

Minutes:

Guideline Development Group Meeting 8th End of life care in children and young people Committee meeting

Date and Time: 20th January 2016 10:00 – 16:30

Place: Royal College of Obstetricians and Gynaecologists, London

Present:

Emily Harrop (EH)	(Present for notes 1 - 12)
Paul Nash (PN)	(Present for notes 3 - 12)
Zoe Picton-Howell (ZPH)	(Present for notes 1 - 12)
Amy Volans (AV)	(Present for notes 1 - 12)
Bobbie Farsides (BF)	(Present for notes 1 – 12)
Fauzia Paize (FP)	(Present for notes 1 - 12)
Stacey Curzon	(Present for notes 1 - 12)
David Hamilton (expert witness)	(Present for notes 1 – 12)
	(Present for notes 1 – 12)
Lucy Coombes (LC)	(Present for notes 1 - 12)
Satbir Jassal (SJ)	(Present for notes 1 - 12)
Afia Manay (AM)	(Present for notes 1 - 12)
Jane Green (JG nee JM)	(Present for notes 1 - 12)

Committee Apologies:

Claire Wensley (CW)

Peter Barry (PB)

Karen Brombley (KB)

In attendance:

NCC-WCH: Paul Jacklin (PJ) Yelan Guo (YG) Gemma Villanueva (GV) Tim Reeves (TR) Kate Coles (KC) Katharina Dworzynski (KD) Stephen Murphy (SM)	Senior Health Economist Research Fellow Research Fellow Information Scientist Project Manager Senior Research Fellow and Guideline Lead Clinical Director	(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) (Present for notes 1-3, 5-12)
External: Jo Taylor (JT) Lizzie Chambers (LCh) Jan Aldridge (JN)	University of York Together for Short Lives Together for Short Lives	(Present for notes 1 –5) (Present for notes 1 - 5) (Present for notes 1 - 5)
NICE: Simran Chawla (SC)	Public Involvement Advisor	(Present for notes 1-5)
Apologies: Katie Perryman-Ford (KPF)	 Guidelines Commissioning Manager	

Observers:

Eva Gonzalez	Research Assistant (NCC)	(Present for notes 1 - 12)
Ferruccio Pelone	Research Assistant (NCC)	(Present for notes 1 - 12)

Notes

1. DV welcomed the group to day one of the fifth end of life care meeting and completed housekeeping. Apologies were received from KPF, CW, PB and KB.
2. New declarations of interest were received from:

JG declared a personal non-financial specific interest - that she is a co-applicant for 'Ambitions for palliative and end of life care'. A national framework for local action 2015 - 2020 that urges local leadership to be at the forefront of improvement in end of life care. (National palliative and end of life care partnership, www.endoflifecareambitions.org.uk)

FP declared a personal non-financial specific interest – that she is currently involved in a multidisciplinary team formulating and co-authoring a document containing a set of guidelines and end of life care plans for neonates in the northwest of England with palliative care needs. My own opinions are expressed in this document but are being reviewed by the group prior to its dissemination across the northwest as part of the neonatal network

LC declared a non-personal non-financial specific - the team she works with have received final approval to conduct a research study entitled 'Pain and symptoms in children with advanced cancer: A longitudinal study to develop a comprehensive symptom inventory'. She is named as chief investigator. They will using a tool already validated in children with cancer (the memorial symptom assessment scale for 7-12 year olds and 10-18 year olds) to see whether there are any missing or redundant items when used in children with advanced cancer. They will also be comparing correlations between parent,

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child and nurse scores.

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

3. The minutes from Committee meeting 7 were presented by KC. These were agreed to be a true and accurate reflection of the meeting.
4. JT, JN and LCh from Together for Short Lives presented the results from the youth focus group work they have been conducting, questions were taken from the committee.
5. The Committee (led by KD, JT, JN and LCh) discussed the focus group findings and the impact that they would have on the current recommendations for the guideline.
6. The Committee, led by KD and KC reviewed all recommendations written for the End of Life Care guideline to date.
7. The results of the evidence review on the ‘what pharmacological and non-pharmacological (excluding psychological) interventions are effective for the management of respiratory distress in infants, children and young people with a life limiting condition was presented by GV. Economic considerations for this were presented by PJ.
8. The Committee discussed the findings of the review on pharmacological and non-pharmacological (excluding psychological) interventions are effective for the management of respiratory distress in infants, children and young people with life limiting conditions, and drafted recommendations while notes were taken.
9. The results of the evidence review on the ‘what pharmacological and non-pharmacological (excluding psychological) interventions are effective for the management of seizures in infants, children and young people with a life limiting condition was presented by GV. Economic considerations for this were presented by PJ.
10. The Committee discussed the findings of the review on pharmacological and non-pharmacological (excluding psychological) interventions are effective for the management of seizures in infants, children and young people with life limiting conditions, and drafted recommendations while notes were taken.
11. PJ presented preliminary discussion points on the health economics related to the service delivery evidence reviews.
12. DV thanked all for attending and closed the meeting.