

**Minutes:**

**Guideline Development Group Meeting 4<sup>th</sup> End of life care in children and young people Committee meeting**

**Date and Time:** 18<sup>th</sup> June 2015 10:00 – 16:00

**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)
Elissa Coster (EC)	(Present for notes 1 - 11)
Jane Morgan (JM)	(Present for notes 1 - 11)
Lucy Coombes (LC)	(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)
Satbir Jassal (SJ)	(Present for notes 1 - 11)

**Committee Apologies:**

Karen Brombley (KB)  
Claire Wensley (CW)  
Bobbie Farsides (BF)

**In attendance:**

<b>NCC-WCH:</b> 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 – 11) (Present for notes 1 - 11) (Present for notes 1 – 11) (Present for notes 1 – 11) (Present for notes 1 – 11) (Present for notes 1 - 11)
<b>NICE:</b> Trudie Willingham (TW)  James Hall (JH)	Guideline Commissioning Manager (covering for Katie Perryman-Ford) NICE Editor	(Present for notes 1 – 7)  (Present for notes 1 – 11)

**Observers:**

None		
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## Notes

1. DV welcomed the group to the fourth end of life care meeting and completed housekeeping. Apologies were received from Karen Brombley, Claire Wensley and Bobbie Farsides.
  
2. New declarations of interest were received from:  
  
EH declared a personal non-financial specific interest - Discussion member as part of BBC Radio 4's 'Inside the Ethics Committee'  
  
ZPH declared a personal non-financial non-specific interest - Interview on Radio 2 programme for carer's week about the experience of caring for her son.  
  
ZPH declared a personal non-financial non-specific interest - Article published for Together For Short Lives newsletter in September 2015 about her son  
  
ZPH declared a personal non-financial non-specific interest - Lay member to the National Patient Enquiry into Patient Outcome and Death, Study Advisory Group  
  
SJ declared a non-personal non-financial specific interest – some of the papers used as evidence in a review for this meeting authored by Hunt contained perspectives from children who were cared for at Rainbows Children's and Young Adult Hospice where SJ is the Medical Director.  
  
JM declared a personal non-financial non-specific interest - reviewed a book called 'Luna's red hat' which relates to a child's grief after the suicide of a parent.  
  
It was agreed that these were within the conflict of interest policy.
  
3. The minutes from Committee meeting 3 were presented by KC. These were agreed to be a true and accurate reflection of the meeting.
  
4. YG presented the evidence report and economic considerations for what information, or types of, are most helpful to bereaved parents or carers. The Committee discussed the review and drafted recommendations, linking them to the evidence.
  
5. GV presented the evidence report and economic considerations for the home based care. The Committee discussed the review and drafted recommendations, linking them to the evidence.
  
6. The Committee reviewed and edited the draft protocol on issues surrounding the communication of information and discussion with patients and parents/carers relating to organ donation.
  
7. The Committee reviewed and edited the draft protocol on the topic of the effectiveness of psychological interventions for family members and carers of those with life limiting conditions.
  
8. The Committee reviewed and edited the draft protocol on the topic of the effectiveness of psychological interventions for infants, children and young people with life limiting conditions.
  
9. The Committee discussed the question wording for distressing symptoms.
  
10. The date was confirmed for the next meeting as the 2<sup>nd</sup> and 3<sup>rd</sup> of September and a change of timings for this meeting was discussed; 5pm on day 1 and 3pm on day 2.

## Notes

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