

4.0.03 DOC Cmte minutes

10th End of Life Care in Infants, Children and Young People Guideline Committee meeting

Date: 07/04/2016

Location: Royal College of Obstetricians and Gynaecologists

Minutes:

Committee members present:		
David Vickers (Chair)		(Present for notes 1 – 7)
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		(Present for notes 1 – 7)
Fauzia Paize		(Present for notes 1 – 7)
Stacey Curzon		(Present for notes 1 – 5)
Satbir Jassal		(Present for notes 1 – 7)
Paul Nash		(Present for notes 1 – 7)
Jane Green		(Present for notes 1 – 7)
Zoe Picton-Howell		(Present for notes 1 – 7)

In attendance:		
Kate Coles	Project Manager	(Present for notes 1 – 7)
Katharina Dworzynski	Guideline Lead	(Present for notes 1 – 7)
Yelan Guo	Senior Research Fellow	(Present for notes 1 – 7)
Gemma Villanueva	Interim Senior Research Fellow	(Present for notes 1 – 7)
Tim Reeves	Information Scientist	(Present for notes 1 – 7)
Paul Jacklin	Health Economist	(Present for notes 1 – 7)
Alexandra Hellyer	Project Manager	(Present for notes 1 – 7)
David Hamilton	Expert Advisor	(Present for notes 1 – 7)
Susan Lee	Expert Advisor	(Present for notes 1 – 7)
Ferruccio Pelone	Research Assistant	(Present for notes 1 – 7)
Gary Waltham	Senior Director, NGA	(Present for notes 4 – 5)

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Observers:

Apologies:

Stephen Murphy	Clinical Director
Karen Bromley	Committee member
Katie Perryman Ford	Guideline Commissioning Manager

1. Welcome and objectives for the meeting
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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: Young People's Focus Group summary of final report, discussion of chapter flow, editorial refresher, discussion and agreement of recommendations

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:

What factors of social and practical support (including care of the body) are effective in end of life care of infants, children and young people with life-limiting conditions and their family members or carers (as appropriate) and what influences attitudes about these before and after death?

AND

What factors of spiritual or religious support (including care of the body) are effective in end of life care of infants, children and young people with life-limiting conditions and their family members or carers (as appropriate) and what influences attitudes about these before and after death?

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"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
Emily Harrop	Consultant, Paediatric Palliative Care, Helen & Douglas House Hospices	Abstract written to submit to 3rd International Paediatric Palliative Medicine conference in Rome (Nov 2016) on antenatal PPM	Personal non-financial non-specific interest	Declare and participate
Emily Harrop	Consultant, Paediatric Palliative Care, Helen & Douglas House Hospices	<p>Contribution to a mini review paper (invited article for a special 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-personal non-financial specific	Declare and participate
Zoe	Lay member	Giving a paper 'in whose best	Personal	Declare

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Picton-Howell		<p>interests' about paediatricians use of the term 'best interests' at Southampton university's 'everyday ethics conference' at RCN London</p> <p>Will be guest of Yours Epilepsy at their Champions Award 2016</p> <p>Received special Recognition Award from the patient experience Network 2015</p>	<p>Personal, non-financial specific</p>	<p>and participate</p>
Amy Volans	<p>Clinical Psychologist and Systemic Family Psychotherapist Diana Children's Community Palliative Care Team East London NHS Foundation Trust</p>	<p>Gave 15 minute presentation of creative approaches to bereavement support for vulnerable children at Child Bereavement UK study day in East London in April 2016 NB - covered bereavement care beyond the scope of this guideline</p>	<p>Personal Non-financial Non-specific</p>	<p>Declare and participate</p>
Amy Volans	<p>Clinical Psychologist and Systemic Family Psychotherapist Diana Children's Community Palliative Care Team East London NHS Foundation Trust</p>	<p>Teaching on 'childhood bereavement' to doctoral students at UCL Doctorate of Clinical Psychology course in May 2010</p> <p>Covers bereavement beyond the scope of the guideline</p> <p>Paid £72</p>	<p>Personal financial Non-specific</p>	<p>Declare and participate</p>
Satbir Jassal	<p>General Practitioner, Bridge Street Medical Practice, Loughborough</p>	<p>Lecture in Moscow on Practical Pain management, DNAR and Criteria for admission to hospice. Expenses only</p>	<p>Personal specific non-financial</p>	<p>Declare and participate</p>

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Bobbie Farsides	Professor of Clinical and Biomedical Ethics Brighton and Sussex Medical School	Member of the UK Donation Ethics Committee which has published a position paper on Children and Organ Donation http://www.aomrc.org.uk/docman?gid=63&view=category it has also commented UKDEC provides £160.00 per day to cover attendance at committee meetings (usually four per year) but does not pay for any work on projects between meetings	Personal specific non-financial	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. Presentations

The Chair introduced Yelan Guo, Senior Research Fellow, and Paul Jacklin, Senior Health Economist, who gave a presentation of the evidence report and economic considerations – What factors of social and practical support (including care of the body) are effective in end of life care of infants, children and young people with life-limiting conditions and their family members or carers (as appropriate) and what influences attitudes about these before and after death?

Yelan Guo and Paul Jacklin took questions from the group.

The Committee thanked Yelan Guo and Paul Jacklin for their presentation and contribution to the development of the guideline.

The Chair introduced Paul Jacklin, Senior Health Economist, who gave a presentation on an update on Health Economics of the guideline

Paul Jacklin took questions from the group.

The Committee thanked Paul Jacklin for their 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 evidence report and economic considerations – What factors of spiritual or religious support (including care of the body) are effective in end of life care of infants, children and young people with life-limiting conditions and their family members or carers (as appropriate) and what influences attitudes about these before and after death?

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 James Hall, Editor, who gave the presentation 'Editorial Refresher'

James Hall took questions from the group

The Committee thanked James Hall for his presentation and contribution to the development of the guideline

The Chair introduced Katharina Dworzynski, Guideline Lead, who gave the presentation 'Young People's focus group summary of final report and impact of guideline LETRs

Katharina Dworzynski took questions from the group

The Committee thanks Katharina Dworzynski for her presentation and contribution to the development of the guideline

The Chair lead a discussion on chapter flow

The Chair took questions from the group

The Committee thanks the Chair 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

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Date of next meeting: 28/04/2016

Location of next meeting: Royal College of Obstetricians and Gynaecologists