

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Guideline scope

Babies, children and young people's experience of healthcare

NHS England has asked NICE to develop clinical guidelines on 'Infant, children and young people's experience of healthcare'.

The guideline will be developed using the methods and processes outlined in [developing NICE guidelines: the manual](#).

This guideline will also be used to develop the NICE quality standard for babies, children and young people's experience of healthcare.

1 Why the guideline is needed

NICE has already produced guidance specifically on patients' experience of adult healthcare: [Patient experience in adult NHS services: improving the experience of care for people using adult NHS services](#), published in 2012.

While this contains some advice that may also be applicable to children and young people, such as knowing the patient as an individual, tailoring services to individual patients, and the importance of continuity of care, the ideal approach to be taken when treating children cannot be extrapolated directly from adult services. Furthermore, the evidence on which this guideline was based relates to the adult population.

Key facts and figures

In 2016 the Care Quality Commission (CQC) conducted a [survey](#) asking children, young people and their parents to provide feedback on their care. This included responses from 11,116 young patients aged 8–15. Feedback from children was generally less positive than their parents' responses.

The results of this survey found

- 91% of children and young people said they had been looked after well
- 86% reported staff talked with them about how they would be cared for
- 92% of those who asked questions received an answer from staff
- of those who had an operation or procedure, 93% said they received an explanation beforehand about what would happen.

Most young people aged 12–15 (90%) were able to talk to a doctor or nurse without their parent or carer being there if they wanted to, and only 3% of children and young people aged 8–15 said that they did not have enough privacy when receiving care and treatment.

Although most aspects of communication with staff were positive, 32% of children and young people said they did not always understand what staff said, and 57% felt they were not involved enough in making decisions about their care or treatment. In addition, 16% of children and young people left hospital without being told who to talk to if they were worried about anything once they were home, and 11% of children and young people said they did not know what was going to happen next with their care.

A number of children spent time on an adult ward and 11% of 12–15 year olds who stayed on an adult ward did not feel the ward was suitable for someone of their age. Some aspects of care were reported as significantly poorer when a child or young person has a self-reported mental health condition, a long-term physical condition, learning disability or if they stayed on an adult ward.

A report by the Children's Commissioner conducted in 2012 (Office of the Children's Commissioner 2012) also identified that complaints procedures are an area where there is very little focus on children's needs. A report prepared for NHS England in 2013 by the Patient Experience Network (Patient Experience Network 2013) (PEN) on 'Improving patient experience for children and young people' identified that the views and opinions of children and young people relating to their care should be listened to, including the use of effective complaints procedures for children.

Current practice

Many NHS providers of healthcare services for children currently carry out user surveys directly with children as well as with their parents or carers, and some run user 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, apart from the children and young people's inpatient survey, these groups are not routinely included in national experience surveys, including the GP patient survey.

Whilst there are some examples of good practice and initiatives to improve children and young people's experience of healthcare, such as those contained in the Patient Experience Network report of 2016, there is variation in practice across the country.

Policy, regulation and commissioning

UN Convention on the Rights of the Child 1989

The rights of children and young people to participate and to express their opinions was enshrined in the UN Convention on the Rights of the Child, 1989, including the right to have a say in matters affecting their social, economic, religious, cultural and political life. Article 24 enshrined the right to enjoy the highest standard of health treatment and rehabilitation. This guideline will respect these rights for children who are accessing NHS services.

The Children Act 1989/The Children (Leaving Care) Act 2000

Looked-after children may not have the same levels of parent/carer support and advocacy and this guideline will include consideration of whether special provision is needed to enable a good experience of healthcare for these children.

Quality criteria for young people friendly health services (Department of Health, 2011) (Also known as 'You're Welcome' criteria)

This defines 10 quality criteria for commissioners and providers, to ensure that health services are young people friendly. They include accessibility,

confidentiality and consent, and the environment. These criteria are currently being updated, and will be taken into consideration when developing this guideline.

NHS Patient Experience Framework (Department of Health 2011)

This outlines those elements which are critical to the patients' experience of NHS services and include patient-centred values, access to services, coordination, continuity and integration of care, information and communication, physical comfort and emotional support. These elements will be taken into consideration when developing this guideline.

World Health Organisation (WHO) standards for improving the quality of care for children and young adolescents in health facilities (WHO 2018)

This document aims to ensure that the care given to all children, including young adolescents, in health facilities is evidence-based, safe, effective, timely, efficient, equitable and appropriate for their age and stage of development. These standards will be taken into consideration when developing this guideline.

2 Who the guideline is for

This guideline is for:

- practitioners providing NHS- or local authority-commissioned healthcare services for babies, children and young people
- commissioners and providers of healthcare services for babies, children and young people
- babies, children and young people (aged 17 and under) using healthcare services, their families and carers, and the public.

It may also be relevant for:

- commissioners and providers of social care services for babies, children and young people
- 18 to 24 year olds using healthcare services.

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](#).

Equality considerations

NICE has carried out [an equality impact assessment](#) during scoping. The assessment:

- lists equality issues identified, and how they have been addressed
- explains why any groups are excluded from the scope.

The guideline will take into account potential inequalities relating to babies, children and young people:

- who have protected characteristics (for example, disability, gender, race, religion or belief, sexual orientation)
- who have communication difficulties or who have learning, sensory or cognitive impairment
- who do not speak English or whose first language is not English
- who do not have parents and carers who can advocate for them (for example, unaccompanied asylum seekers, parents and carers whose first language is not English, children in care or leaving care)
- who have difficulty accessing healthcare services (for example, immigrants and asylum seekers, those who have no fixed abode or are travellers, children in care or leaving care, who are young carers, children who live in a rural or remote location, young offenders or babies who are in prison with their mothers)
- who come from a social or family background that may affect their experience of healthcare (for example, children who live in poverty, are 'children in need' or have a protection plan, or who have a parent in prison)
- who have healthcare needs that may be associated with stigma or discrimination (for example, mental health conditions, HIV).

3 What the guideline will cover

3.1 *Who is the focus?*

Groups that will be covered

- Babies, children and young people (aged 17 and under) accessing NHS physical or mental health services, or local authority-commissioned healthcare services.

The focus of this guideline is on the experience of babies, children and young people but it is recognised that parents or carers play a key role and the views of parents or carers will be taken into consideration when developing this guideline. However, recommendations will not be made to specifically improve parents' or carers' experience of healthcare.

The guideline will aim to make separate recommendations for babies, children and young people, and will distinguish between different age ranges within these groups when necessary. However, if appropriate it will also make over-arching recommendations relating to healthcare experience for all age groups covered.

Groups that will not be covered

- Babies, children and young people with life-limiting conditions who are receiving end of life care are not covered as there is already a NICE guideline on [End of life care for infants, children and young people with life-limiting conditions: planning and management](#).
- Young people aged 18 years or older are not covered as there are already NICE guidelines on [Patient experience in adult NHS services: improving the experience of care for people using adult NHS services](#) and [Transition from children's to adults' services for young people using health or social care services](#).

Settings

Settings that will be covered

- All settings where NHS- or local authority-commissioned healthcare services are provided.

3.2 *Activities, services or aspects of care*

Key areas that will be covered

We will look at evidence in the areas below when developing the guideline, but it may not be possible to make recommendations in all the areas.

- 1 Communication with babies, children, young people and their parents or carers. This includes ensuring that children and young people are listened to, and are involved in planning their care and in making decisions about their health.
- 2 Access to healthcare information for children, young people and the parents or carers of babies or young children.
- 3 Advocacy and support for babies, and advocacy and support for and by children and young people.
- 4 Improving babies, children and young people's experience of their healthcare.
- 5 Involving children, young people and the parents or carers of babies in improving experience of healthcare.
- 6 Healthcare environment (including facilities and equipment) appropriate to the age and needs of babies, children and young people, and across all settings in which healthcare is provided.
- 7 Family and peer relationships, including continuing with social activities and schooling.
- 8 Accessibility, continuity and coordination throughout healthcare pathways.

Areas that will not be covered

- Babies, children and young people's experience of social care.
- Transition from children's to adult services.

- Disease-specific recommendations will not be made.

Related NICE guidance

Published

- [Child abuse and neglect](#) (2017) NICE guideline NG67
- [End of life care for infants, children and young people with life-limiting conditions: planning and management](#) (2016) NICE guideline NG61
- [Transition between inpatient mental health settings and community or care home settings](#) (2016) NICE guideline NG53
- [Transition from children's to adults' services for young people using health or social care services](#) (2016) NICE guideline NG43
- [Looked-after children and young people](#) (2015) NICE guideline PH28
- [Medicines optimisation](#) (2015) NICE guideline NG5

NICE has also produced a number of guidelines for children relating to the management of specific clinical conditions. Many of these contain recommendations relating to children and young people's experience.

In development

- [Children and young people with disabilities and severe complex needs: integrated health and social care support and service guidance. NICE guideline](#). Publication expected February 2021.

NICE guidance about the experience of people using NHS services

NICE has produced the following guidance on the experience of people using the NHS and social care but these guidelines all relate to adults (18 years and over).

- [People's experience in adult social care services: improving the experience of care and support for people using adult social care services](#) (2018) NICE guideline NG86
- [Patient experience in adult NHS services](#) (2012) NICE guideline CG138

- [Service user experience in adult mental health: improving the experience of care for people using adult NHS mental health services](#) (2011) NICE guideline CG136
- [Medicines adherence](#) (2009) NICE guideline CG76

3.3 Economic aspects

We will take economic aspects into account when making recommendations. We will develop an economic plan that states for each review question (or key area in the scope) whether economic considerations are relevant, and if so whether this is an area that should be prioritised for economic modelling and analysis. We will review the economic evidence and carry out economic analyses, using an NHS and personal social services (PSS) perspective, although wider perspectives will be considered if it is appropriate and feasible to do so.

3.4 Key issues and draft questions

- 1 Communication with babies, children, young people and their parents or carers. This includes ensuring that children and young people are listened to, and are involved in planning their care and in making decisions about their health.
 - 1.1 How do children and young people like to be involved in planning their healthcare and making shared decisions about their health?
 - 1.2 How should healthcare staff communicate with babies, children, young people and their parents or carers?
 - 1.3 How should issues about consent, privacy and confidentiality be addressed with children and young people?
- 2 Access to healthcare information for children, young people and the parents or carers of babies or young children.
 - 2.1 How do children and young people, and the parents or carers of babies and young children like to access healthcare information?
 - 2.2 How can children and young people and the parents or carers of babies and young children be supported to make informed decisions, including about risks and benefits?

- 3 Advocacy and support for babies, and advocacy and support for and by children and young people.
 - 3.1 How do children and young people want their parents or carers to be involved in their care and decisions about their care?
 - 3.2 How do children and young people want healthcare staff to support them?
 - 3.3 How can children and young people be empowered to advocate for themselves?
 - 3.4 How can parents or carers, healthcare staff and independent advocates represent the views of babies, children and young people?
- 4 Improving babies, children and young people's experience of their healthcare.
 - 4.1 What factors are important to babies, children and young people to improve their experience of healthcare services?
- 5 Involving children, young people and the parents or carers of babies in improving experience of healthcare.
 - 5.1 How can the perspective of children and young people, and of the parents or carers of babies inform the design of healthcare services?
 - 5.2 How can the experience of babies, children and young people be measured so as to improve their experience of healthcare?
- 6 Healthcare environment (including facilities and equipment) appropriate to the age and needs of babies, children and young people and across all settings in which healthcare is provided.
 - 6.1 What features of the healthcare environment are important to babies, children and young people to improve their experience of care?
- 7 Family and peer relationships, including continuing with social activities and schooling.
 - 7.1 How can health services support engagement in usual activities (for example sibling relationships, other family relationships, schooling, friendships, social activities) for babies, children and young people?
- 8 Accessibility, continuity and coordination throughout healthcare pathways.
 - 8.1 What are the facilitators and barriers for babies, children and young people in accessing healthcare services?

8.2 What factors promote continuity and coordination of care for babies, children and young people?

The key issues and draft questions will be used to develop more detailed review questions, which will guide the systematic review of the literature.

3.5 Main outcomes

The main outcomes and themes that may be considered when searching for and assessing the evidence are:

- children and young people's experience and satisfaction
- parent/carer satisfaction for babies
- quality of life of babies, children and young people
- emotional wellbeing of babies, children and young people

4 NICE quality standards and NICE Pathways

4.1 NICE quality standards

NICE quality standards that may need to be revised or updated when this guideline is published:

- [Cancer services for children and young people](#) (2014) NICE quality standard QS55

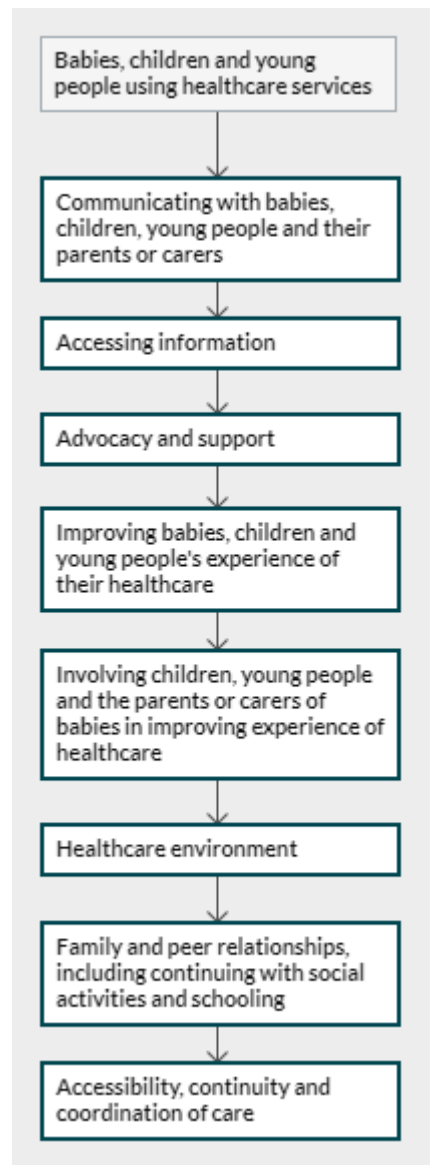
NICE quality standards that will use this guideline as an evidence source when they are being developed:

- Babies, children and young people's experience of healthcare NICE quality standard. Publication date to be confirmed

4.2 NICE Pathways

[NICE Pathways](#) bring together everything we have said on a topic in an interactive flowchart. When this guideline is published, the recommendations will be included in the NICE Pathway on babies, children and young people's experience of healthcare (in development).

An outline based on this scope is included below. It will be adapted and more detail added as the recommendations are written during guideline development.



5 Further information

The guideline is expected to be published in April 2021.

You can follow progress of the [guideline](#) here.

Our website has information about how [NICE guidelines](#) are developed.

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