

**12th End of Life Care in Infants, Children and Young People
Guideline Committee meeting**

Date: 01/09/2016
Location: Royal College of Obstetricians and Gynaecologists, London
Minutes: Final

Committee members present:		
1. Peter Barry		(Present for notes 3 – 7)
2. Karen Brombley		(Present for notes 1 – 7)
3. Lucy Coombes		(Present for notes 1 – 7)
4. Stacey Curzon		(Present for notes 1 – 7)
5. Bobbie Farsides		(Present for notes 1 – 7)
6. Emily Harrop (Deputy Chair)		(Present for notes 1 – 7)
7. Satbir Jassal		(Present for notes 1 – 7)
8. Paul Nash		(Present for notes 1 – 7)
9. Fauzia Paize		(Present for notes 1 – 7)
10. Zoe Picton-Howell		(Present for notes 1 – 7)
11. David Vickers (Chair)		(Present for notes 1 – 7)
12. Amy Volans		(Present for notes 1 – 7)

NGA and NICE staff In attendance:		
13. Katharina Dworzynski	Guideline Lead, NGA	(Present for notes 1 – 7)
14. Yelan Guo	Senior Research Fellow, NGA	(Present for notes 1 – 7)
15. Paul Jacklin	Health Economist, NGA	(Present for notes 1 – 7)
16. Stephen Murphy	Clinical Director, NGA	(Present for notes 1 – 5)
17. Sabrina Naqvi	Project Manager, NGA	(Present for notes 1 – 7)
18. Gemma Villanueva	Interim Senior Research Fellow, NGA	(Present for notes 1 – 7)
19. James Hall	Editor, NICE	(Present for notes 2 – 7)
20. Katie Perryman-Ford	Guideline Commissioning Manager, NICE	(Present for notes 1 – 7)
21. Maroulla Whitely	Business Analyst, NICE	(Present for notes 1 – 7)

Observers:
Simran Chawla, Public Involvement Adviser (Present for notes 1 – 4)

End of life care – 12th Guideline Committee meeting minutes

Apologies:	
Jane Green	Guideline Committee member
Claire Wensley	Guideline Committee member
Tim Reeves	Information Scientist, NGA

1. Welcome and objectives for the meeting

The Chair welcomed Committee members and attendees to the 12th and final meeting on End of Life Care in Infants, Children and Young People. Committee members and other attendees introduced themselves.

The guideline's new Project Manager, Sabrina Naqvi was introduced. Emily Harrop was introduced at the guideline's new Deputy Chair, in recognition of her additional support with the guideline.

Simran Chawla, Public Involvement Adviser at NICE, asked to observe the meeting for the morning session.

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

The Chair outlined the objectives of the meeting, which included discussing the key Stakeholder Consultation Comments, and changes that have been made to the recommendations in response to the aforementioned comments.

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 end of life care in infants, children and young people.

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
Paul Nash	Senior Chaplain, Birmingham Children's Hospital NHSFT and Co-convenor Paediatric Chaplaincy Network (GB&I)	Fundraising to research spiritual emotional needs of children with a sibling with a rare disease - proposal to ethics council late 2016	non-personal financial specific	Declare and participate
Karen Brombley	Nurse Consultant for Children and Young People's Palliative Care, Helen Douglas House	Organised non-medical prescribing study day for specialist nurses in PPC	personal non-financial specific	Declare and participate

End of life care – 12th Guideline Committee meeting minutes

Emily Harrop	Consultant in Paediatric Palliative Care Helen & Douglas House Hospices, Oxford and Oxford University Hospitals	Contributed to non-medical prescription study day at Rainbow Children's Hospice (Talk on novel routes of administration)	personal non-financial specific	Declare and participate
Emily Harrop	Consultant in Paediatric Palliative Care Helen & Douglas House Hospices, Oxford and Oxford University Hospitals	Presented to Association of Palliative Medicine on the topic of Dystonia	personal non-financial specific	Declare and Participate
Satbir Jassal	General Practitioner, Bridge Street Medical Practice, Loughborough	Ad hoc advisor to European Medicine Agency on application made by drug company to produce a liquid form of glyzopyromina (dry mouth secretions). Unpaid. Worked for EMA (not for drug company)	personal non-financial specific	Declare and participate

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. Minutes of last meeting

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.

4. Resource Impact Tools

The chair introduced Maroulla Whitely, Business Analyst (Accountant) from the Resource Impact Assessment Team, who delivered a presentation on Resource Impact Tools.

5. Discussion of stakeholder comments

Katharina Dworzynski, the Guideline Lead, led a discussion on the stakeholder consultation comments. This included discussions on the recommendations on siblings and other family members, DNAR and parallel planning.

Morning break

6. Discussion of stakeholder comments continued

Katharina Dworzynski, the Guideline Lead, continued to lead the discussion on the

End of life care – 12th Guideline Committee meeting minutes

stakeholder consultation comments. This included discussions on the recommendations on organ donation, terminology, Advance Care Plans, symptoms and neonates.

Lunch break

7. Discussion of stakeholder comments continued

Katharina Dworzynski, the Guideline Lead, continued to lead the discussion on the stakeholder consultation comments. This included discussions on the recommendations on lead clinicians and 24/7 as well as on the research recommendations.

Afternoon break

8. Committee feedback on stakeholder comments

Katharina Dworzynski, the Guideline Lead, invited the Committee to feedback on some of the stakeholder comments.

9. Summary of next steps and close

Katharina Dworzynski, the Guideline Lead discussed the key dates for the guideline. She asked the Committee to email any suggestions of academic publications to the Project Manager.

Katharina thanks the Committee for their involvement in the Guideline thus far and closed the meeting.

This is the final meeting for the guideline.