

Minutes:

Guideline Development Group Meeting 6th End of life care in children and young people Committee meeting

Date and Time: 15th October 2015 10:00 – 16.30

Place: Royal College of Obstetricians and Gynaecologists, London

Present:

David Vickers (DV) (Chair)	(Present for notes 1 – 9)
Peter Barry (PB)	(Present for notes 4 – 7)
Karen Brombley (KB)	(Present for notes 1 - 9)
Claire Wensley (CW)	(Present for notes 1 - 9)
Satbir Jassal (SJ)	(Present for notes 1 - 9)
Emily Harrop (EH)	(Present for notes 1 - 9)
Paul Nash (PN)	(Present for notes 1 - 9)
Zoe Picton-Howell (ZPH)	(Present for notes 1 - 9)
Amy Volans (AV)	(Present for notes 1 - 9)
Fauzia Paize (FP)	(Present for notes 1 - 9)
Susan Lee (Expert Witness)	(Present for notes 1 - 9)
David Hamilton (expert witness)	(Present for notes 1 - 9)
Lucy Coombes (LC)	

Committee Apologies:

Jane Green (JG)
Bobbie Farsides (BF)

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 – 9) (Present for notes 1 - 9) (Present for notes 1 – 9) (Present for notes 1 – 9) (Present for notes 1 - 9) (Present for notes 1 - 5 (Present for notes 1 - 8)
NICE: Katie Perryman-Ford (KPF)	Guideline Commissioning Manager	(Present for notes 7 –9)
Apologies:		

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 Jane Green (JG) and Bobbie Farsides (BF). DV raised that that Elissa Coster has resigned from the committee and a replacement member will be sought.

2. New declarations of interest were received from:

AV declared a personal non-financial specific interest - Gave brief presentation at Together for Short Lives regional network summit about the range of psychological services and models currently offered in different regions of the UK

DV declared a personal non-financial specific interest - Speaker on 'Palliative Care' at the BJHM conference (MA publications, current issues in palliative care 2016).

PN declared a non-personal financial specific interest - Co-authored 'Multifaith Care of Sick Children and their Families' JKP. London. June 2015

PN declared a personal financial specific interest - Director of new research study and resource centre, Centre for Paediatric Spiritual Care encouraging research into the area of spiritual well-being in children.

PN declared a non-personal financial specific interest - Co-authored 'Spiritual Care with Sick Children and Young People' JKP. London. September 2015

ZPH declared a personal non-financial non-specific interest - NHS Employers/ NHS Confederation/ Horizon Centre naming their conference suite in Leeds Horizon Centre 'Adam's place' after her son Adam Bojelian and holding a reception to unveil a plaque on 18th December 2015

ZPH declared a personal non-financial non-specific interest - NHS Employers/ NHS Confederation holding/hosting annual Adam Bojelian Memorial talk, 1st talk to be given by Kathy Evans of NHS England on 24/03/16

ZPH declared a personal non-financial non-specific interest - NCEFOD talk on Chronic Disability Programme (unpaid)

ZPH declared a personal non-financial non-specific interest - Disability Matters talk at the RSM conference 'Patients and Families, the new doctors' (unpaid) - on co-production of Disability Matters. 20/10/15

ZPH declared a personal non-financial non-specific interest - Talk on Disability Matters from parent perspective at Disability Matters Roadshow (2nd November)

EH declared a non-personal non-financial specific interest - met with neonatal ethics team for the palliative care funding review.

LC declared a non-personal non-financial non-specific interest - as part of current role in team, responsible for recruiting patients, ensuring the protocol is followed, taking PK studies etc for a phase 1 open label drug study on Naloxegol which is an oral medication for opioid induced constipation.

SJ declared a personal financial non-specific interest - has been asked to do training for Paediatric specialist registrars in January. This will be relating to the prescribing of medication and the legal implications after the death of a child. The training will have no direct relevance to the guidelines.

Notes

SJ declared a personal non-financial specific interest – having a paper published in Journal of Paediatric Health on 'Symptom management'. No recommendations are made and this was written before he joined the guideline.

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 5 were presented by KC. These were agreed to be a true and accurate reflection of the meeting.
4. KD presented an update on the progress of the young person's focus group. The group discussed this.
5. GV presented the clinical evidence report for Psychological interventions for infants, children and young people, their parents and families. PJ provided an update on the economic considerations. The Committee discussed the review and drafted recommendations, linking them to the evidence.
6. The Committee reviewed and edited the draft protocols on service delivery covering :
 - 24/7 specialist telephone health care professional support or parents/carers support and 24/7 community nursing support
 - rapid transfer and compassionate extubation
7. The recommendations which were drafted earlier in the meeting were readdressed by the committee.
8. The Committee reviewed and edited the draft protocols on the following support needs:
 - Social and practical
 - Spiritual and religious
9. DV thanked all for attending and closed the meeting.