

Minutes:

Guideline Development Group Meeting 5th End of life care in children and young people Committee meeting

Date and Time: *Day 1 – 2nd September 2015 10:00 – 17:00*

Place: *Royal College of Obstetricians and Gynaecologists, London*

Present:

David Vickers (DV) (Chair)	(Present for notes 1 – 11)
Peter Barry (PB)	(Present for notes 1 – 9)
Karen Brombley (KB)	(Present for notes 1 - 11)
Claire Wensley (CW)	(Present for notes 1 - 11)
Jane Green (JG)	(Present for notes 1 - 11)
Emily Harrop (EH)	(Present for notes 1 - 11)
Paul Nash (PN)	(Present for notes 1 - 11)
Zoe Picton-Howell (ZPH)	(Present for notes 1 - 11)
Amy Volans (AV)	(Present for notes 1 - 11)
Bobbie Farsides (BF)	(Present for notes 1 - 11)
Fauzia Paize (FP)	(Present for notes 1 - 11)
Susan Lee (Expert Witness)	(Present for notes 1 - 11)
David Hamilton (expert witness)	(Present for notes 1 - 11)

Committee Apologies:

Elissa Coster (EC)
Lucy Coombes (LC)
Satbir Jassal (SJ)

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 – 11) (Present for notes 1 - 11) (Present for notes 1 – 11) (Present for notes 1 – 11) (Present for notes 1 - 4, 6 – 11) (Present for notes 1 - 11)
Melanie Powell (MP)	Assistant Project Manager	(Present for notes 4 - 5)
NICE: Katie Perryman-Ford (KPF)	Guideline Commissioning Manager	(Present for notes 1 –11)
Apologies: Stephen Murphy (SM)	Clinical Director	

Observers:

None		
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Notes

1. DV welcomed the group to day one of the fifth end of life care meeting and completed housekeeping. Apologies were received from Elissa Coster (EC), Lucy Coombes (LC), Satbir Jassal (SJ) and Stephen Murphy (SM). Jane Morgan announced that her surname has been changed and is now known as Jane Green.

2. New declarations of interest were received from:

AV declared a personal non-financial non-specific interest - invited to attend a meeting with Together for Short Lives at the Houses of Parliament.

PN declared a non-personal financial specific interest - Presenting a paper in Glasgow and published a new book (further details required on both). Payment was received but made directly to employer.

KB declared a non-personal non-financial specific interest - Speaking at a regional study day on Advanced Care Planning (specifically about the practical side of completing Advanced Care Plans (how, where, when etc.).

ZPH declared a personal non-financial non-specific interest – Attendance as a delegate at 'Turn up the volume' conference as guest of conference organisers (carerightnow.co.uk)

ZPH declared a personal non-financial non-specific interest – Attended an event for UK Sepsis trust at reception at the House of Commons 08/09/2015

ZPH declared a personal non-financial non-specific interest – attendance at the Health Service Journals Leaders' Summit as a guest of Health Service Journal (HSJ, November 2015).

ZPH declared a personal non-financial non-specific interest - given a talk at the launch of 'NCPD's the child health programme about the patient/parent perspective

LC declared a non-personal specific interest – she contributed to a journal article on 'Palliative and end of life care for children with diffuse intrinsic pontine glioma: results from a London cohort study and international survey'. The article is a retrospective cohort study of children with diffuse intrinsic pontine glioma (DIPG) aged 0-18 years who received treatment at Great Ormond Street or the Royal Marsden. An inventory of symptoms was compiled along with interventions received and a look at current service provision. The discussion is about the current state of palliative and end of life care for children with DIPG.

BF declared a personal non-financial specific interest - part of the UK Donation Ethics Committee (they offer a stipend of £160 per day meeting and meets approximately four times a year.). She was involved in drafting of the guidance on paediatric organ donation but have not spoken or written publicly on the matter.

SJ declared a personal non-financial specific interest - Submitted a paper on symptom management in paediatric child health and rewrote a chapter in The Oxford Handbook in Palliative Care which focuses on the philosophy of care and principles of symptom management.

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 4 were presented by KC. These were agreed to be a true and accurate reflection of the meeting.
4. DH made a presentation on bereavement support. Questions were taken from the Committee.
5. YG presented the clinical evidence report for barriers and facilitators to effective communication. PJ provided an update on the economic considerations. The Committee discussed the review and drafted recommendations, linking them to the evidence.
6. GV presented the clinical evidence report for signs and symptoms for recognising the last days of life. PJ provided an update on the economic considerations. The Committee discussed the review and drafted recommendations, linking them to the evidence.
7. PJ presented an update on the health economics for the guideline.
8. The Committee reviewed and edited the draft protocols on management of the following distressing symptoms:
 - Pain
 - Seizures
9. KD provided an update on the progress of the young person's focus group.
10. KD presented the allocation of topic groups.
11. DV thanked all for attending and adjourned the meeting.

Date and Time: *Day 2 – 3rd September 2015 10:00 – 15:00*

Place: *Royal College of Obstetricians and Gynaecologists, London*

Present:	David Vickers (DV) (Chair)	(Present for notes 12– 19)
	Peter Barry (PB)	(Present for notes 12– 19)
	Karen Brombley (KB)	(Present for notes 12 - 19)
	Claire Wensley (CW)	(Present for notes 12 - 19)
	Jane Green (JG)	(Present for notes 14 - 19)
	Emily Harrop (EH)	(Present for notes 12 - 19)
	Paul Nash (PN)	(Present for notes 12 - 19)
	Zoe Picton-Howell (ZPH)	(Present for notes 12 - 19)
	Amy Volans (AV)	(Present for notes 12 - 19)
	Bobbie Farsides (BF)	(Present for notes 12 - 19)
	Satbir Jassal (SJ)	(Present for notes 12– 19)
	Lucy Coombes (LC)	(Present for notes 12– 19)
	Fauzia Paize (FP)	(Present for notes 14 – 19)

Susan Lee (Expert Witness) (Present for notes 12 - 19)
 David Hamilton (expert witness) (Present for notes 12 - 19)

Committee Apologies:

Elissa Coster (EC)

Minutes:

Guideline Development Group Meeting 5th End of life care in children and young people Committee meeting

In attendance:

<p>NCC-WCH: Paul Jacklin (PJ) Yelan Guo (YG) Gemma Villanueva (GV) Tim Reeves (TR) Kate Coles (KC) Katharina Dworzynski (KD)</p> <p>Melanie Powell (MP)</p> <p>NICE:</p> <p>Apologies: Stephen Murphy (SM) Katie Perryman-Ford (KPF)</p>	<p>Senior Health Economist Research Fellow Research Fellow Information Scientist Project Manager Senior Research Fellow and Guideline Lead</p> <p>Assistant Project Manager</p> <p>Clinical Director Guideline Commissioning Manager</p>	<p>(Present for notes 12– 19) (Present for notes 12 - 19) (Present for notes 12– 19) (Present for notes 12– 19) (Present for notes 12-13,17–19) (Present for notes 12 - 19)</p> <p>(Present for notes 14 - 16)</p>
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Observers:

None		
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12. DV welcomed the group to day two of the fifth end of life care meeting and completed housekeeping. Apologies were received from Elissa Coster (EC), Stephen Murphy (SM) and Katie Perryman-Ford (KPF).

13. New declarations of interest were received from:
 SJ declared Personal ?non-financial ?specific interest - Submitted a paper on XX and rewrote a chapter in XX (further details required on both).
 LC declared Personal ?non-financial ?specific interest - contributed to a journal article on XX (further details required).

It was agreed that these declarations did not constitute a conflict that would preclude participation according to the policy.

14. SL made a presentation on organ and tissue donation. Questions were taken from the Committee.

15. GV presented the evidence report and economic considerations communication and information provision regarding organ and tissue donation. The Committee discussed the review and drafted recommendations, linking them to the evidence.
16. The Committee further reviewed and edited the draft protocols on management of the following distressing symptoms:
 - Respiratory distress
 - Agitation.
17. YG presented the evidence report and economic considerations the MDT. The Committee discussed the review and drafted recommendations, linking them to the evidence.
18. KC reviewed the next steps in the development.
19. DV thanked all for attending and closed the meeting.