

Babies, children and young people's experience of healthcare

Overview of NICE NG204 guidance – published August 2021

Xanthe Hodgson Clinical Specialist Physiotherapist MSc
NIHR Pre-Doctoral Fellow

world class expertise  local care

Royal Free London 
NHS Foundation Trust

Guideline available from: <https://www.nice.org.uk/guidance/ng204>. Some recommendations have been abridged for this presentation. Please see the guideline for the full text of the recommendations.

Introduction

NICE guidance is based on best available evidence, reviewed by experts, service users, carers and the general public

Professionals incl a Guideline Lead – ensures quality and transparency
<https://www.nice.org.uk/process/pmg20/chapter/introduction#key-principles-for-developing-guidelines>

Objectives

- What's it like to be on a NICE committee? What is the commitment and the benefits?
- Understand the main messages from the NICE guidance NG204 and why a positive healthcare experience is important
- Explore how physiotherapists can implement best practice for providing a positive experience of healthcare for children and young people

PLAN

- Introduction to NICE
- Background to this guidance
- NG204 Individual recommendations
- Ideas for implementation
- Visual summary
- Final words

Background

- Adult experience guidance was published over a decade ago
- Children and young people too often report poor patient experience (especially when they have the opportunity to respond themselves, rather than parents/carers responding on their behalf)
- Growing literature on how individual healthcare needs and priorities vary by age/developmental stage, diagnosis and many other factors

Aims

- Describe good patient experience for BCYP and how it can be delivered.
- *Parents or carers play a key role*, but the focus of the guideline is babies, children and young people
- To contribute towards health equality

Who is it for?

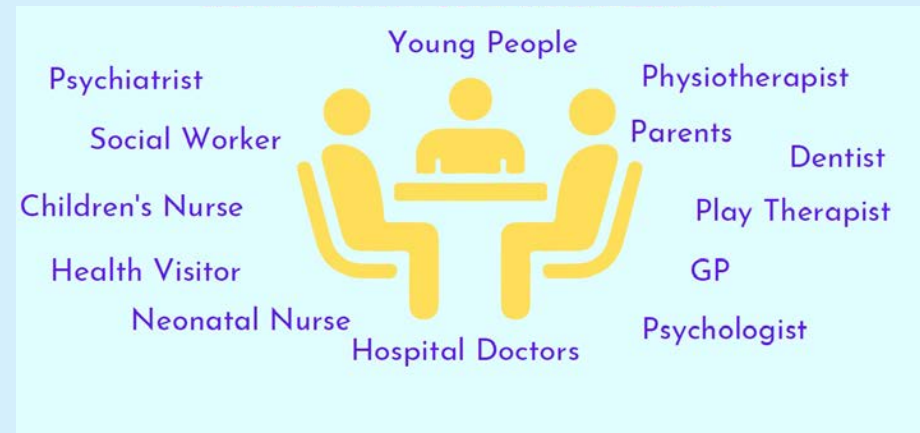
- Healthcare professionals, commissioners and providers of NHS or local authority healthcare services
- Non-clinical staff who come into contact with patients (for example, receptionists, clerical staff and domestic staff)
- People aged 17 and under using healthcare services, their families and carers,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

What settings does it apply to?

- All settings where NHS care is provided (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)

How was the guideline produced?

- Multi-disciplinary committee including 4 young lay members on committee and 2 parent /carer representatives
- 17 specific review questions
- Qualitative and quantitative literature searches undertaken (searched over 27000 articles) and systematic reviews carried out
- Focused grey literature search on national surveys of BCYP healthcare experience



How was the guideline produced?

- Multi-disciplinary committee including 4 young lay members on committee and 2 parent /carer representatives
- 17 specific review questions
- Qualitative and quantitative literature searches undertaken (searched over 27000 articles) and systematic reviews carried out
- Focused grey literature search on national surveys of BCYP healthcare experience
- 22 focus group meetings held with over 200 CYP aged 4 to 14, including consultation on draft guideline



1.1 Overarching principles

Recommendations include:

Safeguarding

Age and developmentally appropriate care:

- ‘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.’

Changes in needs and preferences:

- ‘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).’

1.2 Communication and information

Recommendations include:

Communication by healthcare staff:

- Be friendly and welcoming
- ‘Communicate with children and young people and their parents or carers with:
 - kindness, compassion and respect
 - cultural sensitivity
 - a non-judgemental attitude.’
- Take time to listen
- Be aware that babies, children and young people may not communicate pain, distress or anxiety verbally

Identify
Yes &
No

First language
may not be
English. May
be non-verbal

May need additional
resources –
interpreter/picture-
board/computer based
system

Consider
more
time/specialist
support

1.2 Communication and information

Recommendations include:

Providing information:

- 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.



Where and when they will be seen



Who will be providing the care



Their condition, any treatment options and issues related to these



Any preventative action or lifestyle changes they could make

1.2 Communication and information

What are you doing currently, or how might you adapt your practice to ensure effective communication and provision of information ?



1.3 Planning healthcare

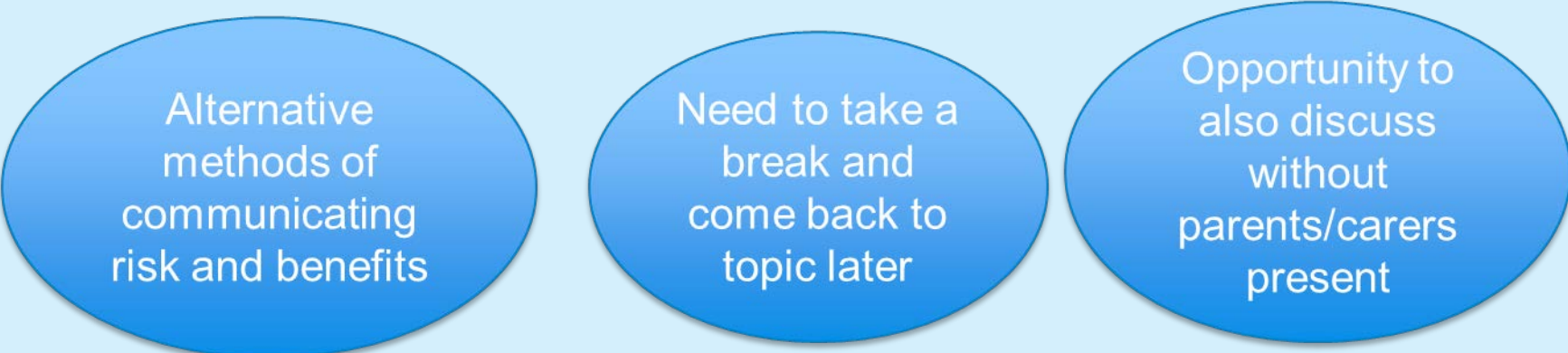
Recommendations include:

Shared decision making:

- Respect and support the right of children and young people to be involved in making decisions about their healthcare.

Risks and benefits:

- ‘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.’



Alternative
methods of
communicating
risk and benefits

Need to take a
break and
come back to
topic later

Opportunity to
also discuss
without
parents/carers
present

1.3 Planning healthcare

What are you doing currently, or how might you adapt your practice to involve children and young people in making decisions about their healthcare, and explain risks and benefits?

1.4 Consent, privacy and confidentiality

Recommendations include:

- ‘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.’
- ‘Maintain privacy and dignity during discussions, examinations and care. Take into account individual preferences, circumstances and cultural sensitivities whenever possible.’
- ‘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 Consent, privacy and confidentiality

What are you doing currently, or how might you adapt your practice to manage consent and maintain dignity, privacy and confidentiality?

1.5 Advocacy and support

Recommendations include:

Involvement of parents or carers:

- ‘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.’

Support from healthcare staff:

- 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.

Self-advocacy:

- 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.

Independent advocates

1.5 Advocacy and support

How can we support and empower children and young people to advocate for themselves?



1.6 Improving healthcare experience

Recommendations include:

Pain-related anxiety:

- ‘Reduce 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, and avoiding language that minimises the child or young person’s experience of pain (for example, do not say a procedure they found painful “didn’t really hurt”).’

1.6 Improving healthcare experience

Recommendations include:

Food:

- Ensure babies, children and young people who are inpatients have access to food that meets their needs.



Staff uniforms and healthcare clothing:

- Ensure children and young people, and parents or carers of babies and young children can easily identify members of staff.



1.6 Improving healthcare experience

What are you doing currently or how might you change your practice to improve the healthcare experience of children and young people?

1.7 Involvement in improving healthcare experience

Recommendations include:

Design of healthcare services:

- Ensure that feedback about the design of services from children, young people and parents or carers is shared and used.

Measuring experience:

- Collect feedback (for example, using questionnaires or surveys) directly from children and young people at different points in their healthcare experience.
- Actively seek out feedback from children and young people from under-represented groups.

1.7 Involvement in improving healthcare experience

What are you doing currently to measure patient experience? Timing?

How could you involve children and young people's opinions in design of healthcare?

1.8 Healthcare environment

Recommendations include:

- Provide a healthcare environment that supports:
 - privacy and dignity
 - confidence in healthcare delivery (for example, equipment is available when needed)
- family-centred care for inpatients
- parents or carers to give developmentally-appropriate care to their children
- children and young people who are inpatients to mix with friends, peers or partner
- a feeling of safety



1.8 Healthcare environment

What are you doing currently/or how might you change your practice to ensure the healthcare environment provides:

Privacy and dignity

Confidence

Family centred

Safe

1.9 Maintaining usual activities

Recommendations include:

- ‘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.’
- In an inpatient setting, ensure free internet access over Wi-Fi.
- 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.

1.9 Maintaining usual activities

What are you doing currently to help children and young people understand how their health condition impacts on engagement in usual activities, and set goals and expectations?



1.10 Accessibility, continuity and coordination

Recommendations include:

Accessing healthcare:

- Develop information about healthcare and healthcare services with input from children and young people themselves.
- ‘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.’

Continuity and coordination of care:

- ‘Maintain continuity of care by providing healthcare from the same professionals or teams when clinically appropriate.’
- ‘Provide contact information so that children and young people know how to obtain advice from the same service or team in the future.’

1.10 Accessibility, continuity and coordination

What are you doing currently/how could you adapt your practice to ensure children and young people's access the services they need, which children or parents might you target?

How do you ensure continuity of care, and good coordination with all agencies involved?

Implementation challenges and priorities

- Promoting a culture of listening to and addressing the needs of babies, children and young people
- Improving training and education
- Sharing best practice
- Workforce and practical constraints
- How can improved healthcare experience mitigate health inequalities among babies, children and young people?

Ask me
Check if I understand things
Ask if I am ok with what is going to happen
Ask if it's ok to share the things we've talked about with other people

Respect me
Trust me as an individual
Take me seriously
Believe me when I tell you something
Let me talk to you in private if I want to

Involve me
In decisions about my healthcare
In planning healthcare for the future
Let me make choices about things that matter to me



Talk to me
Explain things in a clear way that I will understand
Don't use difficult words
Use different ways, like pictures, to help explain

Help me understand
The good and bad bits of what is going to happen
What my rights are
How I can get the help I need

My healthcare experience checklist

Understand me
Don't judge me
I may change my mind about things
Things may change as I get older

Help me feel comfortable
Be friendly and kind
Show an interest in me as a person
Let me see the same people when I can
Make my healthcare environment welcoming and comfortable

Hear me
Find out what I am thinking and feeling
Find out the best way to communicate with me
Give me enough time to talk
Find out what I think about my care, and act on the feedback

Support me
Help me carry on doing the things I enjoy
Help me communicate what I want
Help me stand up for my rights

Take care of me
Keep me safe
Make adjustments if needed to help me use healthcare services

Feedback from focus group participants

- ‘Young person’s voices should be listened to, valued and considered to ensure that that health service can be accessible to all’
- ‘The best thing is giving our opinions and being part of something important’
- ‘Because I like you listening to my views, it’s awesome!’
- ‘I really like that it feels that you all care about my opinion’.



‘Through the publishing of this guideline, I hope that healthcare professionals can actively implement the recommendations and use them throughout their practice, whether that be in primary or secondary care. It’s important for everyone to recognise that **babies, children and young people have a choice and a voice** which is emphasised through this guideline.’

Aishah Farooq, Guideline Committee Lay Member



To see the full guideline, go to:
www.nice.org.uk/guidance/NG204

The guideline referred to in this presentation was produced by the National Guideline Alliance (NGA) at the Royal College of Obstetricians and Gynaecologists (RCOG) for the National Institute for Health and Care Excellence (NICE). The views expressed in this presentation are those of the authors and not necessarily those of RCOG, NGA or NICE.

National Institute for Health and Care Excellence 2021 'Babies, children and young people's experience of healthcare' NG204.