

**Minutes:**

**Guideline Development Group Meeting 1<sup>st</sup> End of life care in children and young people Committee meeting**

**Date and Time:** 5<sup>th</sup> February 2015 – 10:00 – 16:00

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

**Present:**

David Vickers (DV) (Chair)	(Present for notes 1 - 12)
Peter Barry (PB)	(Present for notes 1 - 12)
Karen Brombley (KB)	(Present for notes 1 - 12)
Lucy Coombes (LC)	(Present for notes 1 - 12)
Elissa Coster (EC)	(Present for notes 1 - 12)
Sharon English (SE)	(Present for notes 1 - 12)
Bobbie Farsides (BF)	(Present for notes 1 - 12)
Emily Harrop (EH)	(Present for notes 1 - 12)
Satbir Jassal (SJ)	(Present for notes 1 - 12)
Jane Morgan (JM)	(Present for notes 1 - 12)
Paul Nash (PN)	(Present for notes 1 - 12)
Zoe Picton-Howell (ZPH)	(Present for notes 1 - 12)
Amy Volans (AV)	(Present for notes 1 - 12)
Claire Wensley (CW)	(Present for notes 1 - 12)

**Committee Apologies:** None

**In attendance:**

<b>NCC-WCH:</b> Paul Jacklin (PJ)	Guideline Lead and Senior Health Economist	(Present for notes 1 – 12)
Stephen Murphy	Clinical Co-Director	(Present for notes 1 – 5, 7 - 12)
Yelan Guo (YG)	Research Fellow	(Present for notes 1 – 12)
Rishiraj Caleyachetty (RC)	Research Fellow	(Present for notes 1 – 12)
Tim Reeves (TR)	Information Scientist	(Present for notes 1 – 12)
Vanessa Delgado Nunes (VDN)	Senior Research Fellow and Guideline Lead	(Present for notes 1, 2, 11 and 12)
Shona Burman-Roy (SBR)	Senior Research Fellow	(Present for notes 6-12)
<b>Apologies:</b> Kate Coles (KC)	Project Manager	
<b>NICE:</b> Clifford Middleton	Guideline Commissioning Manager	(Present for notes 1 – 11)
Emma Chambers (EC)	Public Involvement Adviser	(Present for notes 1 – 7)

## Observers:

None		
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## Notes

1. DV welcomed the group to the first end of life care meeting and completed housekeeping. Introductions were made by all attendees and Committee members. Apologies were received from Kate Coles and Oliver Bailey. For the first meeting, the Chair explained that at this stage in the meeting any potential interests would usually be declared but as this was the first meeting, the GDG would be first given a presentation on the NICE declarations of interest policy.
2. The update to the NICE policy for conflicts of interest was presented by VDN. Questions were taken from the group. Declarations were outlined by the Committee and the NCC-WCH attendees. All Committee members completed and resubmitted their declarations of interest forms following discussion in the meeting. Committee members declared the following interests.

AV declared a personal non-financial non-specific interest - Submitted application to make workshop presentation at the 7th International Cardiff Conference on Paediatric Palliative Care (July 2015). The acceptance of the proposal is to be confirmed. The title is "Parents' narratives about compassion in children's palliative care: voices from the multicultural east end of London".

AV declared a personal non-financial specific interest - Contributed to the British Psychological Society and Together for Short Lives responses to the NICE consultation on the End of Life Care for infants, children and young people scope and to the same groups' responses to the House of Commons Select Committee on Palliative and End of Life Care in November 2014.

AV declared a personal non-financial specific interest - Coordinates a special interest group for psychologists working with infants, children and young people with palliative care needs. As part of this she co-chairs the London Children's Palliative Care Network.

BF declared a personal financial non-specific interest - Trustee of Medical Research Foundation - [www.medicalresearchfoundation.org.uk](http://www.medicalresearchfoundation.org.uk)

BF declared a personal non-financial specific interest - Member of UK Donation Ethics Committee and of sub-group considering Children and organ donation

BF declared a personal financial non-specific interest - Member of the Nuffield Council on Bioethics until April 2015 and Chair of their working group on Children's Participation in Clinical Research report to be published April 2015.

CW declared a personal non-financial specific interest - Author of a palliative care chapter in Paediatrics at a Glance – Miall, Rudolf and Smith

CW declared a personal non-financial non-specific interest – Presented a poster at the RCPCH conference Glasgow 2013 and the Royal Society of Medicine meeting December 2012, "What delays discharge in children with life limiting conditions?"

CW declared a personal non-financial specific interest - Member of the steering group for the Yorkshire and Humber Children and Young Persons Paediatric Palliative Care network

CW declared Personal non-financial specific interest - Member of the executive committee for the Yorkshire and Humber Children and Young Persons paediatric palliative care network (lead for the clinical subgroup)

## Notes

DV declared a personal financial non-specific interest - Works for East Anglia's Children's Hospices as Medical Director via a service level agreement with my NHS Trust

DV declared a personal non-financial non-specific interest - Former Trustee, Together for Short Lives (until September 2013), remains a member and a member of Practice and Development Advisory Council

EC declared a personal non-financial specific interest - Developing end of life resources for children, young people and young adults at the Brain Tumour Charity

EC declared a personal non-financial non-specific interest - Member of the recently established national neuro-oncology nurses meeting.

EH declared a personal financial non-specific interest - Contributor to APPM Master Formulary 3rd Edition in November 2014.

EH declared a personal non-financial non-specific interest - Submitted abstract to Cardiff international conference (Summer 2015). This is on the subject of Buccal opioids for breakthrough. It is essentially based on a questionnaire result.

EH declared a non-personal non-financial specific interest - Contributor to second addition of regional advance care planning document (February 2015)

EH declared a personal non-financial non-specific interest –is a member of National Institute of Health Research (NIHR) medicines for children research network pain and palliative care clinical studies group This is a multi-disciplinary group that supports and prioritises research in the area of palliative care and pain. This is an unpaid position, which was competitively gained (i.e. application process). The group looks at / discusses/ evaluates studies on all areas of pain / palliative care.

JM declared a personal non-financial non-specific interest - Community champion volunteer for Havens Hospices.

KB declared a personal non-financial specific interest - Masters dissertation on 'the factors that influence choices about place of care and death in children and young people'.

KB declared a personal non-financial specific interest - Submitted abstract to Cardiff about factors that influence choices about place of care and death in children and young people.

KB declared a personal non-financial non-specific interest - Advisory volunteer role to Well Child charity – their remit is for recommendations on allocation of funding to nursing posts.

KB declared a personal non-financial non-specific interest - Member and deputy chair of pain and palliative care MCRN group.

LC declared a personal financial non-specific interest - In April 2015, will commence a 3 year position as a palliative care research sister. The post is funded by the Caroline Menez Trust through the Royal Marsden Hospital.

LC declared a non-personal financial specific interest - Part of a team developing a research protocol regarding the R&D/ethics on what symptoms life limited children experience towards end of life. Funding of £6000 received from Shooting Star Chase Hospice.

## Notes

PN declared a personal non-financial specific interest - Vice chair of Trustees for Beyond the Horizon, a bereavement and loss support charity.

PN declared a personal non-financial specific interest - The co-convenor of the Paediatric Chaplaincy Network (GB&I), an informal support group for those offering religious and spiritual care in hospitals, hospices and in the community.

PN declared personal financial non-specific interest - The lead for Red Balloon Resources, the publishing arm of Birmingham Children's Hospital chaplaincy team. This organisation produce resources in paediatric spiritual and religious care for palliative, end of life and bereavement care. These are sold not for profit to other care professionals.

PN declared personal financial non-specific interest - Tutor at Midlands Institute for Children, Youth and Mission

PB declared that he had no interests to be declared.

SJ declared a personal non-financial specific interest - Member of the Association of Paediatric Palliative Medicine.

SJ declared a personal non-financial specific interest - Honorary consultant at LOROS an adult hospice

SJ declared a personal non-financial specific interest - Honorary lecturer at Cardiff University in palliative medicine

SJ declared a personal non-financial specific interest – writes the Rainbow manual which the WHO may adopt. This is the hospice's symptom control manual in paediatric palliative medicine.

SJ declared personal non-financial non-specific interest – Author and Editor for the APPM formulary.

SJ declared a personal financial non-specific interest - Co-Authored the Oxford Handbook of Paediatric Palliative Medicine. Royalties of approximately £100 are received per annum.

SJ declared a personal non-financial non-specific interest - Member of and has strong links with Together for Short Lives.

SE declared a personal non-financial non-specific interest - Author of chapter in a textbook titled 'Neonatology at a Glance' on neonatal palliative and end of life care - due to be published in 2015.

SE declared a personal non-financial specific interest - Member of guideline committee for British Association of Perinatal Medicine (BAPM) on perinatal palliative and end of life care. Published 2011 with no remuneration.

SE declared a personal non-financial specific interest - Author of editorial and guest editor for edition of 'seminars in fatal and neonatal medicine on perinatal palliative care. Published in 2013 with no remuneration.

SE declared a personal non-financial non-specific interest - Member of NIHR MCRN clinical studies group on pain and palliative care. No remuneration received.

ZPH declared a personal non-financial non-specific interest - Chair of RCPCH Parent and Carer Advisory Group

## Notes

ZPH declared a personal non-financial non-specific interest - Member of RCPCH Ethics and Law Committee

ZPH declared a personal non-financial non-specific interest - Member of Academy of Royal Colleges Lay Advisory Group

ZPH declared a personal financial non-specific interest - Tutor at the NHS Leadership Academy

ZPH declared a personal financial non-specific interest - Tutor on Health Inequality and Disability Stream at Edinburgh University Medical School

ZPH declared a personal financial non-specific interest - Author of Edinburgh Law School's Course, Law, Rights and Ethics for Paediatrics

ZPH declared a personal financial non-specific interest - Author of Paediatric Modules of Edinburgh Law School's LLM Compassionate Care

ZPH declared a personal non-financial non-specific interest - Author of blog Triangulation of Thought

ZPH declared a personal financial non-specific interest - PhD Researcher Edinburgh University Law School researching how doctors make difficult medical decisions for disabled children with complex health needs.

ZPH declared a personal financial non-specific interest - Author of chapter in disability matters e-learning platform launched in February 2015. The chapter's content was related to Choices and Decision Making and how to support children and young people in making decisions and how to advise those that are incapable of making decisions.

3. An introductory presentation on NICE guideline development was made by CM.
4. An introductory presentation on the role of patient involvement was made by EC.
5. An introductory presentation on the role of information scientist was made by TR...
6. An introductory presentation on the role of the Health Economist was made by PJ.
7. A presentation on the end of life care scope was made by DV.
8. An introductory presentation on the process of reviewing evidence was made by RC.
9. RC took the Committee through the draft protocol on medically assisted hydration. Committee members were invited to comment and RC noted these. It was agreed that amendments to the protocol taking into account the discussion and in collaboration with the DV and SM edits would be made to the protocol.
10. RC took the Committee through the draft protocol on preferences for place of care and place of death and the determinants of those preferences. It was agreed that amendments to the protocol taking into account the discussion and in collaboration with the DV and SM edits would be made to the protocol.
11. DV and VDN took the Committee through the general wording for the review questions.
12. DV thanked all for attending and closed the meeting.

