Guideline	014	019	There is a need to assess capacity when expecting a child or YP to take these actions	Thank you for your comment. We have added a new section to the over-arching principles section on competence, which provides additional guidance on involvement in decision-making and consent at different ages, and includes consideration of competence.

NHS National Services Scotland	Guideline	015	020	Ensure that the Family Integrated Care approach that is now standard in NICU is applied in other healthcare settings for neonates e.g. surgical ward or PICUs	Thank you for your comment. We have made a number of recommendations throughout the guideline which support the concept of family integrated or family-centred care - this includes recommendations on parents' attendance at ward rounds, allowing parents to stay in hospital with their baby or child and ensuring they can remain involved in caring for their baby (such as washing, changing nappies). These recommendations would therefore apply in any setting and not just on NICU.
NHS National Services Scotland	Guideline	017	007	Consider capacity including for those with intellectual disability	Thank you for your comment. The recommendations on consent provide guidance on taking into account individual capacity, and this would include all children and young people, including those with disabilities.
NHS National Services Scotland	Guideline	018	016	Include the right to request a second opinion	Thank you for your comment. The recommendations on difference of opinion suggest involving other people in the discussions, and we have expanded this to specifically include another healthcare professional, and this could include obtaining a second opinion. However, the committee agreed that every situation would be different and the recommendations could not therefore specify the process to be followed in specific cases.
NHS National Services Scotland	Guideline	019	018	Consider the need to confirm the legal status of the carer if they are taking responsibility for giving consent, include mention of Guardianship allocation for Young People who lack mental capacity	Thank you for your comment. The terminology 'parents or carers' is included throughout the guideline and is defined in the 'terms used in this guideline'. We have added guardians as we recognise that they may be involved in discussions and decisions in lieu of parents.
NHS National Services Scotland	Guideline	020	005	Recognise that parents may have different views when making decisions especially if separated and there is currently no provision for the time involved in repeating all information to a second parent if not attending with the child or YP	Thank you for your comment. We appreciate there may be added complications around decision-making where parents are separated. The committee recognised that there might also be situations (for example due to infection control or for practical reasons) where only 1 parent or carer can be present at a consultation. The committee agreed that the recommendations were based on the presumption that the parents would communicate information to each other and it was not always feasible for healthcare professionals to repeat everything that had been said to an absent parent so they were not able to include this in their recommendations. .There are, however,

					recommendations concerning disagreements about consent decisions in the section of the guideline on consent.
NHS National Services Scotland	Guideline	022	005	Organisations and job plans need to recognise the time that these recommendations involve for the health professionals particularly the additional time required to support children, Yps and parents with learning disabilities	Thank you for your comment. The need for additional time to implement some of the recommendations in this guideline has been discussed in the impact sections of the guideline. Amending job plans to allow this additional time is a matter for local implementation, but we will pass on this comment to the NICE team responsible for planning implementation support.
NHS National Services Scotland	Guideline	024	001	Consider how to identify the appropriate independent advocate for a young person with complex needs and learning disabilities	Thank you for your comment. The provision of independent advocates for children and young people in line with statutory requirements would require reasonable adjustments to be made to the advocacy service to meet the needs of children with complex needs or learning disabilities, and this would be included in the commissioning process for the advocacy service. Specific details of what these adjustments might be have not therefore been included in this guideline
NHS National Services Scotland	Guideline	25	016	Consider trauma informed care and the need to understand past history in relation to responses to planned treatment etc	Thank you for your comment. It was not within the scope of the guideline to consider specific clinical conditions or approaches to treatment and no evidence on trauma-informed care was searched for or identified and so this cannot be included in this guideline.
NHS National Services Scotland	Guideline	027	017	Include local educationalists	Thank you for your comment. The committee were aware of a number of feedback mechanisms, but did not identify any evidence that met the protocol criteria for the use of local educationalists in providing feedback so they did not include this in their recommendations.
NHS National Services Scotland	Guideline	029	007	Consider how children are given a choice about who attends ward round reviews	Thank you for your comment. No evidence was identified that met the protocol criteria that suggested children and young people's experience is improved by choosing who attends ward rounds so we have not made a recommendation to advise this. However, we have recommendations about parents or carers discussing with the child or young person about how they would like parents or carers to be involved.

NHS National Services Scotland	Guideline	029	025	Young people especially those with learning disabilities should be offered individual introduction to ward facilities and there might be recommended flexibility around age appropriate care limits for young people with complex disabilities especially if their transition plans are not completed when admitted to hospital	Thank you for your comment. We think the suggestion that children and young people should be introduced to the ward facilities is important for all, not just those with learning disabilities and so have included this in the recommendations. We agree that there may need to be flexibility around age limits and have included in the recommendations in the section on environment that this should take into account preferences and should be appropriate for age and developmental stage.
NHS National Services Scotland	Guideline	031	006	Paid carers for young people with complex disabilities who require aid for self care should continue to be employed while the YP is in hospital	Thank you for your comment. We have not included information about paid carers for young people with complex needs because the scope of the guideline was the healthcare experience of babies, children and young people and it was not within the scope to make recommendations relating specifically to paid carers.
NHS National Services Scotland	Guideline	032	002	Consider specifying the needs accessibility of young people with learning disabilities	Thank you for your comment. We have added children with learning disabilities to the examples of groups of children who may require additional support to access healthcare.
NHS National Services Scotland	Guideline	033	004	There should be acknowledgement that some recommendations may be unrealistic especially where small units lack options for choices being offered	Thank you for your comment. The committee agreed that the guideline recommendations should set the standard for the best possible experience of healthcare, and it is up to local services to determine how fully all the recommendations can be implemented.
NHS National Services Scotland	Guideline	034	009	An elearning module on coordination of care for children and young people with exceptional healthcare needs is in preparation via Turas	Thank you for your comment and for making us aware of the forthcoming eLearning module. We will pass this on to the NICE team who are responsible for implementation support.
NHS National Services Scotland	Guideline	039	023	Consider the needs of those with specific learning difficulties e.g. dyslexia, visual impairment including in Primary Care and pharmacies	Thank you for your comment. This relates to the rationale section, which is a summary of the evidence that was found to support the recommendations. It is not therefore appropriate to add additional information here when it was not specifically identified in the evidence.
NHS National Services Scotland	Guideline	041	021	Consider capacity for consent etc, confirm parental legal responsibility, guardianship	Thank you for your comment. This relates to the rationale section, which is a summary of the evidence that was found to support the recommendations. It is not therefore

					appropriate to add additional information here when it was not specifically identified in the evidence.
NHS National Services Scotland	Guideline	042	028	Ensure the same facilities are provided on adult wards for those young people admitted there	Thank you for your comment. This relates to the impact section, which is a summary of the impact on practice of the recommendations. It is not therefore appropriate to add additional information here that does not relate to the impact on practice.
NHS National Services Scotland	Guideline	043	015	Consider the organisational impact and costs of specialised advocacy services for young people with learning or communication difficulties	Thank you for your comment. This relates to the impact section on support from healthcare staff, and the costs of specialised services for children or young people with learning or communication difficulties are acknowledged in the impact section for the recommendations on communication
NHS National Services Scotland	Guideline	045	025	Action for Sick Children created the /Child's Eye View' teaching video and toolkit emphasising views on the experience of illness and treatment for children aged around 8years	Thank you for your comment. This relates to the rationale section, which is a summary of the evidence that was found to support the recommendations. It is not therefore appropriate to add additional information here when it was not specifically identified in the evidence.
NHS National Services Scotland	Guideline	046	016	Consider including mention of hospice services and their limitations for young adults	Thank you for your comment. This relates to the impact section, which is a summary of the impact on practice of the recommendations. It is not therefore appropriate to add additional information here that does not relate to the impact on practice. In addition, hospices are not included in the settings for this guideline as End of life care is covered by the covered by the separate NICE guideline on End of life care for infants, children and young people (NG61)
NHS National Services Scotland	Guideline	048	005	Specify the need for laundry facilities and refreshments for resident parents	Thank you for your comment. This relates to the rationale section, which is a summary of the evidence that was found to support the recommendations. It is not therefore appropriate to add additional information here when it was not specifically identified in the evidence. In addition, the guideline did not provide recommendations on the experience of parents so it would not have made recommendations on facilities specifically for parents.
NHS National Services Scotland	Guideline	049	005	Recognise the anxiety for YP in hospital adult ward lacking education support when preparing for exams or College work	Thank you for your comment. This relates to the rationale section, which is a summary of the evidence that was found to support the recommendations. It is not therefore appropriate to add additional information here when it was

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					not specifically identified in the evidence. However, the guideline does provide recommendations on educational support.
NHS National Services Scotland	Guideline	050	019	Raise awareness that young people attending university may still be registered with their parent's home GP causing difficulties if they become unwell during term time especially relevant for those with chronic disease or mental disorders.	Thank you for your comment. This relates to the impact section, which is a summary of the impact on practice of the recommendations. It is not therefore appropriate to add additional information here that does not relate to the impact on practice. However, students attending university would usually be 18 years old so would not fall within the scope of this guideline.
Rainbow Trust	Guideline	009	008	We welcome the guidance for healthcare staff to communicate with parents and carers with a non-judgemental attitude. However, a factor relating to the healthcare experience of babies, children and young people which is not currently referenced in the guidance is the practical challenge that parents can experience when visiting a seriously ill baby or child who is an in-patient, or when accompanying their child to an appointment or treatment. Rainbow Trust has supported many families who find it difficult to travel to hospital because they do not drive or do not have access to a car, for whom public transport links may be complex and / or who cannot afford the costs involved in travelling. There can be low levels of confidence in hospital transport services that do exist. In our experience a lack of understanding about these challenges by healthcare staff can result in parents being judged as unwilling to visit and this can result in safeguarding concerns being raised unnecessarily. Better communication between staff and parents can enable parents to open up about the practical obstacles that they face, and could enable parents to be referred to voluntary services that may assist. The experience of a baby, child or young person is likely to be much improved if their parent or carer is supported to accompany them or to visit them.	Thank you for your comment. We agree that non-judgemental communication skills are key and have included recommendations about ensuring all staff demonstrate competencies in communication skills, and that communication should always be non-judgemental. We have also made recommendations to support the presence of parents in hospital with their babies or children. However, it is not within the scope of this guideline to address issues such as travel or expenses for travel.
Rainbow Trust	Guideline	017	016 - 017	A challenge in implementing this guidance can when be parents do not wish a child to be made aware that their	Thank you for your comment and for sharing this situation with us. We agree this emphasises the importance of good

				condition is terminal. For instance in a family supported by Rainbow Trust a 13-year-old child became aware that they were dying because hospital staff did not understand the wishes of the child's parents for this information not to be shared.	communication between healthcare professionals, parents or carers and children and young people, and hope that the recommendations is this guideline will help improve this communication.
Rainbow Trust	Guideline	018	009 - 020	We welcome recognition that there can be differences of opinion between family members. In addition to the examples given, we would highlight that there can often be disagreement between parents as well. For instance, Rainbow Trust has experience of families where parents have been in disagreement about whether to agree on a Do Not Resuscitate instruction for a terminally ill child. This can occur whether or not parents are together or separated / divorced.	Thank you for your comment. We recognise that there may be different types of disagreement but as these are only given as examples in the recommendation the list is not meant to be exhaustive and so we have not added this as an additional example.
Rainbow Trust	Guideline	018	005 - 008	A challenge in implementing this guidance may be that, in our experience, it is not unusual for parents to avoid telling a child their prognosis in order to protect them emotionally, and this in turn affects the ability of a child to make an informed decision or to consent to their treatment.	Thank you for your comment and for sharing this scenario with us. We agree that this would affect the ability of the child or young person to provide informed consent. The section of the guideline on the involvement of parents or carers provides advice on encouraging parents or carers to discuss with their child how they will be involved in decisions about their healthcare and so discussions like this may help the situation you mention
Rainbow Trust	Guideline	022	019 – 022	A challenge in implementing this guidance may be that, in our experience, it is not unusual for parents to avoid telling a child their prognosis, in order to protect them emotionally, and this in turn affects the ability of a child to make an informed decision or to consent to their treatment.	Thank you for your comment and for sharing this scenario with us. We agree that this would affect the ability of the child or young person to provide informed consent. The section of the guideline on the involvement of parents or carers provides advice on encouraging parents or carers to discuss with their child how they will be involved in decisions about their healthcare and so discussions like this may help the situation you mention.
Rainbow Trust	Guideline	034	003 - 009	Rainbow Trust welcomes the recommendation to pay particular attention to communication between professionals and services at key points in care. In our experience, a challenge in practice can arise when a ward needs to free up a paediatric bed to meet demand, and a child who has been a long-term in-patient is discharged at short notice. We would highlight that rushed and poorly managed discharge can result in negative experiences of healthcare for babies, children and	Thank you for your comment and support of our recommendations on the exchange of information at key points in care. It is also interesting to hear that attendance at virtual meetings during the Covid-19 pandemic has improved coordination of care.

				young people. Parents can be highly anxious about taking on responsibility for their baby or child's care after a long stay in hospital with a serious or complex condition, and staff need to be encouraged to communicate sensitively at this time. During the pandemic our Family Support Workers say that coordination has been improved because it has been easier for a range of professionals and services to attend virtual meetings, which were harder to attend in person.	
Rainbow Trust	Guideline	034	012 - 016	Questions 1 and 2: In answer to which area of the guidance may be most challenging to implement, and which may have the most significant cost implications, our experience is that systems to avoid the unnecessary repetition of a child's healthcare history when meeting different healthcare professionals do not yet exist in many cases. For instance, parents often report to Rainbow Trust that they are responsible for large folders of information about their seriously ill child's condition and treatment. If implemented, this guidance would have a positive impact on the experience of a child and their parent or carer. Parents/ carers can feel a weight of responsibility for coordinating care and sharing information related to a child with life-threatening or terminal condition. The use of health passports or digital records for different health professionals to access would be a positive step to improve healthcare experience.	Thank you for your comment and for supporting our recommendations to improve the sharing and availability of information and prevent children or young people having to unnecessarily repeat their medical information.
Rainbow Trust	Guideline	034	002	A challenge in implementing this guidance can be that healthcare professionals have limited knowledge about voluntary sector sources of support which are available. This can mean that there is limited communication between hospital and community services.	Thank you for your comment. We note your concerns for implementation due to the lack of knowledge about voluntary sector support and will pass your comments to the NICE team responsible for planning implementation support.
Ronald McDonald House Charities UK	Guideline	007	001	The recommendation says that children should be able to have their parents present at consultations if they would like this – in some cases, this will be straightforward – but often a child may have lengthy hospital stays in a specialist children's hospital that is a long way from home – this makes the presence of a Ronald McDonald House provided by our charity, even more	Thank you for your comment and for informing us how a Ronald McDonald House can help with the implementation of this guideline.

				important, to enable the rest of the family to stay close to the sick child in hospital	
Ronald McDonald House Charities UK	Guideline	013	022	Staff and resources within a Ronald McDonald House are able to aid families in signposting to appropriate NHS and other charity information which can be made available within the House – computers and internet access are also available for family use	Thank you for your comment and for informing us how a Ronald McDonald House can help families access additional information.
Ronald McDonald House Charities UK	Guideline	015	019	To enable parents to be present at ward rounds – again they need to be able to be present in the hospital and on the ward balancing this with their own work or other caring responsibilities – these things can all be facilitated if the family is able to benefit from staying in a Ronald McDonald House on the hospital campus	Thank you for your comment and for telling us how the facilities provided by the Ronald McDonald House charities can support parents and carers.
Ronald McDonald House Charities UK	Guideline	018	025	The recommendation says that children should have the right to privacy – this is difficult to achieve if they are in hospital and have a parent staying on a drop down bed by their bedside – again, the presence of a Ronald McDonald House on the hospital campus, means that the rest of the family can stay close, whilst still maintaining the patient's privacy	Thank you for your comment and for telling us how the facilities provided by the Ronald McDonald House charities can support families.
Ronald McDonald House Charities UK	Guideline	029	014	The recommendation says that parents should be able to be involved in normal age appropriate care giving – eg bathing and helping to dress – again, if a child is in hospital a long way from home, this may be difficult to achieve if the parent is not able to stay on campus (eg in a Ronald McDonald House), as they may have other children who need their care too – siblings are welcome to stay in our Houses – and the whole family can take part in meal times, story times, bed time routines etc	Thank you for your comment and for telling us how the facilities provided by the Ronald McDonald House charities can support parents, carers and families.
Ronald McDonald House Charities UK	Guideline	029	022	The recommendation says that children should be able to spend time with siblings and peers, away from the ward environment – again, this can be achieved in the spacious day rooms and gardens of a Ronald McDonald House – we have a great example of a pizza party for a teenager with a brain injury – his schoolfriends were able to visit him in a Ronald McDonald House, play a game of pool, enjoy take away pizza, but more importantly, spend time with him, learning about the way he had changed as a result of his condition, and how they	Thank you for your comment and for telling us how the facilities provided by the Ronald McDonald House charities can support parents and carers.

				would be able to support him as he returned to his day to day life	
Royal College of General Practitioners	Guideline	General	General	Can the committee consider reviewing the use of the "family" within it's guidance? As it is currently written, the guidance shows little appreciation that illness in one child affects the whole family. The word 'family' appears for the first time in rec 1.8.2. The ill child should always be the primary focus of attention, but some understanding of the needs of the whole family could be made explicit. Can this be added within the document?	Thank you for your comment. The scope of the guideline was to improve the healthcare experience of babies, children and young people and therefore it was not possible to make recommendations on the impact on the family.
Royal College of General Practitioners	Guideline	008 - 014	1.2	There is nothing in the communication section regarding virtual communication. At a time of increasing use of telephone and video calls and with a digital enabled patient cohort, virtual consultations must be considered as an option to consulting. If added, this section should also include basic safeguarding such as checking who is present in the room with the young person, if the young person can be overheard and signposting to safe ways of communicating digitally for clinicians, including safety netting	Thank you for your comment. The use of remote consultation is included as an option for communication in several sections of the guideline including providing information and accessing healthcare. To address the concerns you have raised about privacy we have added an additional recommendation to the section of the guideline on privacy and confidentiality.
Royal College of General Practitioners	Guideline	031 - 033	1.10	Can the committee consider adding specific points within this section to cover the universal transition that all children and young people go through, regardless of their health needs from consulting with their parents/carers to consulting alone. A statement such as "improve access to services by proactively seeing young people by themselves for part of an appointment when they attend with parents, to help with their transition towards their independent consulting. This can be undertaken in any appointment, even for a routine matter, using the time to check on wellbeing or to explain that they can book appointments for themselves in the future. Please note the RCGP.org.uk has patient leaflets that can help with this.	Thank you for your comment. There are recommendations on the involvement of parents or carers in healthcare decisions and healthcare appointments, and how this involvement changes over time in the section of the guideline on Involvement of parents and carers (1.5). This section of the guideline also provides recommendations on children and young people seeing the healthcare professional on their own for at least some of the appointment. This concept is also included in recommendations on providing information, risks and benefits and privacy and confidentiality. We have also cross-referenced to the NICE guideline on transition from children's to adults services (NG43) which provides additional advice on this. Thank you for telling us about the leaflets on the RCGP website. We will pass this information to the NICE team who plan implementation support.

Royal College of General Practitioners	Guideline	007	Text box	Can the committee please add "where appropriate" to the statement "parent and carers have the right to be involved "where appropriate"… This guidance covers all young people up to and including those who are 17 years of age. If a young person is competent ,they do not need their parent/ carer involved in their care decision making Whilst the linked document does contain this term, many people reading the guidance will not go to an additional page and since this is such an important part of adolescent/ young peoples care it is important to be explicit.	Thank you for your comment. The text in this box has been amended to advise that parents and carers have the right to be involved in planning and making decisions about their baby'shealthcare. We agree that for children and young people who are competent, or for those aged 16 or 17 years, there is no requirement to involve parents in decision-making unless that is what the young person wants, and we have clarified this in an over-arching recommendation at the start of the guideline.
Royal College of General Practitioners	Guideline	009	004	Can the committee consider adding "ensure the clinician respects the name that the young person wishes to be called and the gender they choose to identify as".	Thank you for your comment. We have added an additional recommendation to the section on communication to advise that healthcare professionals should identify how children and young people would like to be addressed, including their names and pronouns.
Royal College of General Practitioners	Guideline	010	015-017	1.2.9. Can the committee consider adding to the checking understanding recommendation. "Beware of the use of echolalia whereby people repeat back comments said to them almost word for word." This does not necessarily mean understanding.	Thank you for your comment. The committee agreed that as they had used the phrase 'explain back to you in their own words' this removed the need to make a specific recommendation on echolalia.
Royal College of General Practitioners	Guideline	010	018	1.2.10 Can the committee consider other factors around management of sensory difficulties that are worth considering in this part of the guidance (based on works by Olga Bogdashina, Visiting Lecturer at Birmingham University and Consultant Psychologist) • Protect from sensory overload (Teach individual to recognise & have strategy) • Create "sensorily safe" environment (Structure & routine help e.g. quiet area, Explain examination & procedures) • Hypersensitivity (Identify & avoid disturbing stimuli e.g. noise, Be aware of your clothes, badges & perfume) • Adjust the way you interact with the child (Learn better with concrete information, Find out if visual, auditory, tactile, etc) Environmental considerations during a consultation which may hinder communication • Visual – room is too dark or too bright, flashing lights	Thank you for your comment. No evidence on sensory difficulties was identified that allowed the committee to make specific recommendations on the management of sensory difficulties as you suggest, but they did include a recommendation in the section of the guideline on environment to reflect that a calm environment with as little background noise as possible would be likely to improve the healthcare experience for babies, children and young people.

				• Auditory – too much background noise, such as traffic, playing children, music, etc • Smell – too much perfume, disinfectant, etc • Touch – e.g. uncomfortable chairs, etc	
Royal College of General Practitioners	Guideline	010	025	1.2.11 When a child or young person does not want to communicate, we must also consider reasons why. Who is with them? Is there a reason they are uncomfortable? Can the committee consider adding to this section “Consider any additional reasons the young person may not wish to talk and offer to talk with the young person alone as an alternative”.	Thank you for your comment. The recommendation suggests alternatives that could be used to overcome communication difficulties, which includes different time, different setting, with different people, or more privacy, and that might include without their parents or carers.
Royal College of General Practitioners	Guideline	014	005	1.3.1 Can the committee consider adding “seeing and consulting with the young person alone” This particularly applies to the adolescent/ young adult population who may want to consult alone and if competent should be allowed to do this.	Thank you for your comment. Recommendations on appointments without parents or carers present, or without them present for some of the appointment are already included in the sections of the guideline on information, privacy and confidentiality and support from parents or carers and self-advocacy so we have not repeated it here as well.
Royal College of General Practitioners	Guideline	018	009	1.4.6 Can the committee consider adding “See the child /young person alone where appropriate to ensure that they are giving their own consent, not reflecting the views of their parents”	Thank you for your comment. There are more detailed recommendations in the section on involvement of parents or carers that provide advice on seeing children or young people alone, so these have not been repeated in the section on consent.
Royal College of General Practitioners	Guideline	030	018	1.9.4 Can the committee consider adding, “ and the use of technology must respect those around them”, for example, some young people in healthcare environments may not tolerate loud noise of flashing lights and it may have a detrimental impact on their feeling of calm/ health.	Thank you for your comment. There are already recommendations in the section of the guideline on usual activities that referred to the use of social media and the privacy of others, so we have extended this to include technology and noise/lights.
Royal College of Nursing	All	General	General	The Royal College of Nursing (RCN) welcome the proposal to develop NICE guidance for Babies, children and young people's experience of healthcare guideline. The RCN invited members who work with people in these settings and care for people with this condition to review and comment on the draft guidelines on our behalf. The comments below, reflect the views of our reviewers.	Thank you for your comment. We have addressed your comments individually below.

Royal College of Nursing	Guideline	General	General	It is not clear why the Guidelines are for use with Young People up to the age of 17, why not up to 18 as per all other children and Young People's guidance. It may be worth adding additional explanation in relation to this.	Thank you for your comment. This guideline covers children and young people until they reach the age of 18. The NICE guideline on patient experience in adult NHS services (CG138) and the NICE guideline on service user experience in adult mental health (CG136) covers those aged 18 years and above. We appreciate that a young person can be defined as someone aged up to 25 years, but it would be confusing to have overlap between guidelines so a cut-off age of up to18 years was agreed at the scoping stage for this guideline. This is stated in the scope for the guideline, which is available on the NICE website.
Royal College of Nursing	Guideline	General	General	The Guidelines purport to cover all environments where babies, children and young people may receive healthcare such as dentists and GP practices, yet it makes no recommendation or acknowledgement that staff in certain areas may not have any specific training on children's development and therefore may not understand what may or may not be appropriate for different ages. Further, they may not be fully cognisant of age appropriate language, behavioural cues etc.	Thank you for your comment. The guideline sets standards for best practice in all healthcare settings which provide healthcare services to children, and it is therefore expected that staff working in all these settings would be trained to provide these services.
Royal College of Nursing	Guideline	General	General	There does not appear to be any acknowledgement of the importance of listening to / asking parents (where not appropriate to ask the child or young person directly) about their child and what is normal for them, thinking in particular in relation to the comments regarding children's vocalisation or lack thereof regarding pain in the Communication recommendation.	Thank you for your comment. We have added extra detail to this recommendation to ask parents or carers about what is usual for their child, as you suggested.
Royal College of Nursing	Guideline	13	1.2.23 and 1.6.5	We welcome the acknowledgement that uniforms and masks etc can be a barrier to communication in places such as theatres – perhaps wonder if this recommendation needs to be revisited in terms of wider applicability due to the use of PPE during and post COVID-19 pandemic. Masks are both a physical and visual barrier to communication and also in terms of building rapport and trust with the child and young person and so the impact of these no matter how normal they may seem now should not be underestimated.	Thank you for your comment. This recommendation was not intended to be specific to theatres, as we recognise that PPE may now be worn in many healthcare situations and settings. We have removed the reference to theatre to make this clear.

Royal College of Nursing	Guideline	008 - 009	1.2.1 and 1.2.4	We applaud the acknowledgement and recommendation to include parents and carers and children and young people in communication but would also suggest that listening to the parent / carer is not prioritised over the voice / wishes of children / young people. Concerned that the way these recommendations are written could mean that it is open to interpretation and that parental voice maybe given more weighting than that of the child's / young persons.	Thank you for your comment. The committee tried to find a balance between making the child the focus of the discussion, while also making sure parents of babies and young children were also involved in communications and made to feel welcome. In these recommendations, we have specified that parents and carers should be involved in discussions where babies and young children are involved. The committee felt that it was very important that the voice of children and young people is heard, and not only that of their parents and carers and the recommendations highlight this.
Royal College of Nursing	Question 1	General	General	• *Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why.* - Given this guideline applies to all settings not just purely Children's inpatient environments, dissemination & spread to Dental Nurses, GPNs, Mental Health settings will require significant focus. - It will be important to ensure that information is provided for CYP & Families/carers about the guideline too to encourage them to use with services to raises the standards collaboratively.	Thank you for your comment. We agree that dissemination to a wide range of settings will be important for the implementation of this guideline. We also agree with the importance of dissemination to children and young people themselves. We have passed your comment onto the NICE team who plan implementation support.
Royal College of Nursing	Question 2	General	General	• *Would implementation of any of the draft recommendations have significant cost implications?* - 'Child Development' is not a routine part of the curriculum for all healthcare staff, therefore support in understanding the 'developmental needs' of babies, children and young people will be required. For example many mental health settings employ adult trained mental health nurses, rather than Children's Nurses, supporting them to achieve a good understanding of child development is vital for high quality care. - Further consideration regarding digital engagement, with the challenges of 'digital poverty' may require on-going focus as a result of learning from the pandemic, it is vital that children remain active participants in	Thank you for your comment, for support of the recommendations and for highlighting these potential areas of resource implications and implementation issues. We will pass your comments to the NICE team who plan implementation support.

				their care and that they are able to access support confidentially should they need to, ie are primary care on-line systems accessible to CYP? - It's excellent to see NICE encouraging consideration of the use of advocates for CYP beyond mental health settings, it will be important for these services to be commissioned/available to professionals delivering health care to CYP. Having the infrastructure/resources to seek out and use feedback from BCYP will vital for all services to embed consistently in their practices.	
Royal College of Nursing	Question 3	General	General	• *What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.)* - Examples of best practice via case studies, publications in a range of journals will assist dissemination and spread, use of posters/infographics will be helpful too. - Perhaps running twitter chats, online conferences would be useful too.	Thank you for your comment and for providing us with some examples of resources to help with implementation. We will pass these ideas onto the NICE team who plan implementation support.
Royal College of Nursing	Guideline	012	1.2.16	It may be worth stressing in this recommendation to try and establish the child's / young person's preferred terminology / language and to use these when communicating with them so as to ensure they feel included and involved in the discussions and decision making process.	Thank you for your comment. We have added that the preferred form of communication should be used, as well as identified.
Royal College of Nursing	Guideline	014	1.3.1	Does there need to be specific reference to the regulations regarding consent and the different age ranges that apply in deciding Gillick Competency – we feel this may be helpful rather than just signposting to other guidance, especially given some areas will not necessarily be that familiar with this concept as they will not be children specific services.	Thank you for your comment. We have added a new section to the over-arching principles section on competence, which provides additional guidance on involvement in decision-making and consent for those aged 16 or over, or for those under 16 years.
Royal College of Nursing	Guideline	031	1.10	It may be useful adding that where children / young people are treated as inpatients then separate facilities need to be made available to facilitate education in an environment that is both age and developmentally appropriate but also removed from sleeping and social spaces.	Thank you for your comment. We have added further detail to the recommendations on the environment to facilitate usual activities to include that children and young people may need a quiet space for studying.

Royal College of Nursing	Guideline	031	1.10	Appreciate there is reference to the guidance on transitioning to adult services, however, it may be worth considering including within the recommendation that planning for this should start well in advance of a child's 18th birthday and should include both the young person as well as clinicians from the adult services and consider a period of joint consultations so that all parties are included and involved in the care whilst providing a period of adjustment for the young person. This would also ensure that the young person does not need to recount their health journey to several people multiple times.	Thank you for your comment. As you state, we have included a link to the guideline of transition to adult services and therefore do not think it is necessary to repeat the recommendations from this guideline.
Royal College of Paediatrics and Child Health	Guideline	General	General	There is some concern that the document is aimed at those ages 17 years and below. Evidence shows that maturity is not dependent on age. The same need for age-appropriate care, appropriate environment etc. applies to young adults whose guidance is always conflated with older adults. The WHO define youth as 10 – 25 years and the NHS Long Term Plan included specific mention of services from 0 – 25 years. The rationale for choosing 17 years and under does not seem clear or take into consideration developmentally appropriate healthcare which is what many of those working with young people are working towards rather than defined age criteria. The impact of having guidelines which allow for more ambitious standards and support commissioning of services that actually are aimed to match the needs of young people would be highly beneficial for this often-under-represented group.	Thank you for your comment. This guideline covers children and young people until they reach the age of 18. The NICE guideline on patient experience in adult NHS services (CG138) and the NICE guideline on service user experience in adult mental health (CG136) covers those aged 18 years and above. We appreciate that a young person can be defined as someone aged up to 25 years, but it would be confusing to have overlap between guidelines so a cut-off age of up to18 years was agreed at the scoping stage for this guideline.
Royal College of Paediatrics and Child Health	Guideline	General	General	The guideline is a good summary of how to provide baby, child and young person-centred care, there is nothing radical within it however pushing clinicians to ensure that young people are aware they have the right to see a doctor alone and ensuring their voices are consistently heard within healthcare settings may well be a cultural shift for many practitioners. Similarly, the idea of co-production of health services with children and young people will represent a cultural shift for many organisations and pushing people to do this in a meaningful, rather than tokenistic way is an important but challenging task.	Thank you for your comment and support of this guideline.

Royal College of Paediatrics and Child Health	Guideline	General	General	In order to meaningfully gather and use the experiences of children and young people or to co-produce services with them, particularly with excluded groups, funding for participation workers and service designers or providing additional training and time for existing staff needs to be considered.	Thank you for your comment. We agree there may some funding or training needs to allow full implementation of the guideline recommendations on co-production, and the potential need for increased resources has been acknowledged in the impact section
Royal College of Paediatrics and Child Health	Guideline	General	General	Association for young people's health have lots of examples of excellent patient experience work, including with vulnerable groups. Their views on what is required to do this well should be considered.	Thank you for your comment. Children and young people were involved throughout the development and consultation period for this guideline, including those from seldom-heard groups. We agree that there is wealth of experience from organisations such as yours, and we plan to include links to such organisations on the Information for the public page of the NICE website.
Royal College of Paediatrics and Child Health	Guideline	General	General	Considering how to provide positive experiences for young people through remote appointments and highlighting how a child/young person's needs to be cared for and have contact with family members may in some cases need to over-ride infection control regulations regarding visiting.	Thank you for your comment. We believe this comment relates to the recommendations on environment and we have amended the recommendation to remove infection control issues as a general exception to family-centred care, as this would need to be considered on a case-by-case basis. We also agree that there may be ways to provide positive experiences through remote consultations which are recommended as one possible method of delivering healthcare, but did not find any evidence to allow us to make any more specific recommendations on this subject.
Royal College of Paediatrics and Child Health	Guideline	General	General	Where children and young people are wearing hearing aids or cochlear implants ensure they are working before communicating, i.e. check batteries are working, ear mould tubing is not blocked etc.	Thank you for your comment. The committee discussed whether details such as this should be included in the guideline and, although they agreed this was important, concluded that providing such specific details on a wide range of possible communication tools would make the guideline unwieldy.
Royal College of Paediatrics and Child Health	Guideline	General	General	If possible, ensure that healthcare facilities are fitted with loop systems e.g. at busy receptions or waiting areas.	Thank you for your comment. The committee discussed whether details such as this should be included in the guideline and, although they agreed this was important, concluded that providing such specific details on a wide range of possible communication tools would make the guideline unwieldy. However, we have made an over-arching recommendation about disabilities and the need to make reasonable adjustments at the beginning of the

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					guideline, and the provision of loop systems would fall into this category.
Royal College of Paediatrics and Child Health	Guideline	General	General	Consider the ambient noise and aim to reduce it during a consultation with a child or young person, some healthcare settings can be very noisy.	Thank you for your comment. We have amended the section on healthcare environment to include a recommendation that the environment should be calm with as little background noise as possible.
Royal College of Paediatrics and Child Health	Guideline	General	General	The use of chaperones should be included within the guidance.	Thank you for your comment. No evidence was found on the experience of children or young people in relation to chaperones, but the committee agreed that chaperones may be used where appropriate in healthcare settings (where they are available), and their use is already highlighted in guidance from the General Medical Council and Nursing and Midwifery Council which has been linked from the guideline. The committee therefore did not make separate recommendations in this guideline. However, the guideline does include recommendations in the section on involvement of parents and carers that children and young people can also choose to have another person (not a parent or carer) with them during consultations.
Royal College of Paediatrics and Child Health	Guideline	General	General	Neonates do not seem to be identified separately. The challenges on the neonatal unit for babies and their parents are somewhat different but looking through the guidance, it does not look like neonates/ their parents are separately covered.	Thank you for your comment. The care of neonates is covered in a number of other NICE guidelines, and only a small amount of evidence was identified relating to the healthcare experience of babies. However, the committee were careful to make separate recommendations regarding the care of babies wherever it was agreed to be necessary - such as inclusion of parents on ward rounds, and recommending that they are able to stay in hospital with their baby and participate in the care of their baby. All other recommendations would apply to neonates unless otherwise stated.
Royal College of Paediatrics and Child Health	Guideline	General	General	This is a timely and worthy document which may be difficult to implement across the wide range of health care settings and to encompass babies, children and young people until the end of their 18th year. There may be problems with providing facilities and private areas particularly in primary care where waiting areas are shared and there should be access to play whilst recognising the need for infection control (not only for COVID-19).	Thank you for your comment. The committee agreed that most healthcare settings would already have access to private areas that could be used if necessary for sensitive discussions, but agreed that there may be additional requirements to ensure adequate infection control with shared facilities, equipment or toys particularly in the post-COVID era.

Royal College of Paediatrics and Child Health	Guideline	General	General	Safeguarding and confidentiality issues must be addressed at all stages and vulnerabilities will vary in the age groups and family circumstances.	Thank you for your comment. Safeguarding is included as an over-arching recommendation at the beginning of the guideline as the committee agreed this is of paramount importance. The committee also made detailed recommendations on privacy and confidentiality, and agree that vulnerabilities will vary so a personalised approach to implementation will be required.
Royal College of Paediatrics and Child Health	Guideline	General	General	This document is welcome. Pandemic times have taught us that more is possible digitally, given certain constraints. Time can also be reallocated to spending more time explaining things and trying to achieve a shared understanding (always challenging).	Thank you for your comment and support of the recommendations to use digital methods where appropriate and acceptable to children and young people. We agree that this may, in some cases, lead to more efficient consultations.
Royal College of Paediatrics and Child Health	Guideline	General	General	Children, young people and families from RCPCH &Us have been sharing their views on the experience of care over the last two years, highlighting the following areas as important for improving their experiences. Their comments are: **Mental Health** – all workers supporting their health need to be trained in mental health first aid and be confident in holding conversations to support sign posting to condition supported mental health services (e.g. CAMHS), mental health support as part of early intervention and prevention (tier 1 & 2 support locally pre CAMHS) and good self-care signposting (e.g. Kooth, MeeTwo, The Mix). There needs to be a MECC approach to mental health in the same way there is for other public health topics. See https://stateofchildhealth.rcpch.ac.uk/voice-matters/#page-section-17 and https://paediatrics2040.rcpch.ac.uk/voice-matters/ and https://www.rcpch.ac.uk/resources/covid-19-summaries-key-findings-children-young-peoples-views for more details based on the views of over 2000 children, young people and families.	Thank you for your comment and for sharing with us the work you have done. It was not within the scope of the guideline to consider how specific physical or mental health conditions are managed so the committee were unable to make recommendations about particular referral pathways or approaches to treatment such as the MECC approach. However, the guideline does include recommendations on communication and signposting which will apply to all settings including mental health services.
Royal College of Paediatrics and Child Health	Guideline	General	General	**Children and young people's rights** is also key to supporting an improvement in their experience of care, particularly for practitioners who do not regularly see children and young people e.g. non paediatric specialists. RCPCH &Us identified that key rights are around access to information, their voices informing and influencing individual care and service decision	Thank you for your comments. The recommendations in the guideline apply to all settings, and so will apply even when children and young people see non-paediatric specialists. We agree that all the areas you have listed (information, supporting individual decision-making, supporting education, privacy and confidentiality and the

				making, health services supporting their right to education by not taking them out for appointments and supporting their right to privacy and confidentiality. See https://www.rcpch.ac.uk/resources/rights-matter-what-un-convention-rights-child-means-us and https://stateofchildhealth.rcpch.ac.uk/voice-matters/#page-section-21 Within rights there is a need for improving advocacy and access to independent individual advocacy for children and young people to help support their voice in their health care.	need to improve access to independent advocacy) are important and these have all been covered by recommendations in the guideline.
Royal College of Paediatrics and Child Health	Guideline	General	General	**Improving digital health experiences** due to the shift created by COVID-19 is also a recurring theme for children and young people. Digital is not the right choice for all children and young people for all health interventions, with their experience being significantly affected when they are having to share mental health experiences in a busy household where there might not be space to find a private space, or where they can't ask questions relating to sex, relationships and their medication due to a lack of privacy from parents on the zoom call, or due to digital inequalities such as poor connection, data poverty or shared devices. More needs to be done to ensure that this is explored and understood by all health services, particularly those who are not paediatric specialists e.g. GPs. See more information at https://www.rcpch.ac.uk/resources/covid-19-summaries-key-findings-children-young-peoples-views and re mental health online https://www.rcpch.ac.uk/resources/covid-19-us-views-rcpch-us#supporting-mental-health-in-a-national-crisis and virtual health services https://www.rcpch.ac.uk/resources/covid-19-us-views-rcpch-us#virtual-health-services.	Thank you for your comment. We have now included an additional recommendation in the section of the guideline on privacy and confidentiality to ensure that this aspect of virtual communication is taken into account. We have also added an over-arching recommendation to the beginning of the guideline about digital access, to ensure that alternatives are offered for people who cannot access or prefer not to use digital methods.
Royal College of Paediatrics and Child Health	Guideline	General	General	The reviewer was overall happy with this draft document on healthcare experience.	Thank you for your comment.
Royal College of Paediatrics and Child Health	Guideline	General	General	The reviewer felt that it is a shame that there wasn't a CYP and easy read version of this consultation to support the active engagement of CYP in responding. Healthcare needs to be defined with CYP as they may have a different understanding and/or expectation to health professionals. It would be good for	Thank you for your comment. It was not possible to produce an easy-read version of the guideline for consultation but a consultation with the reference groups of children and young people who had been involved in developing the guideline was carried out. In addition a

				there to be a visual definition of the principles and standards expected which great a good experience as outlined in the guidelines.	visual summary has been created and will be available when the guideline is published.
Royal College of Paediatrics and Child Health	Guideline	General	Section 1.2	Consider using captioning on any video calls and subtitles on any video information (WHO Report on Hearing March 2021 page 210).	Thank you for your comment. We have added an additional recommendation into the over-arching section at the beginning of the guideline to reinforce the need to make reasonable adjustments in light of the Equality Act 2010. The need to consider captions or sub-titles on video calls would be covered by this, and the committee did not consider it was necessary to make a separate recommendation on this.
Royal College of Paediatrics and Child Health	Guideline	General	Section 1.2	Feedback from RCPCH &Us about the knowledge, skills and attitudes of staff working with CYP in health highlight communication skills as being key, particularly around engaging with CYP identities and cultures: https://paediatrics2040.rcpch.ac.uk/voice-matters/.	Thank you for your comment. The committee agree that communication skills are key and have included recommendations about ensuring all staff are appropriately trained in communication skills, and that communication should always be culturally sensitive.
Royal College of Paediatrics and Child Health	Guideline	General	Section 1.2	There should be a reference to the use of pronouns included here re LGBT+ identities.	Thank you for your comment. We have added an additional recommendation to the section on communication to advise that healthcare professionals should identify how children and young people would like to be addressed, including their names and pronouns.
Royal College of Paediatrics and Child Health	Guideline	General	Section 1.2	Reference to the NHS Accessible Information Standard should be included here to ensure patients with disabilities are having their communication and information preferences met as per legislation.	Thank you for your comment. We have included a cross-reference to the NHS Accessible Information Standard in the section of the guideline relating to the provision of information.
Royal College of Paediatrics and Child Health	Guideline	General	Section 1.2	There should be further exploration of Frazer/Gillick and how this links with experience of care and best interest decision making.	Thank you for your comment. We have included an over-arching recommendation at the beginning of the guideline about the assessment of competence.
Royal College of Paediatrics and Child Health	Guideline	General	Section 1.2	There was a suggestion that a guiding overall principle to communicate with the child or YP rather than the parent as the focus should be included.	Thank you for your comment. We agree that the guiding principle should be to communicate with the child or young person rather than the parent, and this principle is demonstrated by recommendations in the sections on communication, consent, support from parents and carers and self-advocacy.
Royal College of Paediatrics and Child Health	Guideline	General	Section 1.2	The reviewers strongly felt that in this section there should there be mention of remote consultation which is increasingly common. In particular mentioning standards for checking and	Thank you for your comment. The use of remote consultation was already included as an option for communication in several sections of the guideline

				recording who is present, if the young person can be overheard, establishing rapport, safety nettting etc. The YPHSIG has co-produced a joint statement on this with the adolescent group of the RCGP, AYPH and RCPCH available here: https://www.yphsig.org.uk/resources-1/adolescent-healthcare/communication-skills/joint-statement-on-virtual-consultation.	including providing information and accessing healthcare. To address the concerns you have raised about privacy we have added an additional recommendation to the section of the guideline on privacy and confidentiality.
Royal College of Paediatrics and Child Health	Guideline	General	Section 1.10	YPHSIG members have highlighted that section 1.10 needs to cover the universal transition that all children and young people go through regardless of their health needs from consulting with their parents/carers to consulting alone. Also, within this section there needs comments to improve access to services by proactively seeing young people by themselves for part of an appointment when they attend with parents, even for a routine matter. This time can be used to check on wellbeing or to explain that they can book appointments for themselves. There could also be use of leaflets for young people and their parents and carers to explain this (examples are available on RCGP website).	Thank you for your comment. There are recommendations on the involvement of parents or carers in healthcare decisions and healthcare appointments, and how this involvement changes over time in the section of the guideline on Involvement of parents and carers (1.5). This section of the guideline also provides recommendations on children and young people seeing the healthcare professional on their own for at least some of the appointment. This concept is also included in recommendations on providing information, risks and benefits and privacy and confidentiality. Thank you for telling us about the leaflets on the RCGP website. We will pass this information to the NICE team who plan implementation support.
Royal College of Paediatrics and Child Health	Guideline	026 - 027 - 028	Sections 1.7.1 and 1.7.6	In the list of unrepresented groups, the deaf and blind sometimes get forgotten. They should be included in this group.	Thank you for your comment. On reviewing the list of under-represented groups in these 2 recommendations we realised that we had not included those with any kind of physical disability, which would include those who are deaf or blind, so we have added 'physical or sensory disability' to the lists.
Royal College of Paediatrics and Child Health	Guideline	020	Section 1.5	The UNCRPD should also be referenced https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html on the sections below: • 1.5.5 Age and development – supporting independence and self-advocacy ready for transitioning to adult services (if long-term condition/ needs arise) 1.5.10 add in “Support them to advocate for themselves”.	Thank you for your comment. The committee agreed it was not necessary to include a cross-reference to this guidance from the guideline itself but that it should be referenced from the Information for the public tab on the NICE website, which provides details of other resources which may be relevant to the guideline. There are recommendations on the involvement of parents or carers in healthcare decisions and healthcare appointments, and how this involvement changes over time in the beginning of section 1.5 of the guideline on

					Involvement of parents and carers. This section of the guideline also provides recommendations on children and young people seeing the healthcare professional on their own for at least some of the appointment. This concept is also included in recommendations on providing information, risks and benefits and privacy and confidentiality. The recommendations on self-advocacy already provide specific recommendations on supporting children and young people to advocate for themselves, so this has not been added to recommendation 1.5.10.
Royal College of Paediatrics and Child Health	Guideline	005	General	The document opening with an introduction from the children and young people themselves is particularly welcomed.	Thank you for your comment.
Royal College of Paediatrics and Child Health	Guideline	007	Section 1.1	The overarching principles identified are agreed with, but it was suggested that there should be a principle around digital health experiences.	Thank you for your comment. We have added an over-arching recommendation about digital access and an additional recommendation in the section on privacy and confidentiality on privacy during virtual consultations.
Royal College of Paediatrics and Child Health	Guideline	007	Section 1.1	The YPHSIG welcomes the reference to age and developmentally appropriate care.	Thank you for your comment.
Royal College of Paediatrics and Child Health	Guideline	009	Section 1.2.6	Also take into account that some of these children and young people may be deaf hearing aid wearers and therefore are very dependent on lip-reading. This has come very much to the fore with the COVID-19 pandemic where PPE is used, especially in the health service, and face coverings prevent the use of lip reading. This group may not then understand a word that has been said to them. This group of children/young people have different needs from those who communicate using sign language. The type of PPE used must be seriously taken into consideration.	Thank you for your comment. The implications for communication of wearing PPE are included in the recommendations on staff uniforms and healthcare clothing.
Royal College of Paediatrics and Child Health	Guideline	010	Section 1.2.9	This is especially important for those deaf children who rely enormously on lipreading as they may have misheard information rather than not heard and it is therefore interpreted incorrectly.	Thank you for your comment. We have amended this recommendation to include checking that children have taken in the information and understood.
Royal College of Paediatrics and Child Health	Guideline	011	Section 1.2.15	Please include a reminder/ guidance on offering support when breaking bad news.	Thank you for your comment. There is a separate later recommendation on giving information which may have an

					emotional impact and this has now been expanded to include the support that may be needed.
Royal College of Paediatrics and Child Health	Guideline	011	Section 1.2.15	Please remind workers about the need to have relevant and current signposting links for national and local services, charities and support.	Thank you for your comment. We already have a later recommendation in the guideline (1.2.27) that recommends signposting to NHS resources, charities and support groups.
Royal College of Paediatrics and Child Health	Guideline	017	Section 1.4	It would be good to signpost to information that has already been created by CYP on rights and confidentiality, e.g. https://www.rcpch.ac.uk/resources/rights-matter-what-un-convention-rights-child-means-us and https://www.byc.org.uk/uk/nhs-youth-forum/youth-rights-in-healthcare.	Thank you for your comment. The committee reviewed this document but decided that the recommendations already included links to professional guidance and so it was not necessary to link to the United Nations Rights document too.
Royal College of Paediatrics and Child Health	Guideline	018	Section 1.4.6	There was a suggestion for point 1.4.6 to include that when possible professionals offer to see the child /young person alone to ensure that they are giving consent, not simply reflecting the views of their parents (this should be a standard offer of care for young people as part of routine consultations).	Thank you for your comment. There are more detailed recommendations in the section on involvement of parents or carers that provide advice on seeing children or young people alone, so these have not been repeated in the section on consent.
Royal College of Paediatrics and Child Health	Guideline	019	Section 1.4.12	There was a suggestion that point 1.4.12 should clarify that it will be confidential in presence of parents/carers and then when seen alone.	Thank you for your comment. Information discussed in confidence (whether the child is alone or with their parents or carers present) should only be shared without consent in certain circumstances (and we have a recommendation to say these circumstances must be explained the child or young person) so we have not amended this recommendation.
Royal College of Paediatrics and Child Health	Guideline	021	Section 1.5.9	YPHSIG members suggest that in point 1.5.9 it would be important to include that it can take time to build rapport, and so services should be encouraged to try and ensure some continuity of care for children and YP with a HCP whom they trust.	Thank you for your comment. Recommendations on building a rapport to develop trust are already included in section 1.2 of the guideline on communication, and recommendations on continuity of care are already covered in section 1.10 of the guideline on access and continuity so we have not repeated this here as well.
Royal College of Paediatrics and Child Health	Guideline	022	Section 1.6	It would be helpful to have more specific guidance on what “enough time in consultations and appointments” means in practice.	Thank you for your comment. The amount of time required will depend on a number of clinical and patient-related factors and so it is not possible to specify how long an appointment or consultation should be.
Royal College of Paediatrics and Child Health	Guideline	025	Section 1.6	YPHSIG members would suggest including in the bullet points of 1.6.1 that healthy food options should be available to children and young people at times that suit their age and	Thank you for your comment. We have added additional information to the recommendations on food to state that there should be greater flexibility in when food is available.

				stage of development (for example having access to a kitchen in the evening for older children).	
Royal College of Paediatrics and Child Health	Guideline	025	Section 1.6	RCPCH &Us members have also noted the impact on their education due to poor health care experiences. It is felt that this should be noted and highlighted both for inpatient and outpatient CYP.	Thank you for your comment. The committee recognise the impact of healthcare on education and this has been included in the recommendations on maintaining usual activities. There are also recommendations in this section of the guideline and in the section on access to healthcare about minimising the impact of healthcare on education and learning.
Royal College of Paediatrics and Child Health	Guideline	026	Section 1.6.4	It is sometimes helpful to have pictures of staff with their names and roles either on notice boards or files that children and young people can refer to for identification.	Thank you for your comment. There was no evidence identified that met our protocol criteria that children's experience would be improved by the use of notice boards so we have been unable to recommend noticeboards or files as you suggest. There was evidence to suggest name badges are helpful, so we have included a recommendation on that.
Royal College of Paediatrics and Child Health	Guideline	027	020	This section needs to be extended to include more around mixed methods approaches to involvement ensuring that there are opportunities at every level of the decision-making process from consultation through to governance and review.	Thank you for your comment. The recommendations relate to measuring individual children or young people's healthcare experience, and we have suggested that this be carried out by the most appropriate method, at the most convenient time. However, the committee did not have sufficient evidence to provide more detail on the exact methods or time points at which experience should be measured.
Royal College of Paediatrics and Child Health	Guideline	028	Section 1.8	This section should be strengthened to provide specific guidance to different settings, e.g. A&E needs to have a space for children and a different space for young people so that if they are in mental health crisis they do not need to sit with either babies or adults, or for GPs there needs to be an understanding of how to design waiting areas and primary care facilities for CYP. https://stateofchildhealth.rcpch.ac.uk/voice-matters/#page-section-26 and https://www.rcpch.ac.uk/resources/rights-matter-what-un-convention-rights-child-means-us#what-do-children-and-young-people-want.	Thank you for your comment. The recommendations in the healthcare environment section of the guideline are principles that are applicable to all healthcare settings, unless otherwise specified, but we agree that the exact details of how these should be implemented in different settings may vary. The committee did not have sufficient evidence for all possible settings to make recommendations that are more specific. Thank you for sharing these links with us. The committee discussed whether to add these to the guideline but agreed that they did not provide any specific information about the environment.

Royal College of Paediatrics and Child Health	Guideline	030	Section 1.9	Maintaining usual activities has been identified by RCPCH &Us as key linked to article 31 of the UNCRC in a health context with additional support from health providers to work with school, families and wider networks to be able to support their health needs in extracurricular activities, trips, sleep overs etc. This has been shared through work with CYP for the Epilepsy12 audit and NACAP Asthma audit. See Recipes for Rights at https://www.rcpch.ac.uk/resources/rights-matter-what-un-convention-rights-child-means-us#what-do-children-and-young-people-want.	Thank you for your comment and for your support for our recommendations on maintaining usual activities. Thank you for sharing this link with us. The committee discussed whether to add a link to this document but agreed that the resources did not provide additional information about maintaining usual activities that would build on the recommendations.
Royal College of Paediatrics and Child Health	Guideline	031	Section 1.10	Transition between services such as A&E to X-ray to GP as well as transition from children's to adults has been an ongoing challenge for RCPCH &Us children, young people and families. Knowledge, skills and attitudes as part of the https://paediatrics2040.rcpch.ac.uk/voice-matters/ programme highlights this, as does the results around "telling my story once" https://stateofchildhealth.rcpch.ac.uk/voice-matters/#page-section-6.	Thank you for your comment. We have included the need to ensure good communication when babies, children or young people are transferred between different healthcare settings or teams, which we hope, will help with the problems you describe. We have also included recommendations on steps that can be taken to make sure children and young people do not have to unnecessarily repeat their healthcare story.
Royal College of Paediatrics and Child Health	Guideline	031	Section 1.10	RCPCH &Us members have also shared frustrations when it comes to staff members changing, and them not being kept informed which is a particular issue for those with long term conditions. This should be added in e.g. "inform patients of changes in care e.g. workers, location of clinic".	Thank you for your comment. The committee agreed that it would be necessary to inform children and young people if there were changes that affected their access to services (such as a clinic location changing), and this would be covered in the recommendation on clear and timely information about where they will be seen (recommendation 1.2.17). We appreciate that staff changes may be frustrating and affect continuity of care but the committee did not think it would be feasible to notify children and young people whenever staff members changed.
Royal College of Paediatrics and Child Health	Guideline	033	Section 1.10.7	The appointment arrangements aiming to minimise time out of education will be complicated but have been piloted by Vencat Reddy (Consultant in neurodevelopment at Peterborough) with digital help.	Thank you for your comment and for letting us know that some of the guideline recommendations are already being implemented.
Royal College of Paediatrics and Child Health	Guideline	033	Section 1.10.11	Addressing the clinic summary letter to the child or young person and sending them a copy with "you" rather than the third person, is possible and would still be understood by the GP or other recipient.	Thank you for your comment and this suggestion about clinic letters. We have already included a recommendation in the section of the guideline about providing information on addressing letters to children or young people themselves so we have not repeated this in this section.

Royal College of Paediatrics and Child Health	Guideline	034	Section 1.10.12	Transition should be added as an example in the first bullet point.	Thank you for your comment. We have not included transition as the first bullet because transition to adult services is not included in the scope of this guideline. However, we have included a link to the NICE guideline on transition from children's to adult's services (NG43) instead.
Royal College of Paediatrics and Child Health	Guideline	036	Recommendations for Research	It was strongly suggested that there should be a recommendation for research linked to the impact of digital health services on CYP experience and engagement in their health care.	Thank you for your comment. We did not specifically look for evidence on the impact of digital health services on children and young people's experience and engagement, and so do not know what evidence is available on this topic. As a result, we are unable to make a research recommendation on this topic.
Royal College of Paediatrics and Child Health	Guideline	037	Rationale and impact	Stronger practice implications need to be identified around training and skill development for staff within health settings linked to: • Mental health • CYP identities and cultures • Children's Rights • Practical engagement skills Digital health service delivery	Thank you for your comment. We note that this is a general comment relating to all the rationale and impact sections. We have reviewed all the impact sections individually and added that there may be training implications to those where there may be a specific need related to the recommendations that have been made.
Royal College of Speech and Language Therapists	Guideline	General	General	While we are pleased to see the recognition of the need to identify and use the child or young person's preferred forms of communication, it is equally important to recognise that children and young people who communicate verbally may also have communication needs which need to be taken into account and may require others to adapt their own communication style, for example by simplifying their language or using visual support.	Thank you for your comment. We have included recommendations that suggest the use of simple and clear language and using additional tools or specialist help to support effective communication and the provision of information.
Royal College of Speech and Language Therapists	Guideline	General	General	Many children and young people have communication needs that may not be immediately obvious, and often go unidentified. A UK population-based survey found that the prevalence of language disorder in children in mainstream schools was 9.92% and in the vast majority (7.58%) this was not linked with a known intellectual disability or medical diagnosis (Norbury CF, Gooch D, Wray C, Baird G, Charman T, Simonoff E, Vamvakas G, & Pickles A. (2016) The impact of nonverbal ability on prevalence and clinical presentation of language disorder: evidence from a population study, *Journal*	Thank you for your comment and for telling us about the prevalence of language disorders. We have included recommendations on identifying and using children and young people's preferred methods of communication, and using additional tools to support effective communication and the provision of information. The committee are aware of the valuable role of speech and language therapists but no evidence meeting the protocol criteria was identified that demonstrated their role

				of Child Psychology & Psychiatry. 57(11):1247-1257. doi: 10.1111/jcpp.12573.) It is important for healthcare staff to be aware of this, and understand the ways that they can adapt their communication to make it more accessible for all children and young people. They should also be aware that speech and language therapists can provide training and advice on how to communicate effectively with children and young people with communication needs, as well as providing assessment and intervention for individual children where appropriate.	in improving healthcare experience and so the committee were unable to include specific recommendations on this.
Royal College of Speech and Language Therapists	Guideline	007	011	We suggest that the child's communication needs and preferences should be explicitly included here (See wording below in bold): 1.1.2 Ensure that all methods of communication, information and discussions are tailored to the age, developmental stage, level of understanding, **communication needs and communication preferences** of the baby, child or young person.	Thank you for your comment. This over-arching section of the guideline relates to tailoring all aspects of delivery to age and developmental stage, and more detailed recommendations that cover communication needs and preferences are included in the later section on communication (1.2).
Royal College of Speech and Language Therapists	Guideline	009	024	Many children and young people have communication needs that may not be immediately obvious, and often go unidentified. A UK population-based survey found that the prevalence of language disorder in children in mainstream schools was 9.92% and in the vast majority (7.58%) this was not linked with a known intellectual disability or medical diagnosis (Norbury CF, Gooch D, Wray C, Baird G, Charman T, Simonoff E, Vamvakas G, & Pickles A. (2016) The impact of nonverbal ability on prevalence and clinical presentation of language disorder: evidence from a population study, *Journal of Child Psychology & Psychiatry*. 57(11):1247-1257. doi: 10.1111/jcpp.12573.) We would recommend adding a separate but related recommendation to precede this one, as follows:	Thank you for your comment. The recommendations on communication already include the need to identify the child or young person's preferred method of communication, so we do not feel another recommendation is needed to state that children and young people may have these needs. We agree that speech and language therapists may be able to provide specialist support, and have added into this recommendation that specialist support may be needed.

				Be aware that the child or young person may have speech, language and communication needs (whether or not these have been previously diagnosed). Children and young people with speech, language and communication needs may have difficulties understanding and remembering what is said to them; explaining and expressing themselves; or following the 'rules' of social interaction. Where appropriate, speech and language therapists can assess children's speech, language and communication needs and give advice on how to communicate effectively with them.	
Royal College of Speech and Language Therapists	Guideline	009	024	We suggest that this wording should be clarified to reflect the fact that many children will understand information better with additional forms of support, even if their own primary means of communication is verbal language. See suggested addition in bold below: 1.2.6 Identify and use the child or young person's preferred forms of communication **and the strategies that help them to understand.**	Thank you for your comment. We have amended this recommendation to state that preferred forms of communication should be identified and used.
Royal College of Speech and Language Therapists	Guideline	009	024	We suggest an additional bullet point here as follows: • **Some children with communication needs may have a communication passport which sets out their communication preferences – healthcare staff should ask children and young people or their parents if they have a communication passport, to prevent them having to repeat information they have already provided.**	Thank you for your comment. We have not included this in this recommendation, as the recommendations on continuity of care already include recommendations on the use of health passports or digital health records so that healthcare history and information is readily available and so children and young people do not have to repeat information unnecessarily.
Royal College of Speech and Language Therapists	Guideline	010	014	We suggest an additional recommendation explicitly to address children's understanding of communication: **When communicating with children and young people, help them to understand by using appropriate supportive strategies. These may include:**	Thank you for your comment. We agree that all these factors are important and they have all been included in the guideline within the recommendations on providing information. The committee agreed these factors could apply to 'communication' or 'information' but did not want to duplicate them in both sections.

				- **Using simple vocabulary where possible** - **Explaining words they may not understand using more familiar language** - **Using shorter sentences** - **Avoiding idioms or non-explicit language** - **Supporting spoken language with visuals such as pictures and diagrams. This can be particularly useful where information is more complex (e.g. a sequence of events)**	
Royal College of Speech and Language Therapists	Guideline	010	015	We suggest additional wording here (relating to recommendation 1.2.22) **Actively encourage them to ask questions and ensure they know what to do if they do not understand or have questions about their care.**	Thank you for your comment. We already have a later recommendation in the guideline (1.2.24) that states 'actively encourage them to ask questions' so we have included in this an additional bullet point abut knowing what to do if they do not understand or have questions about their care, as you suggest.
Royal College of Speech and Language Therapists	Guideline	010	018	If a child or young person is having difficulty communicating, specialist assessment and advice may be required. We suggest an additional bullet point here: - **seeking advice from or making a referral to a speech and language therapist**	Thank you for your comment. We agree that speech and language therapists may be able to provide specialist support and have included the use of specialist support in the earlier recommendation on providing support for individuals with additional communication needs.
Royal College of Speech and Language Therapists	Guideline	011	008	While in agreement that all staff involved in providing healthcare services to babies, children and young people should have skills and competencies in relevant communication skills, there is a risk that not specifying what those skills are will result in variation and a poor experience for some children and young people. Communication Access UK is an initiative developed in partnership by charities and organisations that share a vision to improve the lives of people with communication difficulties. Together, the partners have developed a free training package which individuals (and organisations) can undertake to improve their awareness of communication difficulties and improve their	Thank you for your comment. It is not within the remit of NICE guidelines to recommend specific training, although the committee discussed whether any particular standard or level could be defined but agreed this may vary for different groups of staff. However, thank you for informing us of the resources from Communication Access UK and we will pass this on to the NICE team who plan implementation support.

				own communication. For more information, see https://communication-access.co.uk/individual-register/	
The Christian Institute	Guideline	023 - 025	General	We have serious concerns about the level of attention given to independent advocates in the guidance, in particular the suggestion of “expanding the availability of independent advocates services to support children or young people who are not eligible under legislation, but who are not adequately represented by their parents”. The phrase, “not adequately represented by their parents” is highly ambiguous and open to interpretation. The recommended promotion of these advocates through posters and leaflets, and the broadening of the role of these advocates, will likely raise concerns about the potential impact on parental authority and family life. There are distinct echoes of the Scottish Government’s statutory Named Person scheme, which attempted to introduce mandatory state officials to monitor children’s ‘wellbeing’. In 2016 the Supreme Court stated that this scheme was incompatible with the rights of children, young persons and parents under Article 8 of the European Convention on Human Rights. Obviously the committee’s recommendations are not directly comparable to the Named Person scheme. Nevertheless, the rationale behind enlarging the role of independent advocates, and the overall trajectory of such a move, should be scrutinised. This is especially the case given that the only evidence found to support these recommendations emerged from a single focus group involving 11-14 year olds. The overall quality of this evidence was classified as ‘low’.	Thank you for your comment. The committee discussed the most appropriate way to word this recommendation suggesting an expansion of independent advocacy services. They agreed that this service should be reserved only for children who could not be adequately supported by their parents or carers or other professionals (for example a social worker, or key worker), and that healthcare professionals would be in a good position to decide if the involvement of an independent advocate should be considered in individual circumstances. The evidence base for the use of independent advocates included the expert testimony of an expert witness, as well as the evidence from the focus group that you have noted.
The Christian Institute	Guideline	022 - 023	General (Self-advocacy)	It is not clear how the repeated emphasis on self-advocacy and empowerment fits with parental rights and the family structure. The guidelines risk giving the impression that children are merely autonomous units, that their decisions carry equal weight to those of their parents, and that ‘empowering’ children to disentangle themselves from family influences and “advocate for themselves” is a chief priority. But it is not the duty of professionals to prematurely remove the scaffolding of family life. To do so could be highly damaging for both the child and their parents. What problem is the emphasis	Thank you for your comment. There was a great deal of evidence from the review questions included in this guideline on communication, shared decision-making, risks and benefits, support from parents or carers and self-advocacy, and from the focus and reference groups, that children and young people wished to be involved in decisions about their healthcare. This included the children from the youngest groups who were aged 4 to 7 years. This was also agreed by the young people on the committee.

				on ‘empowerment’ attempting to correct? We recognise that the committee found evidence that “*young people did not want healthcare professionals to make assumptions about their ability to express their views and opinions.*” This is unsurprising. However, the evidence report goes on to say that the “*over-involvement of parents*” can tend to *“invalidate the child’s or young person’s wishes, feelings or independence.”* It is not clear what this means in practice, because there could be a broad spectrum of situations ranging from the trivial to the life-changing. It is one thing to ask a child, without consulting parents, about what colour bandage they would like; it is quite another to affirm their desire to pursue a life-altering medical pathway in the face of serious parental concerns. A child’s “*wishes, feelings or independence*” is mitigated by a still-developing brain, the turbulent experience of growing up, and the natural degree to which a child is dependent on their parents. The guidance says that professionals should assume that “*all children*” will have views and opinions about their own healthcare. This needs to be qualified. While it would be fair to assume that a child may have a preference about, for example, the flavour of a medication, it would be not be fair to assume that a young child has opinions about more particular, nuanced and complicated medical decisions. The relevant evidence reviews says that “*all children (however young) should be given the opportunity to express their own opinions”* and “*asked about how much they wanted their parents or carers involved”*. It is difficult to see how ‘however young’ can be applied literally.	The committee appreciated that there may be situations where a child or young person is not competent to make a particular decision and have therefore added an additional recommendation to the section on over-arching principles at the beginning of the guideline to clarify the guidance on assessment of competence.
The Christian Institute	Guideline	007	001	We appreciate the emphasis on parents’ right to be involved in decisions about the health of their babies and children. However, given the distinction outlined in paragraph 1.2.1, it may be inferred that while parents are encouraged to be involved in decisions concerning a baby or young child, they do not have this right for older children. We would strongly oppose this inference. The guidelines should stress the positive, comprehensive role of parents at all points in the decisions about their children’s health and care.	Thank you for your comment. Based on the evidence identified for this guideline, the committee agreed that children and young people should be involved in discussions and decisions about their healthcare, and that they should be the focus of these discussions. The guideline provides details on the recommended ways to involve parents and carers in section 1.5.

The Christian Institute	Guideline	009	001	It is good that parents are encouraged to participate in decisions about their babies' and young children's care. However, the paragraph (1.2.1) suggests a distinction between a) children and young people, and b) babies and young children, with the implication that parents are *not* encouraged to contribute to the decisions of children/young people.	Thank you for your comment. Based on the scope and evidence identified for this guideline, the committee agreed that children and young people should be involved in discussions and decisions about their healthcare, and that they should be the focus of these discussions. The guideline provides details on the recommended ways to involve parents and carers in section 1.5.
The Christian Institute	Guideline	012	010 - 015	'When appropriate' is a vague expression. In what situation would it be appropriate to text or telephone a child directly, with the intention of bypassing legitimate parental oversight? Parents should be excluded from communication in only a tiny minority of cases. Ordinarily, the position of parents should be affirmed, and healthcare providers should be at pains to avoid parents being bypassed. If this provision is supposed to serve as a check against the possibility of parental abuse, it must not be assumed that parents are more likely to harm a child than a professional. If it is not generally considered appropriate for a school teacher to text or telephone a child directly, with the intention of excluding their parents, why a healthcare professional?	Thank you for your comment. Based on the evidence identified for this guideline, the committee agreed that children and young people should be involved in discussions and decisions about their healthcare, and that they should be the focus of these discussions. The guideline provides details on the recommended ways to involve parents and carers in the section on this topic, but there was evidence that in many situations children and young people wished to speak to their healthcare professional without their parents present, if they are deemed competent and this could include by letter, text or telephone.
The Christian Institute	Guideline	012	024	The remark about information being 'not judgemental' ought to be taken as a general principle only. Of course, clinicians should avoid making assumptions and moral judgements about a child's (or parent's) behaviour or motivations. However, there will be situations where healthcare decisions involve a moral dimension – a point presupposed by the recommendation itself. In such situations, clinicians should not be required to sidestep their moral responsibility, albeit remaining sensitive and caring.	Thank you for your comment. The focus of the guideline is about the healthcare experience of babies, children and young people and so this recommendation is to ensure that these groups never feel judged by their healthcare professionals. We think this is a separate issue to healthcare professionals having to make a judgement about treatment in the individual's best interests.
The Christian Institute	Guideline	016	015	While it may be unnecessary (and insensitive) to share unqualified information about medical risks with children, this recommendation must not be used to undermine good practice. NHS Greater Glasgow and Clyde faced controversy recently for failing to acknowledge the risks of puberty-blocking drugs. In 2019 the NHS Gender Identity Development Service was likewise found to have omitted important information about the drugs on patient information sheets. Such omissions cannot be justified. For their own good, children must be made	Thank you for your comment. We have amended this recommendation to make it clear that when children or young people are providing informed consent there is a requirement to provide them with information on risks and benefits.

				aware of risks such as these, even if they do not wish to be. To ensure they can make an informed decision (p. 7), the information shared with them must ultimately be determined by the likelihood and level of risk involved – not the preferences of the child.	
The Christian Institute	Guideline	018	002	Even when a child may grasp the meaning of consent as a concept, it does not follow that they are equipped to assess benefits and risks at an adult level themselves to make an informed decision. The recent Keira Bell case saw High Court judges saying it was “highly unlikely” children 13 and under could ever genuinely consent to hormone blockers, and “very doubtful” 14 and 15 year olds could do so. This common-sense observation – that even many teenagers lack the capacity to genuinely consent to certain treatments – is not altered by discussions about consent with the child.	Thank you for your comment. The ability to make healthcare decisions and provide informed consent is covered by guidance on Gillick competence and therefore we have made new recommendations in the over-arching principles section at the beginning of the guideline to provide more clarity on the ages at which children and young people can be deemed competent to give consent.
The Christian Institute	Guideline	019	005	Clear limits must be set on when it is appropriate for children to discuss private matters outside the bounds of parental oversight. Generally, parents should be entitled to know the physical and mental health condition of their child or young person, even if this may cause embarrassment to the child. Parents should be consulted before action is taken. This point is lacking from the guidance. It should be remembered that if this provision serves as a protection against the risk of parental abuse, there must also be an eye to the risk of abuse and manipulation by a medical professional. Transgender healthcare provides a recent fitting example. One detransitioned woman says, *“On the first appointment he said, “Let’s not waste any more time,” and injected me with testosterone. It was what I wanted, but I now think it was wrong — what I really needed was psychotherapy.*” Others now applaud their parents for attempting to prevent them accessing life-altering hormones.	Thank you for your comment. There was a great deal of evidence from the review questions included in this guideline on communication, shared decision-making, risks and benefits, support from parents or carers and self-advocacy, and from the focus and reference groups that children and young people welcome the opportunity to see healthcare professionals on their own, at least for some of the time or in some situations. Furthermore, children and young people aged 16 and over have the right to make their own decisions and to provide informed consent, and those under 16 have this right if they are deemed competent. This has now been clarified in recommendations about competence in a new over-arching section at the beginning of the guideline. We appreciate that children and young people may wish to involve their parents or carers and this guideline supports those who do, but it also supports children and young people who do not wish them to be involved.
The Christian Institute	Guideline	019	015	The emphasis on parental involvement regarding babies and young children is good. However, the distinction outlined in paragraph 1.2.1 could be taken to mean that parental involvement should be *limited to* decisions regarding a baby or young child, and not extend to older children. The guidelines	Thank you for your comment. We have amended recommendation 1.2.1 so that it now includes all parents, and not just parents of babies and young children.

				should also emphasise the role of parents the raising of older children.	
The Christian Institute	Guideline	020	General	In highly exceptional circumstances it may be necessary to exclude parents from a discussion with a child. However, the insistence in the guidance that professionals ought to “regularly” ask children if they want to exclude parents may ultimately be detrimental to the child-parent-carer relationship. Healthcare professionals must be aware that children are often very open to suggestion, and they must not be led to adopt an attitude of suspicion or scepticism towards their parents. Parents have a right to be involved in decisions about their child’s medical pathway, and on rare occasions they may need to exert control over the wishes of their child in a medical dispute. This could be the case, for example, in cosmetic decisions, such as where an orthodontist offers a child a referral to (non-essential) maxillofacial surgery. In such a scenario, the parent may well be in a better position than the child to consider the consequences of such a decision.	Thank you for your comment. There was a great deal of evidence from the review questions included in this guideline on communication, shared decision-making, risks and benefits, support from parents or carers and self-advocacy, and from the focus and reference groups that children and young people welcome the opportunity to see healthcare professionals on their own, at least for some of the time or in some situations. Children and young people aged 16 and over have the right to make their own decisions and to provide informed consent, and those under 16 have this right if they are deemed competent. This has now been clarified in recommendations about competence in a new over-arching section at the beginning of the guideline. We appreciate that children and young people may wish to involve their parents or carers and this guideline supports those who do, but it also supports those children and young people who do not wish them to be involved.
The Christian Institute	Guideline	021	010 - 013	This advice is understandable and helpful in most cases. However, as the guidance emphasises on p. 14 (1.3.1), decision-making must be shared between children, parents, and professionals, and there is a risk that this emphasis may be lacking here. When the guidance says professionals should “discuss with [children] how you will act on what they have said”, it would be helpful if it was clarified that children do not have the right to demand certain treatments. The reference to pain and discomfort does help to clarify what is meant by ‘experiences’. This is helpful. However, while clinicians should adopt a generous and open attitude towards children’s experiences, and resist being sceptical of their claims, this should never undermine good medical practice. Nobody has an unquestionable right to be believed, and it is not the responsibility of professionals to affirm or validate each and every whim of their patients. The relevant evidence review states that “*there was also evidence that children and young people like to be listened to and believed*”. This is an	Thank you for your comment. The recommendations were designed to enable the development of a trusting healthcare relationship but this would not over-ride the professional judgement and professional responsibility of the healthcare professional to provide appropriate care and treatment in the child or young person’s best interest. Healthcare professionals would be acting outside their own professional guidelines if they were to accede to demands for treatments that were inappropriate.

				unremarkable finding which does not provide a justification for unqualified belief and approval of a child’s experience and desire. To “*be seen to believe their experiences”* must not be without qualification.	
Together for Short Lives	Guideline	General	General	In its current form we feel that the draft guideline does not adequately consider babies, children and young people who are not cognitively able and whose experience of healthcare is most likely not straightforward. We have identified several gaps which the guideline should seek to address in order to better represent these children. Firstly, the guideline does not consider that children with complex medical conditions are cared for across multiagency and multi-professional groups. In the guideline there is little mention of sharing good practice and other information. To promote good practice, and call to account poor practice, it is important to have a holistic view of the child’s experience. The guideline must put more emphasis on the sharing of information between agencies and professional groups so to avoid duplication of effort for the child and family. We also feel that the guideline needs to better sign-post to other resources. This would be helpful in ensuring that children who need palliative care have a positive experience of healthcare. This should include *NICE guideline on end of life care for infants, children and young people with life-limiting conditions: planning and management.* Another gap in the guideline is that there is no mention of transitional planning. This is vitally important for children with complex needs and long-term conditions. As noted in Together for Short Lives’ guide to enabling good transition, *Stepping Up*, providing care for young people with life-limiting or life-threatening conditions is complex because of the interaction between the many services that they need to support them,	Thank you for your comment. We recognise that the guideline does not provide specific recommendations for children and young people who are not cognitively able, or those with complex medical conditions who are cared for across multiagency groups. This is because a NICE guideline on 'Disabled children and young people up to 25 with severe complex needs’ is currently in development and due to be published in early 2022, and this will make recommendations that cover the integration of healthcare, education and social care. We also recognise that the guideline does not specifically cover the needs of children who need palliative care. End of life care was excluded from the guideline as this is covered by the separate NICE guideline on End of life care for infants, children and young people (NG61). However, to address your comment we have added a cross-reference and hyperlink to NG61 within the communication section of the guideline. Transitional planning is already covered in existing or future NICE guidelines as well. There is an existing NICE guideline on Transition from children's to adults' services for young people using health or social care services (NG43), and transition from children's to adult services from the point of view of integrated education, health and care will also be covered in the forthcoming guideline on children and young people with severe and complex needs mentioned above. We have added additional wording into the recommendations on possible conflicts of opinion, stating that the child or young person's best interests should be at the heart of the discussions, and we have added in a link to

				from both children's and adults' services. In transitioning to adult services, young people will need support from a range of agencies to enable them to achieve what they want in life, alongside support from health professionals and palliative care services to meet their complex health needs. We feel that this challenge needs to be reflected in the guideline. In addition, it is important for the guideline to capture areas where conflict may arise - either between parent, child or professional. On this, we feel that the guideline needs more emphasis on the best interest of the child. This could refer to the 2004 Children Act in terms of children's rights and interests are defined or Article 3 of the United Nations Convention on the Rights of the Child (UNCRC).	the 1989 Children's Act (and subsequent updates) in the over-arching principles on safeguarding. The guideline also provides recommendations in the section on consent about the approach to be taken if there is a conflict of opinion between parent, child or professional, and also includes reference to the United Nations Convention on the Rights of the Child and states that healthcare professionals should uphold these rights.
Together for Short Lives	Guideline	General		**Question 1: Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why.** n/a **Question 2: Would implementation of any of the draft recommendations have significant cost implications?** n/a **Question 3: What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.)** We think that it would be helpful for the guideline to refer support for children with life-limiting conditions. Specifically, it would be helpful to direct children, families and professionals to Together for Short Lives' Family Support Hub which offers emotional support and practical advice, connections for	Thank you for your comment. We have responded to your answers to these questions individually. Question 3: Thank you for suggesting the Together for Short Lives Family Support Hub. We have not linked directly to the hub from the guideline but have included a link to the NICE guideline on End of life care for infants, children and young people (NG61) and note that there are a number of links from here to the excellent resources produced by Together for Short Lives. Question 4: Thank you for sharing with us the studies and surveys, which have identified the impact of the Covid-19 pandemic on children and their families. We have addressed some of the issues relating to PPE in the guideline recommendations and hope that overall the recommendations in the guideline will help improve the healthcare experience of babies, children and young people, whether at a time of global pandemic or not.

				families, and helping families access free legal advice if they need it. **Question 4: The recommendations in this guideline were largely developed before the coronavirus pandemic. Please tell us if there are any particular issues relating to COVID-19 that we should take into account when finalising the guideline for publication.** During the pandemic, most families caring for a child with a life-limiting condition have felt even more isolated and alone than normal. The pandemic has had a massive impact on communication, with parents unable to be present in healthcare settings, the use of PPE frightening to some children and the lack of therapeutic touch. Published in June 2020, Together for Short Lives' SHARE study, in collaboration with Martin House Research Centre and the University of Southampton, revealed that: - 93% of families felt isolated during the pandemic - 57% said isolation has brought up negative memories - 95% are fearful that their child will catch the virus from their parent - 93% fear their child's treatment will be cancelled or delayed. - Families missed out on vital care and support for their child while many services were suspended	

				In addition, in March 2021 the Disabled Children's Partnership published findings from it's latest survey to parents of disabled children. The survey revealed that disabled children and their families are at risk of developing serious mental health issues as a result of the COVID-19 pandemic. The levels of anxiety, isolation and poor mental wellbeing reported are higher compared to the rest of the population. The survey also found that: - Over 90% of disabled children are socially isolated, with 49% of disabled children not seeing a friend in the last month either online or in person. This sadly isn't limited to children, with three in five parents also socially isolated. - This isolation has had a painful impact on the development of life skills in disabled children. Around half of parents highlighted a negative impact on skills, such as being out and about, communicating with others and interacting with strangers. - As a result, both parents and children are continuing to experience poor emotional wellbeing. On average six out of ten parents are observing symptoms associated with anxiety. 72% of parents report that their child is often unhappy, downhearted, or tearful. Their siblings are also affected with a high proportion of parents reporting that their other children are having negative issues regarding sleep and anxiety. We believe that it is important that this guideline reflect this context of the COVID-19 pandemic in describing a positive	

				experience of healthcare for disabled babies, children, and young people.	
Together for Short Lives	Guideline	General	General	Hospices should be specifically mentioned in the settings where this guideline applies.	Thank you for your comment. Hospices are not mentioned in the settings as end of life care was excluded from the guideline, as this is covered by the separate NICE guideline on End of life care for infants, children and young people (NG61), but a link to this guideline has now been included.
Together for Short Lives	Guideline	007	010	Whilst alternative means of communication are mentioned in the guideline, on the whole the guideline is set up for children who can communicate and wish to advocate for themselves. We are aware that most settings will not have the resources or staff the knowledge base to do this. This guideline should do more to describe in detail these alternative means of communication for children with special educational needs and disabilities.	Thank you for your comment. The guideline included recommendations to use the child or young person's preferred form of communication and to take into account additional resources or time that might be needed. However, we have now made several amendments to the guideline to ensure that the communication is accessible, by including an over-arching recommendation on making reasonable adjustments for disabilities, and included the use of specialist support, augmentative and alternative communication, and included a cross-reference to the NHS Accessible Information Standard. We are also a aware that there is currently a NICE guideline in development on children and young people with severe and complex needs that will address more specifically the integrated healthcare, education and care needs of children and young people with special educational needs and disabilities.
Together for Short Lives	Guideline	009	004	The guideline should put more emphasis on the importance of honesty in communication. This is particularly important for children with serious life-limiting/life-threatening illness. The guideline should also specify the need to be aware of their and their parent carers' understanding of the prognosis. The guideline should also ensure that professionals have the necessary skills in having 'difficult' conversations. Together for Short Lives has helpful resources to guide this.	Thank you for your comment. End of life care was excluded from the guideline as this is covered by the separate NICE guideline on End of life care for infants, children and young people (NG61). However, to address your comment we have added a cross-reference and hyperlink to NG61 within the communication section of the guideline. Thank you for telling us about the resources Together for Short Lives produces, and we note that these are accessible via links on the NICE website pages for NG61.
Together for Short Lives	Guideline	009	009	In discussing communication, there needs to be more focus on the continuity and consistency of communication for children who have multiple experiences of care settings. This should encourage good team working and consistent care by people	Thank you for your comment. The committee agree that continuity, co-ordination of care and communication are very important and recommendations on continuity and coordination of care are contained in section 1.10 of the

				who know and understand the child. This is important as people will need to get to know the nuances of care for the child and the families' specific needs in order to communicate effectively and positively.	guideline. They include recommendations on continuity of health carers, exchange of information and coordination of ongoing care.
Together for Short Lives	Guideline	010	006	In using creative and interactive tools, the guideline should note that it is important to use play therapists to communicate with children through play.	Thank you for your comment. We have included mention of play specialists in some recommendations as examples of some of the types of healthcare professionals who can be involved in supporting children and young people, but we did not have evidence to demonstrate that play specialists should always be used to communicate. Furthermore, the committee were aware that play specialists were not available in all healthcare settings.
Together for Short Lives	Guideline	013	022	Here the guideline should consider referring to information that has the PiFTICK chartermark	Thank you for your comment. The committee were aware of the role of the PiFTICK scheme in accrediting information but did not think it was appropriate to recommend that only PiFTICK accredited information should be used, and so did not amend this recommendation.
Together for Short Lives	Guideline	016	023	The guideline should include a note on having conversations about death and dying, the concept of parallel planning, advance care planning, and also What Matters Most conversations. These conversations should also be recorded.	Thank you for your comment. End of life care was excluded from the guideline as this is covered by the separate NICE guideline on End of life care for infants, children and young people (NG61). NG61 provides detailed advice on conversations about death and dying and advance care planning so we have not included details of these.
Together for Short Lives	Guideline	018	002	In section 1.4 on Consent, privacy and confidentiality, there should be a mention of consent to investigations and consent to participating in research studies. A helpful resource to guide this would be the UK Policy Framework for Health and Social Care Research.	Thank you for your comment. The committee agreed that the principles behind the recommendations on consent were the same, whether the consent was for treatment, investigations or research and so did not add this additional detail into the recommendations.
Together for Short Lives	Guideline	018	009	The guideline could refer to the process of seeking second opinions - the RCPCH is developing new guidance on this.	Thank you for your comment. The recommendations on difference of opinion suggest involving other people in the discussions, and we have expanded this to specifically include another healthcare professional, and this could include obtaining a second opinion. However, the committee agreed that every situation would be different and the recommendations could not therefore specify the process to be followed in specific cases.

Together for Short Lives	Guideline	019	013	Here the guideline should mention foster carers, birth parents, and parents who are separated. This would help ensure clarity about who is communicating with whom.	Thank you for your comment. The terminology 'parents or carers' is included throughout the guideline and is defined in the 'terms used in this guideline'. This definition already includes foster carers and we have clarified that it includes birth and adoptive parents.
Together for Short Lives	Guideline	022	004	Here the guideline should encourage self-agency in young people to prepare them for transition to adult services	Thank you for your comment. The guideline recommendations provide advice to encourage self-advocacy/self-agency and we agree that this will help in transition to adult services. However, it was not within the scope of the guideline to provide specific advice on transition as this is already included in the NICE guideline on transition from children's to adults' services (NG43).
Together for Short Lives	Guideline	026	004	This should refer to the *NICE guideline on end of life care for infants, children and young people with life-limiting conditions: planning and management.* This section should also refer to 'All About Me' documents or health passports for when young people complex needs are admitted to hospital.	Thank you for your comment. Although end of life care is outside the scope of this guideline, we agree that the NICE guideline on end of life care includes excellent advice on pain management so we have included a link to it here. We have included a recommendation in the section on continuity and coordination of care to use health passports or digital health records when children or young people are seen by different healthcare professionals, and this would include young people with complex needs.
Together for Short Lives	Guideline	029	27	In thinking about a healthcare environment, it is important to think about the child's sensory needs. This should be reflected in the guideline	Thank you for your comment. We have added a recommendation that the environment should be calm with as little background noise as possible.
Together for Short Lives	Guideline	030	004	This section should also reflect that older children may also want to talk about relationships and their partner visiting	Thank you for your comment. We have added partners to the examples of usual support networks.
Together for Short Lives	Guideline	033	001	Here the guideline should note that older teenagers may be on adult wards for the first time as an example of something to be taken into account	Thank you for your comment. We have not included this in this recommendation, as the recommendations on environment already include recommendations that the healthcare environment should be appropriate for the age and developmental stage and take into account an individual's preferences.