

9th End of Life Care in Infants, Children and Young People Guideline Committee meeting – Day 2

Date: 03/03/2016

Location: Royal College of Obstetricians and Gynaecologists

Minutes:

Committee members present:		
David Vickers (Chair)		(Present for notes 1 – 7)
Satbir Jassal		(Present for notes 1 – 7)
Peter Barry		(Present for notes 1 – 7)
Amy Volans		(Present for notes 1 – 7)
Claire Wensley		(Present for notes 1 – 7)
Emily Harrop		(Present for notes 1 – 7)
Paul Nash		(Present for notes 1 – 7)
Fauzia Paize (by telephone)		(Present for notes 1 – 7)
Stacey Curzon		(Present for notes 1 – 7)

In attendance:		
Kate Coles	Project Manager	(Present for notes 1 – 7)
Katharina Dworzynski	Guideline Lead	(Present for notes 1 – 7)
Yelan Guo	Senior Research Fellow	(Present for notes 1 – 7)
Gemma Villanueva	Interim Senior Research Fellow	(Present for notes 1 – 7)
Paul Jacklin	Health Economist	(Present for notes 1 – 7)

Observers:		

Apologies:		
Zoe Picton-Howell	Committee member	
Karen Brombley	Committee member	
Bobbie Farsides	Committee member	

4.0.03 DOC Cmte minutes

Lucy Coombes	Committee member
Jane Green	Committee member

1. Welcome and objectives for the meeting

The Chair welcomed the Committee members and attendees to the 9th meeting on End of Life Care in Infants, Children and Young People. The Committee members and attendees introduced themselves.

No members of the public asked to observe the meeting.

The Chair informed the Committee that apologies had been received. These are noted above.

The Chair outlined the objectives of the meeting, which included: presentation and discussion of evidence report and economic considerations, drafting of recommendations, drafting of Linking Evidence To Recommendation (LETR) section for review questions 14–16 - Service Delivery.

Introductions

2. Confirmation of matter under discussion, and declarations of interest

The Chair confirmed that, for the purpose of managing conflicts of interest, the matter under discussion was:

What is the effectiveness of 24/7 specialist telephone health care professional support (or parents/carers support), 24/7 community nursing support, and the combination of the two for the needs of infants, children and young people with life-limiting conditions, and for the needs of their family members and carers (as appropriate) during this time and after death as part of service delivery?

AND

What services have to be in place to make rapid transfer available to take infants, children and young people with a life limiting illness to their preferred place of care in their last days of life and after death as part of service delivery?

The Chair asked everyone to verbally declare any interests that have arisen since the last meeting.

No declarations of interest

3. Minutes of last meeting

4.0.03 DOC Cmte minutes

The Chair asked the Committee if it wanted any changes made to the minutes of the last meeting. The Committee agreed that the minutes were a true and accurate account of the meeting.

4. Presentations

The Chair introduced Paul Jacklin, Health Economist, who gave a presentation on Resource Impact on Guidelines.

Paul Jacklin took questions from the group.

The Chair introduced Yelan Guo and Paul Jacklin, Senior Research Fellow and Health Economist, who gave a presentation on 'Presentation of evidence report and economic considerations – What is the effectiveness of 24/7 specialist telephone health care professional support (or parents/carers support), 24/7 community nursing support, and the combination of the two for the needs of infants, children and young people with life-limiting conditions, and for the needs of their family members and carers (as appropriate) during this time and after death as part of service delivery?'

Yelan Guo and Paul Jacklin took questions from the group.

The Chair introduced Gemma Villanueva and Paul Jacklin, Senior Research Fellow and Health Economist, who gave a presentation on 'Presentation of evidence report and economic considerations – What services have to be in place to make rapid transfer available to take infants, children and young people with a life limiting illness to their preferred place of care in their last days of life and after death as part of service delivery?'

Note. As an integrated part of the rapid transfer programme, particular consideration will be given to ICYP who need compassionate extubation (including all life-sustaining treatment, e.g., non-invasive ventilation) in the preferred place (what services should be in place to facilitate)'

Gemma Villanueva and Paul Jacklin took questions from the group.

The Chair introduced Katharina Dworzynski, Guideline Lead, who gave a presentation on 'Guideline Pathway'.

Katharina Dworzynski took questions from the group.

The Committee thanked Yelan Guo, Gemma Villanueva, Katharina Dworzynski and Paul Jacklin for their presentations and contribution to the development of the guideline.

5. Questions and discussion

The Committee discussed the presented evidence reports and were given the

4.0.03 DOC Cmte minutes

opportunity to ask questions.

6.Any other business

Kate Coles updated the Committee that in June 2015, the RCOG was awarded a six year contract by NICE to bring together the work of the preceding National Collaborating Centres (NCCs); the NCC for Women's and Children's Health (NCC-WCH) already hosted by the RCOG, the NCC for Cancer (NCC-C), previously based at the Velindre NHS Trust, Cardiff; and the NICE component of the NCC for Mental Health (NCC-MH), previously based at the Royal College of Psychiatrists to create a single, multi-disciplinary centre.

Developing fifteen guidelines at any one time, the National Guideline Alliance (NGA) will launch on 1st April 2016. All NICE guidelines in development in the three former NCCs will transfer to the responsibility of the NGA. Committee members should expect minimal changes with continuity of both processes and staff supporting each guideline to be maintained in most instances.

7. Meeting close

The chair thanked the attendees and closed the meeting

Date of next meeting: 07/04/2016

Location of next meeting: Royal College of Obstetricians and Gynaecologists