

**Babies, Children and Young People's experience of Healthcare Guideline
Committee Meeting 4**

Date: 6 September 2019

Location: RCOG, London

Minutes: Confirmed

Committee members present:	
Catherine White (Chair)	Present for notes 1-6
Dougal Hargreaves (Topic Adviser)	Present for notes 1-6
Grace Atkins	Present for notes 1-6
Emma Beeden	Present for notes 1-6
Aishah Farooq	Present for notes 1-6
Nathan Randles	Present for notes 1-6
Joanna Shaw	Present for notes 1-6
Charity Gondwe	Present for notes 1-6
Rachel Elvins	Present for notes 1-6
James McTaggart (via VC)	Present for notes 1-6
Richard Churchill	Present for notes 1-6
Xanthe Hodgson	Present for notes 1-6
Cath Hubbuck	Present for notes 1-6
Paul Ashley	Present for notes 1-6
Catherine Churchill	Present for notes 1-6

In attendance:		
Hilary Eadon	NGA Guideline Lead	Present for notes 1-6
Linyun Fou	NGA Senior Systematic Reviewer	Present for notes 1-6
Anuja Pandey	NGA Systematic Reviewer	Present for notes 1-6
Alice Navein	NGA Systematic Reviewer	Present for notes 1-6
Agnesa Mehmeti	NGA Information Scientist	Present for notes 1-6
Stephanie Armstrong	NGA Health Economist	Present for notes 1-6
Feima Ndoeka	NGA Project Manager	Present for notes 1-6
Gareth Haman	NICE Senior Medical Editor	Present for notes 1-6
Catrina Charlton	NICE Guideline Commissioning Manager	Present for notes 1-6
Joanna Carr	Senior Participation Development Officer, National Children's Bureau	Present for notes 1-4
Apologies: Committee members: Kath Evans Sallie Bloomfield		

Amy Overend
NGA Staff:
Charlie Fairhurst
Rakhee Shah

1. Welcome and objectives for the meeting

The Chair welcomed the committee members and attendees to the fourth guideline committee meeting on Babies, children and young people's experience of healthcare. The chair acknowledged apologies received as noted above.

2. Confirmation of matter under discussion, and declarations of interest

The Chair confirmed that, for the purpose of managing conflicts of interest, the matter under discussion was babies, children and young people's experience of healthcare. The Chair asked everyone to verbally declare any interests that have arisen since the last meeting. One new declaration of interest had been declared by Charlie Fairhurst (NGA Clinical Advisor) who had been appointed as the Chair of the NHSE paediatric neurosciences clinical reference group.

The Chair congratulated some of the members on their exam results and welcomed Joanna Carr from the National Children's Bureau, and Gareth Haman, the senior medical editor from NICE.

The Chair outlined the objectives of the meeting.

3. Minutes of last meeting

The minutes from the last meeting was agreed as an accurate record. The Chair reminded committee members of the outstanding action items.

4. Presentations

The Chair introduced the following presentations:

Joanna Carr, Senior Participation Development Officer, National Children's Bureau gave a presentation on the organisation of the children's reference and focus groups.

Gareth Haman, NICE Senior Editor gave a presentation on the writing of recommendations.

Alice Navein, NGA systematic reviewer, presented an update on the evidence identified for review question 5.2 How can the experience of babies, children and young people be measures so as to improve their experience of healthcare?

Anuja Pandey, NGA systematic reviewer presented the following protocols:

- Protocol 2.2 How should the risks and benefits of healthcare decisions be explained to children and young people and the parents or carers of babies and young children?
- Protocol 3.1 How do children and young people want their parents or carers to be

involved in their care and decisions about their care?

- Protocol 3.2 How do children and young people want healthcare staff to support them?

Alice Navein, NGA systematic reviewer presented the following protocols:

- Protocol 3.3 How can children and young people be empowered to advocate for themselves?
- Protocol 3.4 How can independent advocates best represent the views of babies, children and young people?

Hilary Eadon, NGA Guideline Lead presented an overview of the 'Committee's discussion of the evidence' and the 'Impact and Rationale' sections of the guideline.

The chair thanked all for their presentations.

5. Questions and discussion

The committee discussed the plans for the focus and reference groups and agreed to prioritise the review questions to be discussed by the groups.

The committee discussed the five protocols and agreed changes.

6. AOB

LinYou Fou informed the committee that he was leaving the guideline and would be replaced with another NGA senior systematic reviewer.

Date of next meeting: 16th October 2019

Location of next meeting: RCOG , London