

End of life care – 11th Guideline Committee meeting minutes

11th End of Life Care in Infants, Children and Young People Guideline Committee meeting

Date: 28/04/2016
Location: Royal College of Obstetricians and Gynaecologists
Minutes: Final

Committee members present:		
Bobbie Farsides		(Present for notes 1 – 7)
Peter Barry		(Present for notes 1 – 7)
Amy Volans		(Present for notes 1 – 7)
Lucy Coombes		(Present for notes 1 – 7)
Claire Wensley		(Present for notes 1 – 7)
Emily Harrop (Interim Chair)		(Present for notes 1 – 7)
Fauzia Paize		(Present for notes 1 – 7)
Stacey Curzon		(Present for notes 1 – 7)
Paul Nash		(Present for notes 1 – 7)
Karen Brombley		(Present for notes 1 – 7)
Zoe Picton-Howell		(Present for notes 1 – 7)

In attendance:		
Kate Coles	Project Manager, NGA	(Present for notes 1 – 7)
Katharina Dworzynski	Guideline Lead , NGA	(Present for notes 1 – 7)
Yelan Guo	Senior Research Fellow, NGA	(Present for notes 1 – 7)
Gemma Villanueva	Interim Senior Research Fellow, NGA	(Present for notes 1 – 7)
Tim Reeves	Information Scientist, NGA	(Present for notes 1 – 7)
Paul Jacklin	Health Economist, NGA	(Present for notes 1 – 7)
Alexandra Hellyer	Project Manager, NGA	(Present for notes 1 – 7)
David Hamilton	Expert Advisor	(Present for notes 1 – 7)
Susan Lee	Expert Advisor	(Present for notes 1 – 7)
Katie Perryman Ford	Guideline Commissioning Manager, NICE	(Present for notes 1 – 7)
Stephen Murphy	Clinical Director	(Present for notes 1 – 7)
Adam Stow	Implementation Support	(Present for notes 1 – 7)
Nick Hicks	National Institute Health Research	(Present for note 4)

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Observers: None

Apologies:

Satbir Jassal	Committee member
Jane Green	Committee member
Fauzia Paize	Committee member
David Vickers	Committee member

1. Welcome and objectives for the meeting

The Chair welcomed the Committee members and attendees to the 10th meeting on End of Life Care in Infants, Children and Young People. The Committee members and attendees introduced themselves.

No members of the public asked to observe the meeting.

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

The Chair outlined the objectives of the meeting, which included: discussion of research recommendations, review of current recommendations, supportive framework discussion, health economic updates, presentation of re-runs

Introductions

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:

"The Chair asked everyone to verbally declare any interests that have arisen since the last meeting. 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
Lucy Coombes	"Clinical Nurse Specialist Children and Young	Article entitled 'health related quality of life outcome measures in paediatric palliative care: a systematic review' accepted for publication in palliative medicine. Conclusion - there is currently no	Personal financial non-specific	Declare and participate

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	People's Outreach and Symptom Care Team, Royal Marsden NHS Foundation Trust "	ideal measure - more research needed. Work was for MSc dissertation - funded in part by the NIHR collaboration for leadership in applied health research and care funding scheme (CLAHRC)	c inter est	
Paul Nash	Senior Chaplain, Birmingham Children's Hospital NHSFT and Co-convenor Paediatric Chaplaincy Network (GB&I)	"Presentation at RCPCH annual conference, Young people's health special interest group and ethics and law forum 'Resolving challenging issues in young people's health' Religion, faith and culture. 26 April 2016	Per so nal non- financi al non- specifi c	Declare and particip ate
Paul Nash	Senior Chaplain, Birmingham Children's Hospital NHSFT and Co-convenor Paediatric Chaplaincy Network (GB&I)	Chair for Islamic consultation for our two new resources to encourage families in further engagement with organ donation. 21 April 2016	Per so nal non- financi al non- specif c	Declare and particip ate
Amy Volans	Clinical Psychologist and Systemic Family Psychotherapist Diana Children's Community Palliative Care Team East London NHS Foundation Trust	Organised (booked rooms and registered delegates) for study day for children's palliative care psychologists. Did not make any presentations at the event.	Non- perso nal non- financi al non- specifi c	Declare and Particip ate
Karen	Nurse Consultant	I have contributed to a mini review paper (invited article for a special	Per so nal	Declare and

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Brombley	for Children and Young People's Palliative Care, Helen Douglas House	<p>edition of Journal of Pharmacy & Pharmacology on the subject of Paediatrics), with 6 colleagues (mostly from London School of Pharmacy). This deals with the complex issues faced in practically delivering medication to children in palliative care. This does not recommend specific treatments, it deals with the practical challenges related to the lack of paediatric formulations, in the hope of inspiring researchers to develop these.</p> <p>The title is 'Palliative Medicines for Children – a new Frontier for Research'</p> <p>If accepted this is likely to be published at the very end of 2016 / early 2017.</p> <p>I have not been paid to undertake this work, and do not express personal opinions about the choice of individual treatments.</p>	non-financial non-specific	participate
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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. Presentations

The Chair introduced Yelan Guo, Senior Research Fellow, who gave a presentation of the re-runs done for the review questions in the guideline. Yelan Guo took questions from the group.

The Committee thanked Yelan Guo for her presentation and contribution to the

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development of the guideline.

The Chair introduced Gemma Villanueva, Senior Research Fellow, who gave a presentation of the re-runs done for the review questions from the group. Gemma Villanueva took questions from the group. The Committee thanked Gemma Villanueva for her presentation and contribution to the development of the guideline.

The Chair introduced Katharina Dworzynski, Guideline Lead, who gave a presentation of some supportive framework ideas. Katharina Dworzynski took questions from the group. The Committee thanked Katharina Dworzynski for her presentation and contribution to the development of the guideline.

The Chair introduced Paul Jacklin, Health Economist, who gave a presentation updating the Committee on the health economic aspects of the guideline. Paul Jacklin took questions from the group. The Committee thanked Paul Jacklin for his presentation and contribution to the development of the guideline.

5. Group work, questions and discussion

All attendees were given the opportunity to ask questions and raise queries.

7. Meeting adjourned

The Chair thanked attendees and adjourned the meeting.

Date of next meeting: 01/09/2016

Location of next meeting: Royal College of Obstetricians and Gynaecologists