NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Guideline

Babies, children and young people's experience of healthcare

Draft for consultation, March 2021

This guideline describes good patient experience for babies, children and young people, and how it can be delivered . It is recognised that parents or carers play a key role, and their views have been taken into account where appropriate when developing the recommendations. It aims to make sure that all babies, children and young people using NHS services have the best possible experience of care**.**

The recommendations in this guideline apply to all healthcare experiences, but for some babies, children and young people, interaction with healthcare services will be occasional (for example, visits to a dentist or GP), while for others interactions will be frequent or ongoing (for example, inpatient stays), so an individualised approach to implementation is needed.

Who is it for?

- Healthcare professionals, commissioners and providers of NHS or local authority healthcare services
- Non-clinical staff who come into contact with patients (for example, receptionists, clerical staff and domestic staff)
- People aged 17 and under using healthcare services, their families and carers, and members of the public

What settings does it apply to?

- All settings (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.

What does it include?

- the guideline introduction and context
- the recommendations
- recommendations for research
- rationale and impact sections that explain why the committee made the recommendations and how they might affect practice.

Information about how the guideline was developed is on the guideline's webpage. This includes the evidence reviews, the scope, details of the committee and any declarations of interest.

The recommendations in this guideline were mostly developed before the COVID-19 pandemic. Please tell us if there are any particular issues that have arisen from COVID-19 that we should take into account when finalising the guideline for publication.

For information on experience of adult healthcare services please see the NICE guideline on patient experience in adult NHS services.

Contents

Introduction from the young people involved in the development of this guideline

When babies, children and young people access healthcare it is important that their experience is as positive as possible. This guideline has been written with children and young people who know what it's like to be a patient. It has been an opportunity to share what has and has not worked, and hopefully improve the healthcare experience of many babies, children and young people in the future.

People often see children and young people as passive recipients of healthcare. This can lead to children and young people not being listened to, having a lack of understanding of their own condition and may lead to problems that can affect future care (for example, finding it difficult to trust healthcare professionals or feeling very anxious before procedures). However, having a positive experience can make a child or young person feel confident, empowered and supported to manage decisions about their own health and healthcare, and can improve their perception of their diagnosis and treatment. This positive experience should also ensure that babies, children and young people are treated as individuals with a life outside healthcare, and not just as their condition or diagnosis.

This guideline aims to improve the healthcare experience of babies, children and young people with the hope that this can improve their health outcomes and their wellbeing.

Context

Optimising patient experience has long been recognised as an integral part of effective healthcare for adults. The healthcare experience of babies, children and young people has received less attention in the past, despite the legal rights of children to participate in decisions which affect them. Unfamiliar environments and having to meet and interact with a range of healthcare professionals can be particularly unsettling for babies, children and young people, and may lead to anxiety and distress.

Many NHS providers of healthcare services for children and young people currently carry out user surveys directly with children and young people as well as with their parents or carers, and some run focus groups to obtain feedback from children and young people and their parents or carers, with a view to improving the provision of services and the experience of healthcare. However, surveys of children and young people's healthcare experiences have identified that feedback from children themselves is generally less positive than their parents' responses, with a third of children in one survey reporting that they did not always understand what staff said, and over half felt they were not involved enough in making decisions about their care or treatment.

Whilst there are some examples of good practice and initiatives to improve babies, children and young people's experience of healthcare, there is variation in practice across the country.

This guideline covers babies, children and young people (aged 17 and under) accessing NHS physical or mental health services, or local authority-commissioned healthcare services. The recommendations in this guideline apply to all healthcare experiences, but for some babies, children and young people, interaction with healthcare services may be limited to occasional visits to a dentist or GP, while other babies, children and young people may have medical conditions which require frequent interactions, inpatient stays and an ongoing healthcare relationship with professionals, so an individualised approach to implementation is required.

The guideline provides evidence-based information for healthcare professionals, children, young people and their parents or carers about communication, information, support, the healthcare environment, access and continuity of care. It also provides guidance on maintaining usual activities as babies, children and young people need the opportunity to grow, learn and develop alongside their peers, despite their healthcare needs.

Recommendations

Children and young people have the right to be involved in discussions and make informed decisions about their care, as described in NICE's information on making decisions about your care.

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.

Making decisions using NICE guidelines has information about prescribing medicines (including off-label use), professional guidelines, standards and laws (including on consent and mental capacity), and safeguarding that should be used alongside this guidance.

Making decisions using NICE guidelines also explains how we use words to show the strength (or certainty) of our recommendations.

1.1 Overarching principles

Safeguarding

1.1.1 Adhere to all relevant legislation and follow all national and local safeguarding policies and professional guidelines when implementing these recommendations and when planning and delivering healthcare services for all babies, children and young people, in any setting. See further guidance in the NICE advice on safeguarding.

Age and developmentally appropriate care

1.1.2 Ensure that all methods of communication, information and discussions are tailored for the age, developmental stage and level of understanding of the baby, child or young person.

1.1.3 Recognise that needs and preferences may change as children mature, and that it is necessary to revisit these needs and preferences on a regular basis and to adapt support, information and complexity of discussions accordingly.

Changes in needs and preferences

1.1.4 Recognise that children and young people's needs, preferences and engagement with healthcare professionals and healthcare services (for example, how much they would like to be involved in decision-making or how much support they need) may vary from day to day, at different encounters or may be affected by other factors (for example, how unwell they are feeling).

1.1.5 Ensure that previously expressed needs, preferences or engagement levels are revisited, and give additional or alternative opportunities for discussions or decisions, particularly if personal or clinical circumstances have changed.

For a short explanation of why the committee made these recommendations see the rationale and impact section on overarching principles.

Full details of the evidence and the committee's discussion are in evidence reviews A: Shared decision-making; C: Consent privacy and confidentiality; D: Providing information; E: Risks and benefits; F: Involvement of parents or carers; G: Support from healthcare staff; M: Healthcare environment

1.2 Communication and information

Communication by healthcare staff

1.2.1 Ensure that children and young people (and their parents or carers, as appropriate) have a positive experience by:

- being friendly
- putting the child or young person and the parents or carers of babies and young children at ease
- building a rapport to develop trust

- encouraging children, young people and the parents and carers of babies and young children to contribute to, and be active participants in, discussions and decisions about their care.

1.2.2 Communicate with children and young people and their parents or carers with:

- kindness, compassion and respect
- cultural sensitivity
- a non-judgemental attitude.

1.2.3 When communicating with children and young people, particularly those with ongoing health needs, develop an understanding of them as individuals, not only based on their health condition or diagnosis.

1.2.4 Take time to listen to and address the concerns and fears of children and young people, and of the parents or carers of babies and young children. Treat their concerns and feelings (such as fears and embarrassment) with empathy and understanding.

1.2.5 Identify who is the most appropriate person to communicate with a child or young person, or the parent or carer of a baby or young child (for example, this could be a healthcare professional or other member of the multidisciplinary team, another professional such as a youth worker or social worker). When deciding on the person, take into account:

- the clinical circumstances
- the subjects to be discussed
- the preferences of the child or young person.

1.2.6 Identify and use the child or young person’s preferred forms of communication. Ask their advice, or ask their parents or carers what these are. Take into account that:

- English may not be their first language
- these may be non-verbal (for example, sign language, Makaton)

- these might need additional resources (for example, foreign language or sign language interpreters, picture boards, computer-based systems)
- individuals with additional communication needs might need more time for alternative forms of communication.

1.2.7 Use developmentally appropriate creative and interactive tools to help effective communications with babies, children and young people (for example, play dough, puppets, games).

1.2.8 Help engage babies, children and young people in communication by:

- using both verbal and non-verbal methods (for example, sitting at the same level as them, using body language to show attentive listening, reassuring babies by positive touch or containment holding before or during procedures)
- pausing and allowing time for responses.

1.2.9 When communicating with children and young people, always check understanding (for example, by asking children or young people to explain back to you in their own words).

1.2.10 If a child or young person is uncomfortable or having difficulty communicating, try alternatives that may help. This may include:

- trying again at a different time
- involving a different person
- using a different means of communication
- considering whether more privacy or a different setting is needed (see recommendations 1.4.8 and 1.4.9) .

1.2.11 Respect times when children and young people do not wish to communicate, and be aware that their wish to communicate may vary at different times.

1.2.12 In urgent or emergency situations when time may be limited, give children and young people opportunities to communicate whenever possible, and the opportunity to discuss afterwards.

1.2.13 Be aware that babies, children and young people may not communicate pain, distress or anxiety verbally. Be alert to behavioural cues, for example, crying, refusing to speak or pushing away, or behaviour which appears aggressive such as anger, defiance or biting.

1.2.14 All staff involved in providing healthcare services to babies, children and young people should have skills and competencies in relevant communication skills.

For a short explanation of why the committee made these recommendations see the rationale and impact section on communication by healthcare staff.

Full details of the evidence and the committee's discussion are in evidence review B: Communication by healthcare staff.

Providing information

1.2.15 Ask children and young people, and the parents or carers of babies and young children, about the quantity and type of information they wish to receive, and how they wish to receive it. This should include, but not be limited to, details of:

- their condition and any treatment options and issues related to these (including diagnosis, possible side-effects, long-term outcomes, and symptoms they may experience)
- any preventative action or lifestyle changes they can make
- where they will be seen
- likely timescales and waiting times for their treatment, including keeping them informed about waits or delays at appointments
- who will be responsible for their care
- what will happen at key points in their care (for example, on discharge from hospital, when being referred to a different healthcare team).

Follow the recommendations on age and developmentally appropriate care and changes in needs and preferences

1.2.16 When giving information to the child or young person, or the parents or carers of babies and young children:

- use their preferred method where possible. This may be in person face-to-face or using other methods (for example email, phone call, text message or video call)
- provide written and digital information to back up and supplement face-to-face contact, telephone calls or video calls and to refer to later.

1.2.17 Ensure information for children and young people is provided privately when appropriate, for example:

- without their parents or carers present if this is what they would prefer
- by telephoning or texting them directly
- by addressing letters to children or young people themselves, and not their parents or carers.

1.2.18 Agree with children and young people if there is information that should be provided to their parents or carers, to help their parents or carers support them or look after them (for example, dietary information, post-operative care, or symptoms to look out for).

1.2.19 Provide information for children and young people that is:

- evidence-based
- appropriate for their individual needs
- culturally sensitive
- not judgemental
- easy to understand, avoids jargon and explains medical terms
- presented in accessible formats and language that can be understood by them (for example through an interpreter, translated into another language, or as an easy-read version using pictures and symbols)
- given consistently by all members of the healthcare team.

1.2.20 Provide written or digital information (for example leaflets, websites, apps) for children and young people that is:

- created in partnership with children and young people
- engaging for children and young people (for example, containing appealing images, video, audio or animations).

1.2.21 Provide information at a suitable time, place and pace, for example:

- when possible, at regular, predictable times such as during ward rounds or clinic reviews
- in stages if necessary, so children, young people, parents or carers are not overloaded with too much information at one time.

1.2.22 When children, young people, parents or carers have had time to absorb and reflect on information they are given:

- check they have understood it, and how it applies to them (see recommendation 1.2.9)
- allow time to discuss the information again
- actively encourage them to ask questions.

1.2.23 When giving information to children and young people about their care, recognise:

- the possible emotional impact of any information provided
- that they may feel intimidated by the healthcare professional providing information (if they feel that individual is in a position of authority).

1.2.24 Warn children and young people, parents or carers that some of the medical information available online may be inaccurate and has a limited evidence base. Inform them about additional sources of information related to their care or condition and ensure that recommended sources are:

- up to date

- professional, credible and evidence-based (for example, NHS resources, charities, and support groups).

For a short explanation of why the committee made these recommendations see the rationale and impact section on providing information.

Full details of the evidence and the committee's discussion are in evidence review D: Providing information.

1.3 Planning healthcare

Shared decision making

1.3.1 Respect and support the right of children and young people to be involved in making decisions about their healthcare. This should include:

- ensuring early and ongoing involvement in discussions about their healthcare
- providing opportunities for them to share their opinions
- supporting them to make decisions independently
- taking into account previous discussions or decisions, and checking if these have changed
- including them in any decisions where there is a choice of options, including where there is no impact on health or treatment outcomes (for example, what colour plaster cast they would prefer, whether they prefer their medicine as liquid or tablets).

1.3.2 When involving children and young people in decision making, take into account that:

- the extent and level of their involvement may vary, between individuals and on different occasions. Follow the recommendations on changes in needs and preferences
- on occasions, some children and young people might not wish to be involved in shared decision making, and that this choice should be respected

- they might wish to have help from their parents or carers, or another person or advocate, for support, to help understand information or to help make decisions
- they might need time to think about decisions, so planning discussions in advance to allow for this might be helpful.

1.3.3 When discussing and making decisions about treatment options with children and young people:

- follow the recommendations on communication by healthcare staff and providing information
- clearly articulate the options, and adapt the description of the treatment options so they are understood by the child or young person you are talking to
- use alternative methods for discussions and decisions if necessary (for example, children and young people might prefer to write down or pre-record questions or opinions if they are not comfortable talking about them)
- consider using decision aids to support complex decisions, or if children and young people are having difficulty making a decision.

1.3.4 Involve parents or carers in discussions and decisions relating to the care of their baby or young child (for example, for inpatient care, by allowing parents to be present at ward rounds when their baby or child's care is discussed whenever possible). Follow the same principles as shown in recommendations 1.3.1 to 1.3.3.

For a short explanation of why the committee made these recommendations see the rationale and impact section on shared decision making.

Full details of the evidence and the committee's discussion are in evidence review A: Planning healthcare and making shared decisions.

Risks and benefits

1.3.5 Offer children, young people and the parents or carers of babies and young children information about the potential risks and benefits of healthcare options to allow them to make informed decisions. Follow the recommendations on communication by healthcare staff and providing information.

1.3.6 Ensure this information is:

- provided in a way they can understand, and they can see how it applies to them
- relevant to their individual needs and personal circumstances (for example, health setting, health status, age and developmental stage).

1.3.7 Discuss with children and young people how much information they would like about risks and benefits and take this into consideration. Recognise that some children and young people:

- might not want to know about risks, or not on a particular occasion
- might need additional opportunities to discuss risks and benefits
- might benefit from alternative methods of communicating risks and benefits
- might need to take a break when discussing risk, and to come back to the topic later
- might want to discuss the risks and benefits without their parents or carers present.

1.3.8 When discussing the risks and benefits of healthcare options with the child or young person, parent or carer:

- check their understanding of what the risks mean to them and what the benefits to them would be (see recommendation 1.2.9)
- ask them if they have any particular concerns or worries they would like to talk about (for example, children may want to ask about the risk of death, or fear of dying, however unlikely this may be)

- answer any questions they may have and address any concerns.

1.3.9 Reconfirm understanding of risks and benefits on an ongoing basis. Follow the recommendations on changes in needs and preferences.

1.3.10 Explore, acknowledge and respond to any concerns that children and young people or their parents or carers have about risk, and provide opportunities to discuss concerns and what will be done to reduce risk.

For a short explanation of why the committee made these recommendations see the rationale and impact section on risks and benefits.

Full details of the evidence and the committee's discussion are in evidence review E: Risks and benefits of healthcare decisions.

1.4 Consent, privacy and confidentiality

1.4.1 Have discussions about consent, assent, privacy and confidentiality directly with children and young people if:

- they are able to understand what these concepts mean (with appropriate explanation)
- they can relate them to their own situation.

1.4.2 When discussing consent, assent, privacy and confidentiality:

- ensure that children and young people, and parents and carers, understand their rights and responsibilities
- explain when parents and carers might have to make decisions on behalf of children and young people

1.4.3 For detailed advice on best practice around consent, privacy and confidentiality, refer to relevant professional guidance (for example, the General Medical Council ethical guidance for doctors on decision-making and consent and the 0–18 years: guidance for all doctors, or the Nursing and Midwifery Council code).

Consent

1.4.4 Support children and young people to make informed decisions to assent to, consent to or refuse treatment, taking into account their individual capacity.

1.4.5 Provide children and young people with clear explanations about why treatment in their best interest has to go ahead if it is not possible to obtain their consent or assent before treatment (for example, in an emergency situation).

1.4.6 If there is a difference of opinion about consent, assent or refusal for a procedure (for example, if the views of the child or young person are different from those of their parents or carers, or the views of the child, young person or parent or carer are different from those of healthcare professionals):

- consider involving other members of the multidisciplinary team, independent advocates, or a named or designated professional for child protection
- discuss with the child, young person and their parent or carer that you would like to involve other people
- ensure that the child, young person and parent or carer are offered support.

1.4.7 Reconfirm a child or young person's understanding and consent decisions on an ongoing basis. Follow the recommendations on changes in needs and preferences.

Privacy and confidentiality

1.4.8 Maintain privacy and dignity during discussions, examinations and care. Take into account individual preferences, circumstances and cultural sensitivities whenever possible.

1.4.9 Discuss potentially sensitive topics in places where they are less likely to be overheard when possible, for example, in a clinic room or side-room rather than behind bed space curtains.

1.4.10 Be aware that information sharing, privacy and confidentiality laws also apply to babies, children and young people. Only share their information with their consent for the purposes of care and treatment, or when in the baby, child or young person's best interest to do so.

1.4.11 Offer children and young people the opportunity to see and talk to a healthcare professional without the presence or involvement of their parent or carer, and explain that this discussion will be confidential.

1.4.12 Explain to children and young people that it may be necessary to share information without their consent in certain circumstances (for example, if they or others may be in danger).

For a short explanation of why the committee made these recommendations see the rationale and impact section on consent, privacy and confidentiality.

Full details of the evidence and the committee's discussion are in evidence review C: Consent, privacy and confidentiality.

1.5 Advocacy and support

Involvement of parents or carers

1.5.1 Give all children and young people opportunities to express their opinions about their health needs independently, including:

- asking them about the extent to which they want their parent or carer to be involved in their healthcare
- offering to see them separately from their parents or carers for part of the consultation.

1.5.2 Be aware that their wish for parental involvement may depend on the circumstances (for example, what the appointment is about, if they have to have any procedures) or may vary. Follow the recommendations on changes in needs and preferences.

1.5.3 Encourage children and young people to develop their confidence in making decisions for themselves (for example, by giving them opportunities to do this), and encourage their parents or carers to support them with this.

1.5.4 Encourage parents and carers to talk to their child or young person about how they will be involved in decisions about their healthcare. This might include:

- finding out whether the child or young person would like to know more about what will happen at appointments (for example, what healthcare procedures might take place), even if the parent or carer might feel they should leave out details so as not to worry them
- the parent or carer reassuring their child or young person that they can have part or all of an appointment without them being present if they would prefer that
- regularly confirming with their child or young person that they can change their mind at any time about how involved they want them to be.

1.5.5 Ensure that children or young people who do not have a parent or carer to support them, or whose parents or carers are not able to support them, are offered other sources of support (for example, an advocate, social worker, youth worker, nurse or play specialist).

For a short explanation of why the committee made these recommendations see the rationale and impact section on involvement of parents or carers.

Full details of the evidence and the committee's discussion are in evidence review F: Involving parents or carers in healthcare and healthcare decisions.

Support from healthcare staff

1.5.6 All staff involved in providing healthcare services to babies, children and young people should uphold children's rights in accordance with the United Nations Convention on the Rights of the Child.

1.5.7 Advise children and young people about how they can be supported by healthcare staff in a specific setting and encourage them to express their preferences about the support they would find helpful.

1.5.8 Be aware that some children and young people may need more support from healthcare staff than others and that this support may change over time. Follow the recommendations on changes in needs and preferences.,

1.5.9 When building a healthcare relationship with children and young people:

- introduce yourself, explain your role and how you can help support them
- listen to and be seen to believe their experiences (for example, symptoms such as discomfort, how they are feeling)
- reassure them that you will take their concerns seriously
- discuss with them how you will act on what they have said

1.5.10 Help children and young people to speak up about things that matter to them, and their views and preferences by:

- advocating for them and upholding their preferences if they are unable or unwilling to do this themselves
- acting as a trusted person for them to talk to when they feel their concerns are not being listened to.

1.5.11 Encourage children and young people to ask for the support they need to help with their healthcare experiences or encourage them to use coping techniques they have already developed. These could include:

- their parent or carer to be with them or someone's hand to hold
- music to listen to, a soft toy to cuddle, playing a game on a phone or tablet, a support animal or pet to stroke
- individual coping techniques

Ask them if these techniques help or if they would like to try other techniques.

1.5.12 Provide advice and access to other forms of support available, including help from education or the voluntary sector.

For a short explanation of why the committee made these recommendations see the rationale and impact section on support from healthcare staff.

Full details of the evidence and the committee's discussion are in evidence review G: Support from healthcare staff.

Self-advocacy

1.5.13 Facilitate self-advocacy in children and young people. This may include:

- allowing enough time in consultations and appointments
- providing confidential and private spaces
- providing information on their rights to advocate for themselves
- establishing the child or young person's preferred method of communication, paying particular attention to those who do not communicate verbally

1.5.14 Assume that all children and young people have views and opinions about their own healthcare, and actively encourage them to express what matters to them. In particular:

- do not make assumptions that certain groups of children or young people will not want or will not be able to advocate for themselves
- recognise that children and young people from different backgrounds may have different levels of confidence or skills to advocate for themselves.

1.5.15 Empower children and young people to advocate for themselves by:

- providing information so they can develop an understanding of their own condition and health needs
- making them central to discussions about their healthcare

- agreeing with them when and how they would like their parents or carers included in discussions and decision-making, and ensure this agreement is followed
- working collaboratively with them to discuss healthcare needs and treatment options and include them in decisions about their care
- taking into account their own culture, experiences, needs, wishes and feedback
- considering the use of age- and developmentally-appropriate healthcare-management applications, such as smartphone apps. Apps should meet the criteria specified in the NICE evidence standards framework for digital health technologies. See the NHS Apps library for details of NHS approved apps.

1.5.16 Support children and young people to develop skills in advocating for themselves by offering opportunities to be involved in feedback, service design or improvement or other engagement activities (see recommendations 1.7.1 to 1.7.9).

For a short explanation of why the committee made these recommendations see the rationale and impact section on self-advocacy .

Full details of the evidence and the committee's discussion are in evidence review H: Empowering children and young people to advocate for themselves.

Independent advocates

1.5.17 Children and young people must have access to an independent advocate in line with statutory requirements. This includes the Mental Health Act 2007 the Care Act 2014 and the Mental Capacity Act 2005.

1.5.18 Where children and young people are eligible, inform them that, they can have another person, known as an independent advocate, present with them when speaking to healthcare professionals, rather than their parent or carer. See also recommendation 1.3.2 about support from other people for shared decision-making.

1.5.19 Provide children and young people who are eligible for support from an independent advocate with information about independent advocates. Include:

- the role of an independent advocate (including confidentiality and independence from the healthcare team).
- how to access an independent advocate. This information should be readily available (for example, posters on noticeboards, leaflets, free dial access phones or from the independent advocates themselves when they make routine visits to wards or clinics)
- the option to express a preference for an advocate of a particular gender, or how to change advocate

1.5.20 Support eligible children and young people to contact and meet with an independent advocate (for example by providing a private space and time to meet).

1.5.21 Independent advocates should work with eligible children and young people to support and empower them in discussions and decisions about their healthcare. This should include:

- building a trusting relationship, ensuring continuity where possible
- ensuring confidentiality
- providing guidance on healthcare systems, pathways and processes, where necessary
- providing explanations of medical information and terminology, where necessary
- empowering children and young people to make their own decisions

1.5.22 Independent advocates should provide a mechanism for children or young people to give feedback on the advocacy service and to check that the relationship is working effectively for the benefit of the child or young person.

1.5.23 Commissioners should consider 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 or carers or other professionals.

For a short explanation of why the committee made these recommendations see the rationale and impact section on independent advocates .

Full details of the evidence and the committee's discussion are in evidence review I: Independent advocacy in healthcare for children and young people.

1.6 Improving healthcare experience

Food

1.6.1 Ensure babies, children and young people who are inpatients have access to food that meets their needs. This should include:

- a balanced diet that will help with their recovery
- a choice of food options that are culturally and dietetically appropriate at every meal
- food choices and menus that have been developed in conjunction with children and young people.

For babies who are breast or bottle fed ensure there are suitable facilities to support this.

Pain-related anxiety

1.6.2 Minimise the fear and anxiety about pain which may be experienced by babies, children and young people during healthcare interventions by:

- preparing them with information about interventions or procedures
- being honest about possible pain and what will be done to alleviate pain
- using therapeutic play and distraction techniques before, during and after procedures or interventions which are likely to be painful
- upholding children and young people's experiences of pain, showing them they are believed

- avoiding language that minimises the child or young person's experience of pain (for example, saying a procedure they found painful "didn't really hurt").

1.6.3 Ensure adequate pain assessments are carried out and acted upon. See NICE guidelines for the management of pain in specific conditions such as the NICE guideline on Cerebral palsy for under 25s for advice on assessing pain in verbal and non-verbal children and young people, and the NICE guideline on Sickle cell disease.

Staff uniforms and healthcare clothing

1.6.4 Ensure children and young people, and parents or carers of babies and young children can easily identify members of staff. This could include:

- visible name badges with easy to understand job roles or titles
- recognisable uniforms, particularly if they help differentiate between professions.

1.6.5 Be aware that healthcare clothing (for example theatre gowns, masks or visors) can be frightening for babies, children and young people and they may be unable to recognise staff or see their facial expressions or smiles. This is particularly important for children who rely on lip reading or facial cues for communication.

For a short explanation of why the committee made these recommendations see the rationale and impact section on improving healthcare experience .

Full details of the evidence and the committee's discussion are in evidence review J: Improving experience of healthcare.

1.7 Involvement in improving healthcare experience

Design of healthcare services

1.7.1 When designing services that will be used by babies, children and young people:

- involve children and young people and obtain their views, or for babies and young children, involve their parents or carers
- actively seek out children and young people from under-represented groups (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 services before).

1.7.2 Assume all children and young people have relevant opinions on services they use and their care, and will give them if asked in a suitable way.

1.7.3 Make it as simple as possible for children and young people to contribute to service design by:

- using appropriate methods to engage them, capture their views and enable them to contribute (for example, internet surveys, social media, forums and groups)
- addressing any practical issues that could be barriers to involvement (for example, transport, timing, language, travel costs).

1.7.4 Ensure that feedback about the design of services from children, young people and parents or carers is shared and used. Explain how their input has shaped design of services (for example, using social media or posters to describe methods such as 'Ask Listen Do' and 'You Said We Did').

For a short explanation of why the committee made these recommendations see the rationale and impact section on design of healthcare services.

Full details of the evidence and the committee's discussion are in evidence review K: Design of healthcare services.

Measuring experience

1.7.5 Collect feedback (for example, using questionnaires or surveys) directly from children and young people at different points in their healthcare experience. Collect feedback for babies and young children from their parents or carers.

1.7.6 Actively seek out feedback from children and young people from under-represented groups (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 services before).

1.7.7 Make it easier for people to give meaningful feedback by using tools that:

- have been co-produced with the appropriate age group
- are appropriate for, and selected together with, the intended group
- are provided at a convenient time and place, and by a convenient method, for respondents (for example, voting systems in a healthcare setting, or an online survey to be completed at home).

1.7.8 Ensure that the feedback on healthcare experiences from children, young people and parents or carers is shared and used. Explain how their input has been used to improve healthcare experiences (for example, using social media or posters to describe methods such as ‘Ask Listen Do’, ‘You Said We Did’).

1.7.9 Inform children and young people, and the parents or carers of babies and young children, of their right to complain. Ensure that it is easy for children and young people to make a complaint if they need to.

For a short explanation of why the committee made these recommendations see the rationale and impact section on measuring experience.

Full details of the evidence and the committee’s discussion are in evidence review L: Measuring experience .

1.8 Healthcare environment

1.8.1 Care for babies, children and young people in an environment that:

- meets their clinical and personal needs
- takes into account their preferences about their place of care (or the preferences of parents or carers for babies or young children)
- is appropriate for their age and developmental stage, is physically accessible and has adaptations available, if needed.

1.8.2 Provide a healthcare environment that supports:

- privacy and dignity
- confidence in healthcare delivery (for example, equipment is available when required)
- family-centred care for inpatients, (for example, the option for a family member to stay and sleep, including in non-paediatric areas). This may not be appropriate in all settings (for example, on mental health wards or if there are infection control issues)
- parents or carers to give developmentally-appropriate care to their children (for example, changing their baby's nappy, helping children wash and dress)
- other family members, siblings, or those important to the child or young person to be present (if this is what they would like)
- easily accessible, age-appropriate play and recreation for children and young people, including to reduce boredom and anxiety while waiting for appointments or interventions
- children and young people who are inpatients to mix with friends and peers (for example, flexible visiting times, access to social media, spaces away from clinical areas to meet)
- a feeling of safety (for example, easy access to call bells or other means of summoning help, knowing that someone is around to help).

1.8.3 Provide a healthcare environment that:

- is clean, comfortable and homely
- separates treatment areas from those for play and recreation
- is designed and decorated in a suitable way for the age group it is for (including layout, lighting and directional sign posting)

- in an inpatient setting is quiet enough for rest and sleep, particularly at night.

For a short explanation of why the committee made these recommendations see the rationale and impact section on healthcare environment.

Full details of the evidence and the committee's discussion are in evidence review M: Healthcare environment.

1.9 Maintaining usual activities

1.9.1 Give children and young people ongoing opportunities to identify aspects of their lives that are important to them (for example, physical, social and recreational activities, schooling and education, their developmental, cultural and emotional needs).

1.9.2 Discuss with children and young people, particularly those with ongoing health needs:

- how their health condition and their healthcare will impact on their ability to engage in usual activities
- what their expectations and goals may be for their future involvement in usual activities, and how they can be helped achieve them.

1.9.3 Ensure that babies, children and young people are able to continue with their usual activities of daily life with minimal disruption while receiving healthcare and, when clinically appropriate, make reasonable adjustments to their environment to facilitate this.

1.9.4 In an inpatient setting, ensure free internet access over Wi-Fi, and that any Wi-Fi codes or passwords are freely available so that children and young people can maintain their usual contacts and networks. Advise children and young people that use of social media must not compromise the privacy of other people.

1.9.5 Recognise that the wishes and needs of each baby, child and young person to engage in the activities they have identified as important to them will vary between individuals and over time. Integrate these needs into the delivery of healthcare.

1.9.6 Make sure that the baby, child or young person's usual support networks (for example, parents and carers, siblings and friends) can be involved in maintaining activities of daily living (for example, washing, getting dressed, eating) and other usual activities.

1.9.7 Ensure coordination between healthcare, education and social care to maintain an individual's usual activities, including education and learning. This could include education support roles, Early Help or making adjustments such as scheduling treatment appointments around school commitments.

1.9.8 Help children and young people to use cultural, spiritual or religious beliefs that they find helpful in their lives as a source of support if they wish. This could include facilitating religious activities such as prayer time, or letting them know about chaplaincy services or other religious support available.

For a short explanation of why the committee made these recommendations see the rationale and impact section on maintaining usual activities.

Full details of the evidence and the committee's discussion are in evidence review N: Supporting participation in usual activities and evidence review J: Improving experience of healthcare

1.10 Accessibility, continuity and coordination

Accessing healthcare

1.10.1 Provide children and young people with targeted information about:

- when an illness or condition means they should seek medical help
- that healthcare services are there to help them
- that feeling afraid or embarrassed about asking for help is normal but healthcare professionals will understand and provide support

- what services are available (for example, using the NHSGo app)
- when and how they can access services

Follow the recommendations on providing information.

1.10.2 Develop information about healthcare and healthcare services with input from children and young people themselves and in collaboration with healthcare professionals (for example play specialists, child psychologists), and other sectors (for example, education, social care, the voluntary sector).

1.10.3 Provide information for parents and carers to support them in accessing healthcare services for their child (for example, the eRed Book app).

1.10.4 Provide information to children and young people on:

- what services they can access with or without their parents or carers
- whether their parents or carers will need to be told if they access services.

1.10.5 Take into account the views of children and young people, and for babies and young children the views of their parents and carers, when designing new, and redesigning existing, healthcare services. Include:

- personal factors, such as the age range, gender and developmental stage(s) of the children and young people using the service
- social factors, such as the religious, cultural or social background of the children and young people using the service.

See recommendations 1.7.1 to 1.7.4 on involving children and young people in design of healthcare services.

1.10.6 Provide children and young people with support and help to access the healthcare system. Ensure additional support, such as one-to-one support from a named healthcare or social care professional, is available for those who need it (for example, looked after children, children in institutional care, care leavers).

1.10.7 Take into account access needs specific to children and young people. This might include:

- accommodating preferences about the gender of the healthcare professional who they see
- offering flexible appointments that meet an individual's and family's needs, for example minimising regular appointments during school hours
- providing services in locations that are easier for children and young people to access, or co-locating with other services that children and young people access (for example, youth centres and schools).

1.10.8 Use flexible methods where clinically appropriate, agreed with the child or young person to deliver healthcare services (for example, telephone or video calls, digital media such as websites and apps) as alternatives to in person face-to-face services to help overcome access difficulties, such as travelling to appointments or relying on parents for transport.

1.10.9 Use feedback from children and young people to improve the accessibility of healthcare services. See recommendations 1.7.5 to 1.7.9 on measuring experience of care.

For a short explanation of why the committee made these recommendations see the rationale and impact section on accessing healthcare.

Full details of the evidence and the committee's discussion are in evidence review O: Accessing healthcare.

Continuity and coordination of care

1.10.10 Maintain continuity of care by providing healthcare from the same professionals or teams when clinically appropriate.

1.10.11 Ensure clear and timely exchange of relevant patient information:

- between healthcare professionals and children and young people or the parents or carers of babies and young children

- between healthcare professionals
- between healthcare, education and social care professionals.

1.10.12 Pay particular attention to communication between healthcare professionals and services and the coordination of ongoing care:

- at key points in care (for example, on discharge from hospital, or when being referred to a different healthcare team)
- for groups of children and young people who might need additional support (for example, care leavers, homeless young people, children or young people with complex needs or disabilities).

For advice on transition to adult services, see the NICE guideline on transition from children's to adults' services.

1.10.13 Ensure systems are in place so that children and young people and the parents or carers of babies and young children do not need to unnecessarily repeat their healthcare history when being seen by different healthcare professionals (for example, by using health passports or digital health records).

1.10.14 Ensure children and young people and the parents or carers of babies and young children have access to their healthcare records. Access must meet the requirements of the Access to Health Records Act 1990.

1.10.15 Provide contact information so that children and young people know how to obtain advice from the same service or team in the future.

For a short explanation of why the committee made these recommendations see the rationale and impact section on continuity and coordination of care.

Full details of the evidence and the committee's discussion are in evidence review P: Continuity of care .

Terms used in this guideline

This section defines terms that have been used in a particular way for this guideline. For other definitions see the NICE glossary.

Assent

Agreement given by a child or young person to a course of action or procedure, when they are not legally empowered to give consent.

Consent

Agreement (which can be verbal, non-verbal or written) to a course of action or procedure after a discussion of the risks and benefits.

Containment holding

Placing both hands firmly but gently on a baby and holding the position very still, to provide reassurance and comfort.

Focus and reference groups

A series of focus and reference groups with children and young people were conducted to obtain their views and opinions. These views and opinions were considered by the committee as part of their review of the evidence.

National surveys

A review of recent national surveys of children and young people's views on healthcare was carried out. The findings of these surveys were considered by the committee as part of their review of the evidence.

Parents or carers

Parents or carers refers to the primary care-givers for a baby or child at any given time. This can include, as well as the parents, other members of the extended family who provide care such as siblings, grandparents, aunts and uncles. It can also include foster carers or others nominated by the parents. It does not refer to nurses, healthcare assistants or other professional carers.

Usual activities

Activities that form part of a baby, child or young person's daily life and which may be disrupted by illness or the need to access healthcare services. This may include activities of daily living (bathing, showering, eating), interactions with family and friends, social and emotional development, education and schooling, sports, hobbies and interests, social activities and use of social media.

Recommendations for research

The guideline committee has made the following recommendations for research.

Key recommendations for research

1 Risks and benefits

What decision aids are the most cost-effective and acceptable when explaining the risks and benefits of healthcare interventions to children and young people?

For a short explanation of why the committee made this recommendation see the rationale section on risks and benefits.

Full details of the evidence and the committee's discussion are in evidence review E: Understanding the risks and benefits of healthcare decisions.

2 Independent advocacy

How can the views of babies, children and young people be best represented by independent advocates?

For a short explanation of why the committee made this recommendation see the rationale section on independent advocates.

Full details of the evidence and the committee's discussion are in evidence review I: Independent advocacy in healthcare for children and young people .

3 Improving healthcare experience

What elements of healthcare matter most to babies, children and young people to create positive experiences of healthcare?

For a short explanation of why the committee made this recommendation see the rationale section on improving healthcare experience.

Full details of the evidence and the committee's discussion are in evidence review J: Improving experience of healthcare .

4 Measuring experience

How can the experience of babies, children and young people be measured so as to improve their experience of healthcare?

For a short explanation of why the committee made this recommendation see the rationale section on measuring experience.

Full details of the evidence and the committee's discussion are in evidence review L: Measuring experience .

Rationale and impact

These sections briefly explain why the committee made the recommendations and how they might affect practice.

Overarching principles

Recommendations 1.1.1 to 1.1.5

Why the committee made the recommendations

The committee were aware, based on their own knowledge and experience, that safeguarding was an important consideration that applied to all aspects of healthcare services, and so made an overarching recommendation to state this.

There was evidence from a number of reviews that all discussions, support and information need to be suitable for the age, developmental stage and level of understanding for an individual child or young person, and that as children develop and mature their healthcare needs and preferences change, and that this should be recognised and information and discussions adapted accordingly. There was also evidence that preferences could vary between occasions, and that determining needs and preferences was not a static one-off decision, but something that should be revisited regularly.

How the recommendations might affect practice

The recommendations are in line with current practice and should have little impact on resources, but may require extra time to have revisit needs and preference on a regular basis. Return to recommendations

Communication by healthcare staff

Recommendations 1.2.1 to 1.2.14

Why the committee made the recommendations

There was good evidence that children and young people like healthcare professionals to communicate in a friendly, compassionate and respectful manner, reading behavioural cues, giving them sufficient time, listening to them and getting to know them on a personal level.

There was good evidence that different methods of communication should be used when appropriate, and this included using verbal and non-verbal communication, and identifying the best way to communicate for individuals.

How the recommendations might affect practice

Healthcare professionals might need more time to communicate with children and young people and this could mean some consultation times are longer, which would create a resource impact for the NHS. Additional help to communicate may be required (for example, use of foreign language or sign language interpreters) and that may also have a resource impact for the NHS.

Ensuring that all staff are competent to communicate effectively might also need additional time and resources.

Return to recommendations

Providing information

Recommendations 1.2.15 to 1.2.24

Why the committee made the recommendations

There was good evidence from the systematic literature review on the preferred sources of information, with in person face-to-face information provided by a healthcare professional one of the preferred and most trusted forms of information. The evidence also showed that healthcare professionals should provide information clearly in a way that is easy for children and young people to understand. It is also important that healthcare professionals consider when and how to deliver information, as sufficient information needs to be provided, but this should not be overwhelming. The evidence also showed that children and young people, and the parents of babies and young children, want information in a variety of formats, including written materials, websites and smartphone applications and digital sources.

There was evidence that written and digital information should be clear, easy to understand and relevant.

There was evidence that children and young people would want their parents or carers to have information tailored to their condition and needs in order to provide support and look after them.

There was evidence that whatever the format, information should be age and developmentally appropriate, and should be available in different versions (for example, easy-read versions) and languages to allow as many people to access it as possible.

The evidence from the focus and reference groups and some limited evidence from the national surveys reinforced the systematic literature review evidence, showing that the quantity of information should not be overwhelming, and that there is a need for clear, understandable verbal and written information.

How the recommendations might affect practice

The recommendations may mean additional time and resources are needed to deliver and produce information in suitable formats (for example leaflets, websites, apps) in partnership with children and young people. However, it was acknowledged that many services are already using a variety of alternative ways of proving information to children or young people and the overall resource impact in this area will be modest.

Return to recommendations

Shared decision making

Recommendations 1.3.1 to 1.3.4

Why the committee made the recommendations

There was evidence from the systematic literature review, focus and reference groups and from the national surveys that most children and young people want to be involved in making shared decisions about their healthcare, but that the level of preferred involvement may vary between different children, on different occasions and may change as children get older. There was some evidence on children and young people's preferences for how the shared decision-making process should be undertaken, for example by starting discussions as soon as possible, making sure information was presented clearly, tailoring its complexity, providing it at a suitable pace and using decision aids if they are available. The committee also used their knowledge and experience to make additional recommendations to adhere to these principles when making shared decisions with parents and carers on behalf of babies and young children.

How the recommendations might affect practice

Additional time may be required to carry out meaningful discussions around shared decision making.

Return to recommendations

Risks and benefits

Recommendations 1.3.5 to 1.3.10

Why the committee made the recommendations

There was limited evidence that decision aids improve knowledge about risks and benefits and reduce decisional conflict, but as there was insufficient evidence to allow the committee to give advice on their use a research recommendation was made on this topic. There was some evidence from the focus and reference groups that children and young people vary in their views about how much information they like to receive on risks. Based on this evidence, and on their knowledge and experience, the committee made recommendations on the best ways to discuss risk and benefits with children and young people, including pacing this information, having discussions without parents and carers, and ensuring understanding.

How the recommendations might affect practice

The recommendations might mean additional time and resources are needed to help children, young people and the parents or carers of babies and young children understand the risks and benefits of healthcare decisions.

Return to recommendations

Consent, privacy and confidentiality

Recommendations 1.4.1 to 1.4.12

Why the committee made the recommendations

No evidence relating to consent was found, but the committee discussed that children and young people have the legal right to consent to, or refuse, treatment as set out in UK law and the UN Convention on the Rights of the Child. Therefore, the committee used their experience and expertise to make recommendations on how children and young people could be best supported to make decisions on consent. The committee also used their knowledge and experience of how differences of opinion over consent, assent or refusal of treatment should be approached. This could include involving other healthcare professionals, but the committee also recognised that the child, young person, parents or carers should be offered support so that they did not feel outnumbered in discussions.

There was some low quality evidence on privacy and confidentiality that showed that children are aware of the risks to anonymity and privacy with digital information applications, but that they also recognised that in some cases it was valuable to share information (for example, with parents, or to allow peer-to-peer support). The committee therefore also used their experience and expertise on best practice at maintaining privacy, discussing private and confidential information with children and young people, and the sharing of information with parents or carers.

How the recommendations might affect practice

There are already examples of good practice across the NHS concerning consent, privacy and confidentiality, and these recommendations are designed to increase consistency throughout the NHS. Implementing these recommendations might mean extra time is needed for healthcare professionals to discuss and explain issues surrounding consent, privacy and confidentiality with children and young people. There may also be a need to consider the environment in which healthcare is delivered to provide privacy and ensure confidentiality.

Return to recommendations

Involvement of parents or carers

Recommendations 1.5.1 to 1.5.5

Why the committee made the recommendations

There was evidence that children and young people wanted to be able to express their opinions independently from their parents, but they also valued their parent or carers’ presence or support. There was evidence that the extent of support they wanted varied depending on the circumstances and the child or young person, and that it should be discussed between parents or carers and their children. The committee were aware from their knowledge and experience that certain groups of children and young people did not have parents or carers to support them, and that it is particularly important that these children and young people should be offered alternative support.

How the recommendations might affect practice

The recommendations are in line with current practice and should have little impact on resources, but may require extra time to have these discussions, and to see children with their parents and carers and separately.

Return to recommendations

Support from healthcare staff

Recommendations 1.5.6 to 1.5.12

Why the committee made the recommendations

There was evidence that children and young people have differing preferences for the support they wish to receive from healthcare professionals, so this should be individualised based on their preferences at any time (as these preferences can change depending on different factors). There was also evidence around needing to build a trusting relationship. Based on their knowledge and experience the committee agreed that it was essential that healthcare professionals support children and young people's rights and advocate for them where necessary. There was also evidence that children and young people appreciate support to identify and use coping techniques, and to be advised on other sources of support.

How the recommendations might affect practice

Additional time may be required to build trust, discuss and provide the support according to the preferences and needs of children and young people.

Return to recommendations

Self-advocacy

Recommendations 1.5.13 to 1.5.16

Why the committee made the recommendations

There was evidence from the systematic literature review and the focus and reference groups for strategies that would enable children and young people to advocate for themselves with respect to their healthcare and related decisions. This included providing time, space and adequate information.

There was evidence that some children and young people felt as though healthcare professionals have a preconceived idea of their ability and motivation to engage with healthcare decisions. This often resulted in missed opportunities to encourage vulnerable children and young people to engage in their care and advocate for their choices.

The evidence also showed that engaging children and young people in feedback, service design and other activities could improve and facilitate their self-advocacy skills.

Based on the evidence and their knowledge and experience, the committee identified approaches to empower children to advocate for themselves.

How the recommendations might affect practice

Additional time may be required to discuss and provide the adequate support to children and young people so they can be empowered to advocate for themselves.

Return to recommendations

Independent advocates

Recommendations 1.5.17 to 1.5.23

Why the committee made the recommendations

The recommendations reflect current UK legislation in respect of access to independent advocates in certain situations for children and young people. Based on their knowledge and experience, the committee recognised the potential benefits of independent advocacy in wider healthcare situations, not currently covered by the legislation.

There was evidence from an expert witness and the focus and reference groups that eligible children and young people may not be aware when they could use an independent advocacy service. Therefore, they should be provided with this information and supported throughout the process.

There was evidence from the expert witness and the focus and reference groups about the role of independent advocates, which involves supporting children and young people in decisions about their healthcare and, in order to be most effective, independent advocates should take time to build a trusting and confidential relationship with children and young people.

As there was no evidence from the systematic review of the literature for this review, the committee made a research recommendation.

How the recommendations might affect practice

The recommendations regarding access to an independent advocate are in line with current UK legislation, with little additional impact on resources. However, the suggested expansion of this service to children and young people who are not adequately represented by parent and carers may lead to an increase in the number of independent advocates needed by NHS services which will need an increased level of funding. There may be an increased amount of time for healthcare professionals to facilitate this use of independent advocates.

Return to recommendations

Improving healthcare experience

Recommendations 1.6.1 to 1.6.5

Why the committee made the recommendations

The qualitative and quantitative evidence identified four aspects of healthcare that were important to children and young people but which had not been covered in other evidence reviews. These were food, pain-related anxiety, staff uniforms and healthcare clothing, and religious, cultural and spiritual support. Based on their expertise and experience the committee made additional recommendations on these topics. The committee agreed that the recommendations on religious support related to maintaining usual activities, and therefore they placed this recommendation in that section of the guideline.

As there was limited quantitative evidence on the elements of healthcare that matter most to babies, children and young people to create a positive experience of healthcare, the committee made a research recommendation.

How the recommendations might affect practice

The recommendations reflect best practice and may reduce variation in practice.

Return to recommendations

Design of healthcare services

Recommendations 1.7.1 to 1.7.4

Why the committee made the recommendations

There was some evidence that children and young people are keen to contribute to the design of healthcare services, and appreciate the opportunity to do so. There was also evidence that the children and young people recognise there could be practical difficulties with involvement (for example, time, travel, number of events, and content not being age or developmentally appropriate). There was evidence that ways to obtain feedback should be age- and developmentally-appropriate. There was evidence that children and young people want their views to be taken seriously, and that they appreciate being told how their input had changed practice.

How the recommendations might affect practice

There are already examples of good practice across the NHS, but practice is inconsistent. These recommendations aim to standardise how children, young people, parents and carers should be involved in the design of services, to encourage more consistent practice across the whole NHS.

Implementing this across the NHS might mean increased resources are needed to develop the tools, identify participants, aid involvement and evaluate and feedback the results.

Return to recommendations

Measuring experience

Recommendations 1.7.5 to 1.7.9

Why the committee made the recommendations

There was some evidence from the focus and reference groups that children and young people are keen to provide feedback, that they are willing to use a variety of methods to do this, and that surveys should be quick and easy to complete. The evidence also showed that children and young people also prefer giving their feedback at or towards the end of treatment but based on their knowledge and experience the committee agreed this should be at various points in treatment. There was a very small amount of evidence from the national surveys on the problems children and young people had had using complaints systems. The committee also used their own knowledge and experience on helping people give feedback to optimise responses.

As there was very limited evidence from the systematic review of the literature on measuring children and young people's experience, the committee made a research recommendation.

How the recommendations might affect practice

Experience may already be measured in a number of different ways across the NHS and these recommendations will increase measurement of experience, reinforce best practice and make practice more consistent.

Implementing this across the NHS might mean more resources are needed to develop the tools, identify participants, aid involvement and evaluate and feedback the results.

Return to recommendations

Healthcare environment

Recommendations 1.8.1 to 1.8.3

Why the committee made the recommendations

There was some evidence from young people about their preferences, and from parents of babies in neonatal units, and the committee agreed that all babies and young children (represented by their parents), children and young people, should be able to express views about the preferences for place of care. The committee used this and their own knowledge and experience to agree how settings should be appropriate, comfortable and acceptable to the people who need to use them. There was evidence that young people prefer their care environment to be age appropriate, and that they may feel uncomfortable in paediatric settings aimed at young children. There was also evidence that they like to be able to meet visitors in an appropriate space, to have areas for recreation facilities, to have adequate directional signs, and for there not to be too much noise. They also expressed wanting to feel safe in healthcare environments.

There was evidence from parents or carers of babies about the need for privacy, comfortable furniture and furnishings, and facilities so they have the option to stay with their babies. Although there was no evidence about privacy for children and young people, the committee agreed that offering privacy is important, based on their knowledge and experience.

How the recommendations might affect practice

The recommendations aim to make best practice more consistent across the NHS. Some changes to improve the healthcare environment might be easy to make, but changing or redesigning healthcare environments can be an expensive process, and some of the recommendations could need considerable resources to implement.

Return to recommendations

Maintaining usual activities

Recommendations 1.9.1 to 1.9.8

Why the committee made the recommendations

Based on their knowledge and experience the committee made recommendations on the importance of determining what usual activities were important to children and young people, and making adjustments to allow these to continue. The committee agreed that providing support to continue with usual activities would need to be individualised to account for different needs, preferences and developmental stages The committee recognised the benefits to the wellbeing of children and young people of continuing with usual activities, which may include a reduction in boredom, anxiety and distress. There was evidence that some children preferred to receive help with personal care from their family, as would happen if the child were at home. There was also evidence that children and young people wanted to continue with social activities and keeping in touch with their friends. There was no evidence from the systematic literature review specifically about WiFi access but the committee agreed that the ability to instantly contact friends was a part of everyday life for most children and young people and this was reinforced by evidence from the focus and reference groups and the national surveys.

The evidence on educational support reinforced the committee's experience that maintaining educational provision and liaison with education services is very important.

There was evidence that some children and young people found religious or spiritual support or beliefs helpful when they were unwell. Other aspects from this evidence are reflected in the recommendations on improving healthcare experience, where this evidence is described in more detail.

How the recommendations might affect practice

The recommendations aim to reduce variation in practice across the NHS, and might mean extra staff time or changes in practice are needed to implement them.

Return to recommendations

Accessing healthcare

Recommendations 1.10.1 to 1.10.9

Why the committee made the recommendations

There was evidence about factors that could be barriers for children and young people to access health services, and the committee used this evidence to make recommendations designed to overcome these barriers. The evidence from the national surveys also identified that certain groups of children and young people may need additional help and support to navigate the health system.

How the recommendations might affect practice

Additional resources may be needed to promote and deliver accessible and flexible services.

Return to recommendations

Continuity and coordination of care

Recommendations 1.10.10 to 1.10.15

Why the committee made the recommendations

There was good evidence that children and young people prefer to see the same healthcare professional(s) whenever possible, and that this promotes improved engagement and continuity of care. The committee were aware that children and young people prefer to be able to contact their healthcare professionals or teams directly.

There was good evidence that children and young people do not want to have to repeat their healthcare history on multiple occasions, and that good and timely communication between healthcare professionals, services, and children and young people and the parents or carers of babies and young children could help with this. There was also some evidence for the use of different methods to help improve communication and continuity of care, and in particular the use of electronic health records.

How the recommendations might affect practice

There are some electronic and paper methods to improve communication already in use, including electronic health records. Implementing more integrated systems to share information with and between healthcare professionals, other services and children and young people or the parents and carers of babies and young children will have resource implications for the NHS. In addition, there may be a need for improved administration support to help with the sharing of information, which will also have some resource implications.

Return to recommendations

Finding more information and committee details

To find NICE guidance on related topics, including guidance in development, see the NICE webpages on infants and neonates. and children and young people.

For details of the guideline committee see the committee member list.

Minor changes since publication

[Month year]: