

Minutes:

Guideline Development Group Meeting 7th End of life care in children and young people Committee meeting

Date and Time: 25th November 2015 10:00 – 16:30

Place: Royal College of Obstetricians and Gynaecologists, London

Present:	David Vickers (DV) (Chair)	(Present for notes 1 – 13)
	Peter Barry (PB)	(Present for notes 1 – 13)
	Karen Brombley (KB)	(Present for notes 1 – 8)
	Claire Wensley (CW)	(Present for notes 1 - 13)
	Emily Harrop (EH)	(Present for notes 1 - 13)
	Paul Nash (PN)	(Present for notes 1 - 13)
	Zoe Picton-Howell (ZPH)	(Present for notes 1 - 13)
	Amy Volans (AV)	(Present for notes 1 - 13)
	Bobbie Farsides (BF)	(Present for notes 1 – 8)
	Fauzia Paize (FP)	(Present for notes 1 - 13)
	Susan Lee (Co-opted member)	(Present for notes 1 - 13)
	David Hamilton (Co-opted member)	(Present for notes 1 – 13)
	Elissa Coster (EC)	(Present for notes 1 – 13)
	Lucy Coombes (LC)	(Present for notes 1 - 13)
	Satbir Jassal (SJ)	(Present for notes 1 - 13)
	Afia Manay (AM)	(Present for notes 1 - 13)

Committee Apologies:

Jane Green (JG nee JM)

In attendance:

NCC-WCH: Paul Jacklin (PJ) Yelan Guo (YG) Gemma Villanueva (GV) Tim Reeves (TR) Kate Coles (KC) Katharina Dworzynski (KD)	Senior Health Economist Research Fellow Research Fellow Information Scientist Project Manager Senior Research Fellow and Guideline Lead	(Present for notes 1 – 13) (Present for notes 1 - 13) (Present for notes 1 – 13) (Present for notes 1 – 13) (Present for notes 1 – 13) (Present for notes 1 - 13)
Stephen Murphy (SM)	Clinical Director	(Present for notes 1 – 13)
External: Jo Taylor (JT) Lizzie Chambers (LCh)	University of York Together for Short Lives	(Present for notes 1 – 8) (Present for notes 1 - 8)
NICE: Katie Perryman-Ford (KPF)	Guideline Commissioning Manager	(Present for notes 1 –13)

Observers:

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Notes

- DV welcomed the group to day one of the fifth end of life care meeting and completed housekeeping. Apologies were received from JG nee JN.
 - New declarations of interest were received from:
 - ZPH declared a personal non-financial non-specific Interest - will be speaking at the NHS leadership conference on the 02/02/16. Lessons from the life of Adam
 - ZPH declared a personal non-financial non-specific interest - In December 2015, NHS Confed/ NHS Employers hosted a reception and unveiled Ads Place at their Horizon Centre
 - ZPH declared non-personal financial non-specific interest - NHS Confed Corporate Christmas Card was created in honour of Adam and a donation was made to Sepsis UK in his interest.
 - ZPH declared a personal non-financial non-specific interest - there was an article in the Yorkshire Post about Adam and his relationship with the NHS leaders
 - CW declared a personal non-financial specific interest - she will be speaking at Yorkshire and Humber Children's and Young people's palliative care network annual conference on 10th March 2015 on symptom control specific symptom to be confirmed.
 - CW declared a personal non-financial specific interest – on the 20th of February she will be doing a workshop at APM medical students' conference in York on paediatric palliative care.
- It was agreed that these declarations did not constitute a conflict that would preclude participation according to the policy.

Notes

3. The minutes from Committee meeting 6 were presented by KC. These were agreed to be a true and accurate reflection of the meeting.
4. LC and KB presented on non-pharmacological considerations in the end of life care for infants' children and young people.
5. AM presented on the pharmacological considerations in the end of life care for infants' children and young people.
6. The results of the evidence review on the 'what pharmacological and non-pharmacological (excluding psychological) interventions are effective for the management of pain in infants, children and young people with a life limiting condition was presented by GV. Economic considerations for this were presented by PJ.
7. The Committee discussed the findings of the review on pharmacological and non-pharmacological (excluding psychological) interventions are effective for the management of pain in infants, children and young people with life limiting conditions, and drafted recommendations while notes were taken.
8. LCh and JT (from the University of York and Together for Short Lives presented on the progress of Together for Short Live's work with a topic group of children and young people with life limiting conditions.
9. KC presented on the progress of the guideline development to date including upcoming work, topic groups and LETR's.
10. The results of the evidence review on what pharmacological and non-pharmacological interventions (excluding psychological) are effective for the management of agitation in infants, children and young people with life limiting conditions who are approaching the end of life was presented by YG. Economic considerations were presented by PJ.
11. The Committee discussed the findings of the review on pharmacological and non-pharmacological (excluding psychological) interventions are effective for the management of agitation in infants, children and young people with a life limiting condition, and drafted recommendations while notes were taken.
12. The Committee discussed the next steps in the guideline process.
13. DV thanked all for attending and closed the meeting.