National Institute for Health and Care Excellence

Care of the Dying Adult

Stakeholder Comments – Draft Scope

NOTE:

NICE is unable to accept comments from non-registered organisations or individuals. If you wish your comments to be considered but are not a registered stakeholder, please register via the NICE website or contact the registered stakeholder organisation that most closely represents your interests and pass your comments to them.

Please fill in both the 'stakeholder organisation' and 'name of commentator' fields below in order for your comments to be considered.

This scope is focused on the last few days of life. NICE would be grateful for your views on whether this is the correct timeframe within which to focus this guidance.

Some of the areas the scope proposes to cover may arise in specific terminal conditions at an earlier stage, perhaps weeks before death occurs. NICE would be grateful for your views on aspects of difficulty with clinical decision-making and symptom management in the last few weeks of life, where a formal review of evidence may guide

Stakeholder organisation:	**Faculty of Intensive Care Medicine**
Name of commentator:	**Dr C M Danbury**

Comment No.	Section number Indicate **number** or **'general'** if your comment relates to the whole document	Comments Please insert each new comment in a new row. Please do not paste other tables into this table, as your comments could get lost – type directly into this table
Example	3.4.6	Our comments are as follows …….
Proformas that are not correctly submitted as detailed in the line above may be returned to you.		
1	3)b) & 3)c)	In the Intensive Care setting, there can be disagreement between the treating clinical team and family members. It would be helpful for the NICE guidance to address this issue (see: Aintree University Hospitals NHS Foundation Trust v James [2013] UKSC 67 also Tracey, R (on the application of) v Cambridge University Hospitals NHS Foundation Trust & Anor [2014] EWCA Civ 33)

2	3)d) & 3)e)	The Intensive Care clinical team is faced with difficult discussions with families on a regular basis (vide supra) and therefore has a wealth of experience that could be shared with other clinical teams that have less experience.
3	3.1)a)	Annually, 28000 patients, who are admitted to Intensive Care, die on ICU [figures from ICNARC 2012/13]. Therefore, 5.6% of the annual deaths in England occur on Intensive Care. Therefore, we consider that the consultation should consider the deaths occurring in ICU as a separate group within the overall guideline. The Intensive Care Community would be prepared to participate in this process.
4	3.2)c)	This is an integral component of good Intensive Care Medicine. Intensive Care clinicians have extensive experience of these drugs and others that are not available on a general ward (such as propofol, dexmetomidine, remifentanil amongst others)
5	4.1.1	We would advocate special group to be considered: Patients requiring Level 2 or Level 3 care (as defined in DH document 'Comprehensive Critical Care' 2000, DH http://tinyurl.com/nzbdsmd
6	4.3.1	We support the aims of this section, but consider that there are aspects to dying in the Intensive Care Unit that have not been considered – i.e. the issues around withholding or withdrawing organ support on Intensive Care
7	4.3.1	We are of the opinion that the guidance should address whether cardiopulmonary resuscitation should be delivered to patients who are actively dying, and if so identify why? If a patient is successfully resuscitated after cardiopulmonary arrest, then they would require multi-organ support on ICU. If they have been identified as dying, then all that has been achieved by resuscitating them is that their dying process has been prolonged. In our opinion the need/requirement for resuscitation needs clear guidance, particularly in light of Tracey, R (on the application of) v Cambridge University Hospitals NHS Foundation Trust
8	4.4	We support this section
9	4.5	We support this section, but note that the answers to some of these questions are significantly different in the Intensive Care environment, particularly if they have been sedated for some time during their period of active treatment.

Please add extra rows as needed.

Please email this form to: CareofDyingAdult@nice.org.uk

Closing date: 5pm on 29 August 2014.