

**Minutes:**

**Guideline Committee Meeting**

**2<sup>nd</sup> End of life care in children and young people Committee meeting**

**Date and Time:** 26<sup>th</sup> March 2015 – 10:00 – 16:00

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

**Present:**

David Vickers (DV) (Chair)	(Present for notes 1 - 13)
Karen Brombley (KB)	(Present for notes 1 - 13)
Lucy Coombes (LC)	(Present for notes 1 - 13)
Elissa Coster (EC)	(Present for notes 1 - 13)
Bobbie Farsides (BF)	(Present for notes 1 - 13)
Emily Harrop (EH)	(Present for notes 1 - 13)
Satbir Jassal (SJ)	(Present for notes 2 - 13)
Jane Morgan (JM)	(Present for notes 1 - 13)
Paul Nash (PN)	(Present for notes 1 - 13)
Amy Volans (AV)	(Present for notes 1 - 13)
Claire Wensley (CW)	(Present for notes 1 - 13)

**Committee Apologies:**

Sharon English (SE)

Zoe Picton-Howell (ZPH)

Peter Barry (PB)

**In attendance:**

<p><b>NCC-WCH:</b> Katharina Dworzynski (KD)</p> <p>Paul Jacklin (PJ) Stephen Murphy Yelan Guo (YG) Tim Reeves (TR) Kate Coles (KC)</p>	<p>Senior Research Fellow and Guideline Lead Senior Health Economist Clinical Co-Director Research Fellow Information Scientist Project Manager</p>	<p>(Present for notes 1 – 13)</p>
<p><b>NICE:</b> Clifford Middleton (CM)</p>	<p>Guidelines Commissioning manager (NICE) Covering for KPF</p>	<p>(Present for notes 1 – 13)</p>
<p><b>Apologies:</b> Katie Perryman-Ford (KPF)</p>	<p>Guidelines Commissioning manager (NICE)</p>	

**Observers:**

**Notes**

1. DV welcomed the group to the second cerebral palsy guideline committee meeting and completed housekeeping. Introductions were made by all attendees and committee members. Apologies were received from Zoe Picton-Howell and Peter Barry. Apologies were also received from Sharon English who has now resigned from the committee.
2. All attendees were asked for declarations of interest.
3. DV declared a personal non-financial non-specific interest - Co-author of paper submitted to Cardiff International CPC Conference June 2015 on a mode of provision of out of hours care.  
  
EH declared a personal non-financial specific - Named Consultant for Advance Care planning at Children's Hospital in Oxford (part of the John Radcliffe). A teaching and coordinating role within current Honorary Contract. No change in remuneration or role description.  
  
AV declared a non-personal non-financial specific interest - Employer MDT service has applied to contribute data to the NHS England Palliative Care Funding Review Team currency testing data collection point. This will involve submitting "activity" and "cost" data about patient care provided by the service to the Palliative Care Funding Team at NHS England who will analyse and interpret the data.  
  
JM declared a personal non-financial non-specific interest - Applied to study Child Nursing BSc (Hons) at Anglia Ruskin University in Chelmsford  
  
It was agreed that these were within the conflict of interest policy.
4. The minutes from GC1 were presented by KC. These were agreed to be a true and accurate reflection of the meeting and will be presented in GC2 following DOIs being clarified.
5. The draft health economic plan was presented by PJ. Questions were taken from the GC and amendments were made to the draft.
6. Minimally important differences were presented by KD. Questions were taken from the GC.
7. The results of the evidence review on preferences for place of care and death were presented by KD.
8. The GC discussed the findings of the review on preferences for place of care and death, drafted recommendations and notes were taken.
9. The results of the evidence review on medically assisted hydration was presented by KD.
10. The GC discussed the review, drafted recommendations and notes were taken.
11. The draft protocol for home based care was presented by KD. Comments and suggestions were made by the GC and the protocol was edited on screen and agreed by attendees.
12. The draft protocol for the multidisciplinary team was presented by KD. Comments and suggestions were made by the GDG and the protocol was edited on screen and agreed by attendees.

## Notes

13. The draft protocol for medically assisted nutrition was presented by KD. Comments and suggestions were made by the GDG and the protocol was edited on screen and agreed by attendees.
14. DV thanked all for attending and closed the meeting.