

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 quality standards for 'Babies, children and young people's experience of healthcare'.

1 Why the guideline is needed

NICE has already produced guidance specifically on adults' experience of 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 (<https://www.cqc.org.uk/publications/surveys/children-young-peoples-survey-2016>) 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.

1 The results of this survey found

- 2 • 91% of children and young people said they had been looked after well
- 3 • 86% reported staff talked with them about how they would be cared for
- 4 • 92% of those who asked questions received an answer from staff
- 5 • of those who had an operation or procedure, 93% said they received an
- 6 explanation beforehand about what would happen.

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

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

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

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

1 **Current practice**

2 Many NHS providers of healthcare services for children currently carry out
3 user surveys directly with children as well as with their parents or carers, and
4 some run user groups to obtain feedback from children and young people and
5 their parents or carers, with a view to improving the provision of services and
6 the experience of healthcare. However, apart from the children and young
7 people's inpatient survey, these groups are not routinely included in national
8 experience surveys, including the GP patient survey.

9 Examples of good practice in the delivery of children's healthcare services
10 contained in the Patient Experience Network (Patient Experience Network
11 2013) report include:

- 12 • the provision of appropriate accommodation and spaces on children's
13 wards (for example, ensuite bathrooms, room for parents to stay,
14 teenagers' recreation rooms)
- 15 • use of feedback apps on smartphones to obtain anonymous and timely
16 feedback from parents and children
- 17 • patient experience board games (to gather feedback from those with visual
18 impairment and learning difficulties)
- 19 • involving children in the design of new children's wards
- 20 • inviting schoolchildren to review the toys and entertainment available on
21 wards
- 22 • encouraging year 12 and 13 students to act as ward volunteers.

23 Another hospital has introduced an electronic tablet-based food ordering
24 system with pictures of the meals available.

25 **Policy, regulation and commissioning**

26 **UN Convention on the Rights of the Child 1989**

27 The rights of children and young people to participate and to express their
28 opinions was enshrined in the UN Convention on the Rights of the Child,
29 1989, including the right to have a say in matters affecting their social,
30 economic, religious, cultural and political life. Article 24 enshrined the right to

1 enjoy the highest standard of health treatment and rehabilitation. This
2 guideline will respect these rights for children who are accessing NHS
3 services.

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

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

9 **Quality criteria for young people friendly health services (Department of** 10 **Health, 2011) (Also known as 'You're Welcome' criteria)**

11 This defines 10 quality criteria for commissioners and providers to consider to
12 ensure health services are young people friendly and includes accessibility,
13 confidentiality and consent, and the environment. These criteria are currently
14 being updated, and will be taken into consideration when developing this
15 guideline.

16 **NHS Patient Experience Framework (Department of Health 2011)**

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

22 **World Health Organisation (WHO) standards for improving the quality of** 23 **care for children and young adolescents in health facilities (WHO 2018)**

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

2 Who the guideline is for

This guideline is for:

- healthcare professionals 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 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.

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 are immigrants
- who are asylum seekers
- whose first language is not English
- whose parents or carers may be unable to advocate for them, including those whose parents or carers do not speak English
- with learning disabilities or communication difficulties
- with mental health conditions

- 1 • with physical or sensory disabilities
- 2 • from different ethnic or religious groups
- 3 • who have no fixed abode, for example travelling families
- 4 • who identify as LGBT+
- 5 • who are looked-after babies and children, for example those in care, or
- 6 living with foster carers
- 7 • who are defined as 'children in need' or who have a protection plan
- 8 • who are leaving care
- 9 • who are young carers
- 10 • who live in a rural or remote location
- 11 • who are young offenders
- 12 • who are babies in prison with their mothers
- 13 • who come from a disadvantaged socioeconomic background

14 **3 What the guideline will cover**

15 **3.1 *Who is the focus?***

16 **Groups that will be covered**

- 17 • Babies, children and young people (0 to 17 years) accessing NHS or local
- 18 authority commissioned healthcare services.

19 The focus of this guideline is on the experience of babies, children and
20 young people but it is recognised that parents or carers play a key role and
21 the views of parents or carers will be taken into consideration when
22 developing this guideline.

23 **Groups that will not be covered**

- 24 • Babies, children and young people with life-limiting conditions receiving end
- 25 of life care are not covered as they are already included in the NICE
- 26 guideline on [End of life care for infants, children and young people with life-](#)
- 27 [limiting conditions: planning and management.](#)

- 1 • Young people aged 18 years or older are not covered as they are already
2 included in NICE guideline on [Patient experience in adult NHS services:
3 improving the experience of care for people using adult NHS services.](#)

4 **Settings that will be covered**

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

7 **3.2 *Activities, services or aspects of care***

8 **Key areas that will be covered**

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

11 1 Communication with babies, children, young people and their parents or
12 carers, including ensuring that children and young people are listened to,
13 and are involved in planning their care and in making decisions about
14 their healthcare.

15 2 Access to healthcare information for babies, children, young people and
16 their parents or carers.

17 3 Advocacy and support for and by children and young people.

18 4 Improving babies, children and young people's experience of healthcare.

19 5 Involving babies and their parents, children and young people in
20 improving experience of healthcare.

21 6 Healthcare environment (including facilities and equipment) appropriate
22 to the age and needs of babies, children and young people.

23 7 Family and peer relationships, including continuing with social activities
24 and schooling.

25 8 Accessibility, continuity and coordination of care.

26 **Areas that will not be covered**

- 27 • Babies, children and young people's experience of social care.
28 • Transition from children's to adult services.
29 • Disease-specific recommendations will not be made.

1 **Related NICE guidance**

2 ***Published***

- 3 • [End of life care for infants, children and young people with life-limiting](#)
4 [conditions: planning and management](#) (2016) NICE guideline NG61
- 5 • [Transition between inpatient mental health settings and community or care](#)
6 [home settings](#) (2016) NICE guideline NG53
- 7 • [Transition from children's to adults' services for young people using health](#)
8 [or social care services](#) (2016) NICE guideline NG43
- 9 • [Looked-after children and young people](#) (2015) NICE guideline PH28
- 10 • [Medicines optimisation](#) (2015) NICE guideline NG5

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

14 ***In development***

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

18 **NICE guidance about the experience of people using NHS services**

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

- 22 • [People's experience in adult social care services: improving the experience](#)
23 [of care and support for people using adult social care services](#) (2018) NICE
24 guideline NG86
- 25 • [Patient experience in adult NHS services](#) (2012) NICE guideline CG138
- 26 • [Service user experience in adult mental health: improving the experience of](#)
27 [care for people using adult NHS mental health services](#) (2011) NICE
28 guideline CG136
- 29 • [Medicines adherence](#) (2009) NICE guideline CG76

1 **3.3 Economic aspects**

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

10 **3.4 Key issues and draft questions**

11 1 Communication with babies, children, young people, and their parents or
12 carers including ensuring that children and young people are listened to,
13 and are involved in planning their care and in making decisions about
14 their healthcare:

15 1.1 How do children and young people like to be involved in planning
16 their care and making shared decisions about their care?

17 1.2 How should healthcare staff communicate with babies, children,
18 young people and their parents or carers?

19 1.3 How should issues about consent, privacy and confidentiality be
20 addressed with children and young people?

21 2 Access to healthcare information for babies, children, young people and
22 their parents or carers:

23 2.1 How do parents or carers of babies, and children and young people,
24 like to access healthcare information?

25 3 Advocacy and support for and by children and young people:

26 3.1 How do children and young people want their parents or carers to be
27 involved in their care and decisions about their care?

28 3.2 How do children and young people want healthcare staff to support
29 them?

30 3.3 How can children and young people be empowered to advocate for
31 themselves?

- 1 3.4 How can parents or carers, healthcare staff and independent
2 advocates represent the views of babies, children and young people?
3 4 Improving babies, children and young people's experience of healthcare:
4 4.1 What factors are important to babies, children and young people to
5 improve their experience of healthcare services?
6 5 Involving babies and their parents, children and young people in
7 improving experience of healthcare:
8 5.1 How can the perspective of babies, children and young people
9 inform the design of healthcare services?
10 5.2 How can the experience of babies, children and young people be
11 measured so as to improve their experience of healthcare?
12 6 Healthcare environment (including facilities and equipment) appropriate
13 to the age and needs of babies, children and young people:
14 6.1 What features of the healthcare environment are important to babies,
15 children and young people to improve their experience of care?
16 7 Family and peer relationships, including continuing with social activities
17 and schooling:
18 7.1 How can engagement in usual activities (for example family
19 relationships, schooling, peer friendships, social activities) be maintained
20 while children and young people are in hospital?
21 8 Accessibility, continuity and coordination of care:
22 8.1 What are the facilitators and barriers for babies, children and young
23 people in accessing healthcare services?
24 8.2 What factors promote continuity and coordination of care for babies,
25 children and young people?
26 The key issues and draft questions will be used to develop more detailed
27 review questions, which will guide the systematic review of the literature.

28 **3.5 Main outcomes**

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

- 31 • children and young people's experience/satisfaction
- 32 • parent/carer and sibling experience/satisfaction

- 1 • quality of life
- 2 • emotional wellbeing.

3 **4 NICE quality standards and NICE Pathways**

4 **4.1 NICE quality standards**

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

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

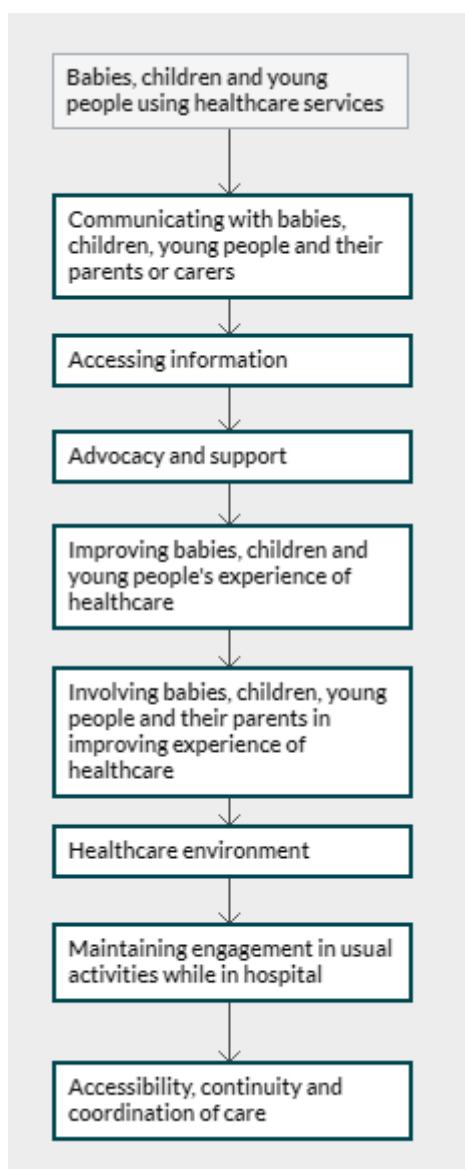
9 **NICE quality standards that will use this guideline as an evidence source** 10 **when they are being developed**

- 11 • To be confirmed.

12 **4.2 NICE Pathways**

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

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



1

2 **5 Further information**

This is the draft scope for consultation with registered stakeholders. The expected consultation dates are 13 December 2018 to 08 January 2019.

The guideline is expected to be published in April 2021.

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

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

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