

Developmental follow-up of preterm babies Committee meeting 9

Date: 07/09/2016 & 08/09/2016 **Location:** Royal College of Obstetricians and Gynaecologists, London **Minutes:** Confirmed

Committee members present:		
1. Gillian Baird (Chair)	Present for items 1-15 – days 1 & 2	
2. Jennifer Baulcomb	Present for items 1-15 – days 1 & 2	
3. Joe Fawke	Present for items 1-15 – days 1 & 2	
4. Joanna Goodman	Present for items 1-15 – days 1 & 2	
5. Celia Harding	Present for items 1-15 – days 1 & 2	
6. Betty Hutchon	Present for items 1-15 – days 1 & 2	
7. Sarra Hoy	Present for items 1-7 day 1 only	
8. Sally Jary	Present for items 1-8 – day 1 only	
9. Samantha Johnson	Present for items 1-15 – days 1 & 2	
10. Nashwa Matta	Present for items 1-15 – days 1 & 2	
11. Nicola O'Connor	Present for items 1-15 – days 1 & 2	
12. Tilly Pillay	Present for items 1-15 – days 1 & 2	
13. Claire Rohan	Present for items 1-15 – days 1 & 2	
Co-opted committee member:		
14. Neil Marlow	Present for items 5-16 – days 1 & 2	
15. Jugnoo Rahi	Present for items 9-12 – day 2 only	
NGA staff in attendance:		
16. Maija Kallioinen	NGA Research Assistant	
17. Stephen Murphy	NGA Clinical Adviser – present for items 1-7, day 1 only	
18. Sabrina Naqvi	NGA Project Manager	
19. Vanessa Delgado Nunes	NGA Guideline Lead	
20. Matthew Prettyjohns	NGA Senior Health Economist	
21. Tim Reeves	NGA Information Scientist – present for Day 1 only	
NICE staff in attendance:		
22. Katie Perryman Ford	NICE Guideline Commissioning Manager – present for Day 2	
Apologies:		
Katie Perryman Ford	NICE Guideline Commissioning Manager	Day 1
Sally Jary	Committee Member	Day 2
Sara Hoy	Committee Member	Day 2
Stephen Murphy	NGA Clinical Adviser	Day 2
Tim Reeves	NGA Information Scientist	Day 2
Yelan Guo	NGA Senior Research Fellow	Days 1 and 2

Day 1: Wednesday 7th September 2016

1. Welcome, housekeeping, introductions, apologies and minutes from last meeting

The Chair welcomed the Committee members and attendees to 1st day of the 9th meeting on Developmental follow-up of preterm babies.

The Chair introduced Matthew Prettyjohns, Senior Health Economist, who will be replacing Alex Bates on the guideline. The Chair also introduced Sabrina Naqvi, the new interim Project Manager for the guideline.

The Chair informed the Committee that apologies had been received. These are noted above.

The Committee were invited to an evening meal, for which the details were arranged.

The Chair asked the Committee if it wanted any changes made to the minutes of the last meeting. The Committee agreed that the minutes were a true and accurate account of the meeting, barring one amendment to the date on the minutes.

The Chair confirmed that all matters arising had been completed or were in hand.

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 Developmental follow-up of preterm babies

The Chair asked everyone to verbally declare any interests that have arisen since the last meeting.

Name	Job title, organisation	Declarations of Interest, date declared	Type of interest	Decision taken
Samantha Johnson	Developmental Psychologist and Senior Research Fellow, Leicester Uni	2 papers accepted for publication: Learning disabilities among extremely preterm children without neurosensory impairment; and Charting the survival, health and development of extremely preterm infants	Specific, personal, nonfinancial	No action needed

Neil Marlow	Professor of Neonatal Medicine - UCL EGA Institute for Women's Health	16 Publications most directly related to outcomes for preterm children	Specific, personal, nonfinancial	No action needed
Neil Marlow	Professor of	Presentation to FDA	Specific,	No action

	Neonatal Medicine - UCL EGA Institute for Women's Health	(Washington DC) about the use of outcome data in regulatory trials (July; sponsored by Shire)	personal, nonfinancial	needed
Neil Marlow	Professor of Neonatal Medicine - UCL EGA Institute for Women's Health	Presentation to EMA meeting on the role of long term follow up in regulatory trials (sponsored by International Neonatal Consortium)	Specific, personal, nonfinancial	No action needed
Neil Marlow	Professor of Neonatal Medicine - UCL EGA Institute for Women's Health	Advice to Novartis and Shire on outcome measures for trials (remunerated through consultancy agreement).	Specific, personal, nonfinancial	No action needed
Neil Marlow	Professor of Neonatal Medicine - UCL EGA Institute for Women's Health	Lectures including long term outcomes data to: Neonatal Ethics Conference Oxford 2 June; & 24th Annual International Neonatal Conference 10 June	Specific, personal, nonfinancial	No action needed
Neil Marlow	Professor of Neonatal Medicine - UCL EGA Institute for Women's Health	Media: BBC Radio 4 Inside the ethics committee (Broadcast 11 August)	Specific, personal, nonfinancial	No action needed
Neil Marlow	Professor of Neonatal Medicine - UCL EGA Institute for Women's Health	Involvement in the following industry led studies: SHIRE – consultancy for trial design Novartis – consultancy for trial design GSK – member of Data Monitoring Committee	Personal, financial, specific	No action needed

Joe Fawke	Consultant Neonatologist - University Hospitals Leicester NHS trust	Paediatric Training Programme Director for HE	Specific, nonpersonal, nonfinancial	No action needed
Nashwa Matta	Associate specialist in neonatology and Child dev. - Princess Royal maternity hospital	Lecture to Specialist Children Service for Scottish Government	Specific, nonpersonal, nonfinancial	No action needed
Nashwa Matta	Associate specialist in neonatology and Child dev. - Princess Royal maternity	Member of group to promote family centred care; responsible for staff education and speaking with parents	Specific, nonpersonal, nonfinancial	No action needed

	hospital			
Nicola O'Connor	Lay member	Parent speaker at the Joint Annual Study Day for professionals in neonatal care – protecting baby brains	Specific, personal, nonfinancial	No action needed

The Chair and a senior member of the Developer's team noted that the interests declared did not prevent the attendees from fully participating in the meeting.

3. Evidence review on support to parents and carers of preterm infants and children.

The Chair introduced Vanessa Delgado Nunes, Guideline Lead, who presented the evidence review on support to parents and carers of preterm infants and children, on Sadia's behalf in her absence.

Morning break: 11:30-11:45

4. Drafting recommendations on support to parents and carers of preterm infants and children

The Chair led the Committee through drafting recommendations on the topic, which were documented in Evidence Review on support for parents and carers of preterm babies draft chapter.

Lunch break: 11:15-13:45

5. Lay Member Forum

There were no service user or carer concerns.

6. Evidence Review on models for service delivery

The Chair introduced Maija Kallioinen, Systematic Reviewer, who presented the evidence review on models for service delivery.

7. Evidence Review and Drafting Recommendations

The Chair led the Committee through drafting recommendations on the topic, which were documented in the Evidence Review on service delivery draft chapter.

8. Any other business

There were no other items of business.

The meal will be held in the evening, and the 2nd day of the Guideline Committee meeting will begin at 9.30am (with tea and coffee from 9am).

Day 2: Thursday 8th September 2016

9. Welcome, objectives for the meeting, and minutes from last meeting

The Chair welcomed the Committee members and attendees to the 2nd day of the 10th meeting on Developmental Follow-up of Preterm Babies.

The Chair informed the Committee that apologies had been received. These are noted above.

The Chair introduced Professor Jugnoo Rahi, Professor of Ophthalmic Epidemiology, Institute of Ophthalmology UCL and Honorary Consultant Ophthalmologist, Great Ormond Street Hospital NHS Foundation Trust.

10. Declarations of interest

No new interests were declared.

11. Health Economics

The Chair introduced Matthew Prettyjohns, Senior Health Economics, who presented the Health Economics model.

12. Follow-up in preterm children for visual impairment- expert presentation

The Chair introduced Professor Jugnoo Rahi, Professor of Ophthalmic Epidemiology at Great Ormond Street Hospital, who delivered a presentation on follow-up in preterm children for visual impairment. Professor Rahi invited questions from the Committee following her presentation.

Morning break: 11.10-11.25

13. Reviewing recommendations on models for service delivery (continued from day 1)

The Chair led the Committee through a review of the recommendations drafted on models for service delivery. *Lunch break: 12:30-13:00*

14. Reviewing recommendations

The Chair led the Committee through a review of recommendations drafted to date.

15. AOB

There were no other items of business. The Chair thanked everyone for their attendance and closed the meeting.

Date of next meeting: 11/10/2016

Location of next meeting: Royal College of Obstetricians and Gynaecologists