

Babies, children and young people's experience of healthcare

Evidence from reference and focus groups

NICE guideline <TBC>

Supplement 4

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Draft for Consultation

These supplementary materials were developed by the National Guideline Alliance which is part of the Royal College of Obstetricians and Gynaecologists

Disclaimer

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or service users. The recommendations in this guideline are not mandatory and the guideline does not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian.

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Contents

Reference and focus groups	5
Reference and focus groups - overview	5
Quality assessment	9
NCB report	9

Reference and focus groups

This supplement contains 3 sections:

1. An overview of the reference and focus groups that were conducted in order to obtain input from children and young people directly into the development of the guideline, and details of the way the information was captured.
2. An overview of the quality assessment of the reference and focus groups
3. The report provided by the National Children's Bureau (NCB) who conducted the reference and focus groups on behalf of NICE and the NGA. This provides information on how the children and young people were recruited, a summary of the age and demographics of the children and young people involved, how the meetings were conducted, and how their input was collected. See separate document Supplement 4b.

Reference and focus groups - overview

A total of 22 meetings were held with children and young people aged from 4 years to 14 years to obtain their input into the guideline. A national reference group of young people aged 11 to 14 years met 4 times for full-day meetings, 3 reference groups of children aged 7 to 11 each met 4 times for 1.5 hour meetings, and a series of 6 one-off 45 minute focus groups were held with children aged 4 to 7 years (see Table 1).

Children aged under 4 and young people aged 15 to 17 years were not included in the focus and reference groups as they were represented directly on the guideline committee by 6 lay members:

- Children under 4 were represented by 2 parent members:
 - 1 parent of a baby (0 to 1 years), whose baby had used NHS healthcare services sometime in the last 2 years
 - 1 parent of a child who had used NHS healthcare services when the child was aged 1 to 4 years
- Young people aged 15 to 17 were represented by 4 young members:
 - 2 young people (aged 16 and above) with significant experience of NHS healthcare services as children
 - 2 young people (aged 16 and above) with significant experience of NHS healthcare services when aged 15-17

Ethical approval

The project group at NCB, after confirming the proposal for delivery, concluded that the proposal did not meet the threshold for submission to NCB's Research Ethics and Advisory Group because of the planned delivery methods.

Recruitment

The NCB used its existing networks to invite young people aged 11 to 14 years to participate in the national reference group and, for the younger age groups, to invite schools to participate in the project. Groups were set up with the aim of obtaining views from children from a range of geographical locations and different socio-economic and ethnic groups.

Table 1: Reference and focus groups

Age	Location	Date	Format	Topics discussed
11-14	National group	09/11/2019	1-day face-to-face workshop in London	<ul style="list-style-type: none">• Best and worst aspects of healthcare

Age	Location	Date	Format	Topics discussed
				<ul style="list-style-type: none"> • Factors important to a good healthcare experience • Participation in usual activities • Collecting feedback on healthcare experiences
11-14	National group	08/02/2020	1-day face-to-face workshop in London	<ul style="list-style-type: none"> • Involvement in healthcare decisions • Asking questions of healthcare professionals • Help and support with decision-making • Understanding risks and benefits
11-14	National group	03/10/2020	1-day virtual meeting (due to Covid-19)	<ul style="list-style-type: none"> • Consent, privacy and confidentiality • Access to healthcare • Advocacy and self-advocacy
11-14	National group	March or April 2021 - TBC	TBC	<ul style="list-style-type: none"> • Consultation on final guideline
7-11	Shoreditch, London	22/11/2019	1.5 hours face-to-face meeting in school	<ul style="list-style-type: none"> • World's best and world's worst healthcare • Usual activities
7-11	Shoreditch, London	14/02/2020	1.5 hours face-to-face meeting in school	<ul style="list-style-type: none"> • Factors important to a good healthcare experience • Involvement in healthcare decisions • Asking questions of healthcare professionals
7-11	Shoreditch, London	07/10/2020	1 hour face-to-face meeting in	<ul style="list-style-type: none"> • Consent, privacy and confidentiality

Age	Location	Date	Format	Topics discussed
			school (split into 2 groups)	<ul style="list-style-type: none"> • Access to healthcare
7-11	Shoreditch, London	March or April 2021 - TBC	TBC	<ul style="list-style-type: none"> • Consultation on guideline
7-11	Cambridge	04/12/2019	1.5 hours face-to-face meeting in school	<ul style="list-style-type: none"> • World's best and world's worst healthcare • Usual activities
7-11	Cambridge	13/02/2020	1.5 hours face-to-face meeting in school	<ul style="list-style-type: none"> • Factors important to a good healthcare experience • Involvement in healthcare decisions • Help and support with decision-making • Asking questions of healthcare professionals
7-11	Cambridge	21/10/2020	1.25 hours face-to-face meeting in school	<ul style="list-style-type: none"> • Consent, privacy and confidentiality • Access to healthcare
7-11	Cambridge	March or April 2021 - TBC	TBC	<ul style="list-style-type: none"> • Consultation on guideline
7-11	Blackpool	11/12/2019	1.5 hours face-to-face meeting in a pupil referral unit	<ul style="list-style-type: none"> • World's best and world's worst healthcare • Usual activities
7-11	Blackpool	10/02/2020	1.5 hours face-to-face meeting in a pupil referral unit	<ul style="list-style-type: none"> • Factors important to a good healthcare experience • Involvement in healthcare decisions • Asking questions of healthcare professionals
7-11	Blackpool	14/10/2020	1 hour virtual meeting with pupil referral unit	<ul style="list-style-type: none"> • Consent, privacy and confidentiality • Access to healthcare

Age	Location	Date	Format	Topics discussed
7-11	Blackpool	March or April 2021 - TBC	TBC	<ul style="list-style-type: none"> • Consultation on guideline
4-7	Shoreditch, London	05/10/2020	45 mins face-to-face meeting in school	<ul style="list-style-type: none"> • Communication by healthcare staff • Support from healthcare staff • Improving experience of healthcare
4-7	Crowle	20/10/2020	45 mins face-to-face meeting in school	<ul style="list-style-type: none"> • Communication by healthcare staff • Support from healthcare staff • Improving experience of healthcare
4-7	Basingstoke	16/10/2020	45 mins face-to-face meeting in school	<ul style="list-style-type: none"> • Communication by healthcare staff • Support from healthcare staff • Improving experience of healthcare
4-7	Halifax	22/10/2020	45 mins virtual meeting with school	<ul style="list-style-type: none"> • Communication by healthcare staff • Support from healthcare staff • Improving experience of healthcare
4-7	West Sussex	19/10/2020	45 mins virtual meeting run by school and NCB	<ul style="list-style-type: none"> • Communication by healthcare staff • Support from healthcare staff • Improving experience of healthcare
4-7	Banbury	12/10/2020	45 mins virtual meeting run by school and NCB	<ul style="list-style-type: none"> • Communication by healthcare staff • Support from healthcare staff • Improving experience of healthcare

A report was produced by the NCB after each meeting and provided to the NGA. This report contained the raw data collected at the meeting, mainly in the form of direct quotes from the participants, in response to questions, as part of discussions, or as a results of games and

activities carried out as part of the meeting. Photographs of drawings, ranking games or other outputs were also included in these reports.

The outputs from the meeting reports were collated by the NGA for each age group and mapped to the guideline review questions to which they related. This provided an overall summary document (see Supplement 4a). When the evidence relating to a review was presented to the committee, the evidence from the focus and reference groups was included in appendix M of the evidence report, and was presented to the committee at the meeting. The committee then used the evidence from the focus and reference groups when discussing and writing their recommendations.

Quality assessment

The quality of the evidence of the reference and focus groups is summarised in Table 2.

Table 2: Quality assessment

Source of evidence	Limitations
Reference and focus groups ^a	<p><u>The quality of the qualitative evidence was assessed using the CASP checklist for qualitative studies</u></p> <p>1: Was there a clear statement of the aims of the research? Yes 2: Was a qualitative methodology appropriate? Yes 3: Was the research design appropriate to address the aims of the research? Yes. A qualitative design using interviews with children and young people was used to explore their opinions and experiences of healthcare 4: Was the recruitment strategy appropriate to the aims of the research? Can't tell. Children and young people were recruited from a range of settings across the country, but not enough detail regarding how they were selected to participate in the project was provided 5: Were the data collected in a way that addressed the research issue? Yes. Reference groups and focus groups were used, although there was no detailed information on interview guides 6: Has the relationship between the researcher and participants been adequately considered? No. Descriptions of potential bias/influence between researcher and participants were not described 7: Have ethical issues been taken into consideration? Yes, ethical issues have been taken into consideration 8: Was the data analysis sufficiently rigorous? No, only quotes are reported, no data analysis was carried out 9: Is there a clear statement of findings? No, no explanation of findings was reported 10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability) 1. No, it does not contextualise findings in the literature. 2. Possibly yes. The study was conducted with participants from different backgrounds across the country.</p> <p>Overall judgement of quality: serious concerns.</p>

^aQuality assessment conducted on the evidence available before the NCB completed their final report.

NCB report

The report prepared by the NCB is included as a separate document, Supplement 4b.