Specialist neonatal care NICE National Institute for Health and Care Excellence

Consultation on draft scope – deadline for comments 5pm on 9/2/17
email: NeonatalCare@nice.org.uk

	Please read the checklist for submitting comments at the end of this form. We cannot accept forms that are not filled in correctly or arrive after the deadline. We would like to hear your views on these questions: 1. Which interventions or forms of practice might result in cost saving recommendations if included in the guideline? Developing NICE guidance: how to get involved has a list of possible areas for comment on the draft scope.
Organisation name – Stakeholder or respondent (if you are responding as an individual rather than a registered stakeholder please leave blank):	**Together for Short Lives**
Disclosure Please disclose any past or current, direct or indirect links to, or funding from, the tobacco industry.	**None.**
Name of person completing form:	**Patrick McKenna**
Type	[for office use only]

Comment No.	**Page number** or **'general'** for comments on the whole document	**Line number** or **'general'** for comments on the whole document	**Comments** Insert each comment in a new row. Do not paste other tables into this table, as your comments could get lost – type directly into this table.
Example	3	55	The draft scope currently excludes people who have already been diagnosed. We feel this group should be included because….
1	3	11	This will be relevant to voluntary palliative care organisations including children's hospices, children's community nursing teams and universal services provided by GPs, paediatricians and health visitors.
2	3	13	Change to 'parents and carers of babies admitted onto the neonatal unit', as 'children' cannot be admitted to neonatal units.

3	4	4	Some of the babies within the scope of this guideline will die as neonates; their palliative care may be planned using the principles of the Together for Short Lives Extubation Pathway and the Together for Short Lives Neonatal/Perinatal Pathway. http://www.togetherforshortlives.org.uk/assets/0000/1059/Extubation_Care_Pathway.pdf http://www.togetherforshortlives.org.uk/assets/0000/7095/Neonatal_Pathway_for_Babies_5.pdf
4	4	13	The list of settings should include voluntary sector palliative care organisations including children's hospices and baby hospice organisations.
5	4	13-14	End sentence at neonates, or change 'neonates' to babies to be more accessible to parents using this document, as children are not admitted onto neonatal units.
6	5	19	Some of these babies will die as neonates; professionals' communications with their parents and carers should follow the principles set out in the Together for Short Lives Neonatal/Perinatal Pathway (see comment 2 for link). Their care should include parallel planning, which means also planning for end of life care while taking account of the often unpredictable course of life-limiting conditions. It involves making multiple plans for care and using the one that best fits the baby's circumstances at the time. Parallel planning can help a family to achieve the best quality of life and best quality of death possible for their baby. Families will also need to be offered end of life care and bereavement care.
7	5	21	Discharge planning must take into account the infant being discharged to a location which may not be the family home. This may be a children's hospice, for example.
8	General	General	When considering resuscitation, advance care planning is vital. An advance care plan (ACP) is agreed in advance between professionals and families if possible, and is based on families' needs and wishes. Writing this plan can help to eliminate some of the family's anxieties, aid them in creating positive memories around the death of the child and make sure that their wishes and priorities are respected. Advance care planning with parents should begin during pregnancy if there is an antenatal diagnosis of a life-limiting condition.
9	6	5	This section should include NG 61 End of Life Care for infants, children & young People (Dec 2016). This describes the care and support that babies, children and young people with life-limiting conditions - and their families - should expect to receive from the point at which their needs are recognised until the end of their lives.

Please add extra rows as needed

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10	7	12	This should include planning for not intubating and not resuscitating. This should be included where possible in the anticipatory care planning process. Professionals may suggest to families that it may not be in their baby's best interest to be resuscitated; however, the precise details about what the family want and do not want should be fully explored and documented in an anticipatory care plan as stated by NICE NG 61 End of Life Care for infants, children & young People (Dec 2016). A written personal resuscitation plan should form part of an anticipatory care plan and be developed with the family, their consultant and other care team members. These plans allow families, in partnership with their health team, to tailor what interventions are appropriate for their baby. They will also assist communication between different professionals. If such a plan is not in place and there is no 'do not resuscitate' order in place, NICE guidelines NG 61 End of Life Care for infants, children & young People (Dec 2016) are to attempt to resuscitate the baby emphasising the importance of the anticipatory planning process to reflect appropriate interventions for the baby. The Royal College of Paediatrics and Child Health has published 'Making Decisions to Limit Treatment in Life-Limiting and Life-Threatening Conditions in Children: A Framework for Practice' (RCPCH 2015) at http://adc.bmj.com/content/100/Suppl_2/s1.full Practical guidance for the management of palliative care on neonatal units, published by Chelsea and Westminster Neonatal Team and endorsed by The British Association for Perinatal Medicine (2014) also provides supportive information about difficult decision making. This is available to access at: http://www.bapm.org/publications/documents/guidelines/NICU-Palliative-Care-Feb-2014.pdf It can be useful when there is disagreement within the team or family to seek an Ethics review by the local ethics group. This can be a very useful way in resolving some of the issues.
11	8	16	The needs of siblings, grandparents and other family members is crucial too. This support can be planned using the principles of the Together for Short Lives Neonatal/Perinatal Pathway (see comment 2 for link) and may need to start as early as the 20-week scan if this is when there is a diagnosis or recognition that the baby has a life-threatening or a life-limiting condition.
12	8	28	'and children' should be deleted from this line as babies are discharged from neonatal services, not children.
13	8	31	For many parents, the knowledge that their baby needs palliative care, combined with their new status as potential parents, may lead to them making a choice to be discharged somewhere other than their own home. This may be a children's hospice, a relative's home or even their local hospital. If the baby is going to stay in hospital, a palliative care approach is still appropriate in parallel to their ongoing care. Discharge planning should therefore involve professionals from palliative care teams, hospices and community nursing teams.

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14	9	18	A good quality of death is an extremely important outcome and should be planned for in parallel to planning for quality of life.
15	9	18	Siblings, grandparents and other relatives/carers, where appropriate, should be included in discussions about choices regarding quality of life.
16	9	19	Families of babies who have died should be interviewed about their experiences too and followed up if accessing them via a bereavement service.
17	9	18	A family should be able to express a choice about where their child receives care; the location in which the care is provided should reflect both the family's preference and the what can realistically be offered locally. It is also important to remember that families may change their mind about a preferred location of care, in response to changing circumstances, and that plans may therefore need to be made in parallel. This is a time of continuing uncertainty and many parents feel overwhelmed with the many decisions and choices they are asked to make. Ongoing conversations providing the opportunity to talk are essential.
18	11		Perinatal palliative and end of life care and death of the baby should be reflected in pathway.

Add extra rows if needed

Checklist for submitting comments

- Use this form and submit it as a Word document (not a PDF).
- Complete the disclosure about links with, or funding from, the tobacco industry.
- Include page and line number (not section number) of the text each comment is about.
- Combine all comments from your organisation into 1 response. We cannot accept more than 1 response from each organisation.
- Do not paste other tables into this table – type directly into the table.
- Underline and highlight any confidential information or other material that you do not wish to be made public.
- Do not include medical information about yourself or another person from which you or the person could be identified.
- Spell out any abbreviations you use
- For copyright reasons, do not include attachments such as research articles, letters or leaflets. We return comments forms that have attachments without reading them. The stakeholder may resubmit the form without attachments.

Note: We reserve the right to summarise and edit comments received during consultations, or not to publish them at all, if we consider the comments are too long, or publication would be unlawful or otherwise inappropriate.

Comments received during our consultations are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the comments we received, and are not endorsed by NICE, its officers or advisory Committees.

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