

NICE GUIDELINE SUMMARY NG204: Babies, children and young people's experience of healthcare

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NHS services strive to provide safe, effective responsive healthcare for the people they see. This is critically important for babies children and young people, whose experiences will inform a life time of engagement (or otherwise) with health care. Positive experiences of healthcare also play an important part in health equality, ensuring that every contact counts to build up trust.

This guideline covers babies, children and young people (aged up to 18 years) accessing NHS physical or mental health services, or local authority-commissioned healthcare services, in any setting where this care is provided. It is the first patient experience guideline for this age group setting out what contributes to good experiences of healthcare

The guideline development process involved:

- a multi-disciplinary committee including four young lay members with experience of receiving healthcare as a child or young person and two parent /carer representatives with lived experience of accessing healthcare services for their children
- 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 babies, children and young people's healthcare experience
- 22 focus group meetings held with over 200 children and young people aged 4 to 14, including consultation on draft guideline

Aishah Farooq, one of the committee young lay members, endorsed the guideline by saying:

"I hope that healthcare professionals can actively implement the recommendations and use them throughout their practice... It's important for everyone to recognise that babies, children and young people have a choice and a voice."

Summary of Recommendations

This guideline makes recommendations for key components of good experiences, including communication, information and advocacy and support. This guideline has been abridged, and a selection of recommendations is summarised here with a mix of direct quotes from the guidance and key messages. Please see (<https://www.nice.org.uk/guidance/ng204;>) for the full recommendations

1.1 Overarching Principles

Safeguarding Adhere to all safeguarding legislation, national and local policies and professional guidelines when implementing this guidance

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"

1.2 Communication and Information

Communication by healthcare staff: "Ensure that children and young people, and their parents or carers have a positive experience by:

- introducing yourself and anyone else present
 - asking them how they wish to be addressed (for example, their preferred name and pronouns)
 - putting the child or young person and their parents or carers at ease by being friendly and welcoming (for example smiling, saying hello, using eye contact)
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- building a rapport to develop trust
- encouraging children, young people and the parents and carers of babies and young people to contribute to, and be active participants in, discussions and decisions about their care"

Identify the child or young person's preferred forms of communication and use these when communicating with them. A key message from this section of the guidance recommends healthcare workers establish a child or young person's 'yes' and 'no' response which may be non-verbal.

"Communicate with children and young people, their parents or carers with:

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

Other key messages are the need to take time to listen, and be aware that babies, children and young people may not communicate pain, distress or anxiety verbally.

A key message from the providing information section: 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.

1.3 Planning 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".

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

1.4 Consent, Privacy and Confidentiality

"When discussing consent, assent, privacy and confidentiality:

- ensure that children and young people, and parents or carers, understand their rights and responsibilities
- explain when parents or 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."

1.5 Advocacy and Support

Involvement of parents or carers: "Involve parents or carers in discussions and decisions about the care of babies and young children. Recognise that parents or carers will be their principal caregivers/advocates".

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, a family member, advocate, social worker, youth worker, nurse or play specialist).

"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".

Other key messages from this guidance include:

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: "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.”

1.6 Improving Healthcare Experience

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 (for example, blood tests and injections)
- being honest about possible pain and what will be done to alleviate pain
- using therapeutic play and distraction techniques and creating a calm environment before, during and after interventions or procedures that 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”).

Key messages from other recommendations in this section 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.

1.7 Involvement in improving healthcare experience.

The key messages from this section 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 underrepresented groups.

1.8 Healthcare Environment

The key messages from this section include:

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
- parents or carers to give developmentally-appropriate care to their children
- a feeling of safety

1.9 Maintaining Usual Activities

“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”

A key message from this section of the recommendation is to 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

1.10 Accessibility, continuity and coordination of care

“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”.

Accessing healthcare: A key message from this section is to develop information about healthcare and healthcare services with input from children and young people themselves.



Figure 1: Visual Summary of NICE GUIDANCE NG204: Babies, Children and Young People's experience of healthcare

Resources: The full guidance is here: <https://www.nice.org.uk/guidance/ng204>; follow this link for interesting reflection on the guidance, led by two lay committee members <https://blogs.bmj.com/bmj/2021/10/08/healthcare-in-our-hands-putting-babies-children-and-young-people-at-the-centre-of-their-care/>



Author's comment: Being part of this guideline committee was really worthwhile. I would encourage any interested physiotherapists to apply to be on a NICE committee – it is great to be part of the collaborative process, learn more about research and contribute your experiences.

The input from the lay members – both young adults who had experienced healthcare as a child or young person, and parents of children with experience of healthcare – served to enrich the guidance. There was also separate group work with children and young people carried out by the National Children's Bureau. All of

this informed the final result which is a robust guidance that supports child centred practice in our services. Communication principles are central and it is very important that we are encouraging children and 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. It challenges us to get this right in our individual interactions with babies, children and young people, and champion the child and young person-centred approach within the services we work.

To explore this further, we plan a Webinar on the guidance which will include a workshop to look at how we can incorporate the advice into our practice.

The guideline referred to in this article 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 article are those of the authors and not necessarily those of RCOG, NGA or NICE.

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