

Minutes:

Guideline Development Group Meeting 3rd End of life care in children and young people Committee meeting

Date and Time: 30th April 2015 – 10:00 – 16:00

Place: Royal College of Obstetricians and Gynaecologists, London

Present:

David Vickers (DV) (Chair)	(Present for notes 1 - 12)
Peter Barry (PB)	(Present for notes 1 - 12)
Karen Brombley (KB)	(Present for notes 1 - 12)
Lucy Coombes (LC)	(Present for notes 1 - 12)
Emily Harrop (EH)	(Present for notes 1 - 12)
Paul Nash (PN)	(Present for notes 1 - 12)
Zoe Picton-Howell (ZPH)	(Present for notes 1 - 12)
Amy Volans (AV)	(Present for notes 1 - 12)
Claire Wensley (CW)	(Present for notes 1 - 12)

Committee Apologies:

Bobbie Farsides (BF)
 Elissa Coster (EC)
 Jane Morgan (JM)
 Satbir Jassal (SJ)
 (Neonatologist position still being recruited)

In attendance:

<p>NCC-WCH: Paul Jacklin (PJ) Yelan Guo (YG) Gemma Villanueva (GV) Tim Reeves (TR) Kate Coles (KC) Grammati Sarri (GS)</p> <p>Apologies Katharina Dworzynski</p> <p>NICE: Katie Perryman-Ford (KPF)</p> <p>James Hall (JH)</p>	<p>Senior Health Economist Research Fellow Research Fellow Information Scientist Project Manager Senior Research Fellow and Guideline Lead (covering for KD)</p> <p>Senior Research Fellow and Guideline Lead</p> <p>Guideline Commissioning Manager NICE Editor</p>	<p>(Present for notes 1 – 12) (Present for notes 1 - 12) (Present for notes 1 – 12) (Present for notes 1 – 12) (Present for notes 1 – 12) (Present for notes 1 - 12)</p> <p>(Present for notes 1 – 12)</p> <p>(Present for notes 1 – 12)</p>
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Observers:

None		
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Notes

1. DV welcomed the group to the first end of life care meeting and completed housekeeping.
2. Introductions were made by all attendees and Committee members. Apologies were received from. Bobbie Farsides, Elissa Coster, Jane Morgan and Satbir Jassal, Katharina Dworzynski and Stephen Murphy.
3. Committee members declared the following interests.

AV declared a personal non-financial non-specific interest - Participated in interview with journalist writing an article for the Guardian on how school teachers can support each other and the wider community when a student has Palliative needs.

AV declared a personal non-financial non-specific interest - Invited to speak at Barts Hospital Bereavement Conference on healthcare staff can support each other and sustain themselves in work with bereaved families.

AV declared a personal non-financial specific interest - Abstract accepted for the Cardiff International Children's Palliative Care Network Conference 'Parents narrative about compassion in Palliative care'

AV declared a non-personal non-financial non-specific interest - The service she works for is submitting data on staff clinical activity to NHS England's Palliative Care Funding Review "testing the currency"

CW declared a personal non-financial non-specific interest - Wrote a chapter for an undergraduate paediatric text book

CW declared a personal non-financial specific interest - Two articles published by the RCPCH - 'What delays discharge in children with life limiting conditions?' (2012) and 'Unannounced, single site, inter-professional real time simulation' (2015)

It was agreed that these were within the conflict of interest policy.
4. The minutes from Committee meeting 1 and 2 were presented by KC. These were agreed to be a true and accurate reflection of the meeting.
5. The draft protocols for Signs and symptoms, Service delivery, Care planning and Communication were presented by YG and GV. . Comments and suggestions were made by the Committee. The protocols were edited on screen and agreed by attendees.
6. PJ took the Committee through the general wording for the review questions. Notes were taken by the technical team.
7. The results of the evidence review on medically assisted nutrition were presented by GV.
8. The Committee discussed the findings of the review on medically assisted nutrition, drafted recommendations and notes were taken.
9. The results of the evidence review on the clinical and cost effectiveness of a defined multi-disciplinary team was presented by YG.
10. The Committee discussed the review on the clinical and cost effectiveness of a defined multi-disciplinary team, drafted recommendations and notes were taken.
11. A presentation on the role of the NICE editorial team and principles for recommendation wording was made by JH.

Notes

12. DV thanked all for attending and closed the meeting.