## National Institute for Health and Care Excellence

## Addendum to update the recommendations on reducing the risk of sudden infant death syndrome (SIDS), Post-natal Care

## **Stakeholder Comments**

## NOTE:

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

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Stakeholder Organisation:		Baby Milk Action			
Name of	F	Patti Rundall			
commer	ntator:				
Order number	Document	Section Number	Page Number	Comments	
(For internal use only)	We are only inviting comments on the addendum to the full guideline.  Comments on the original guideline will be deleted.	Indicate number or 'general' if your comment relates to the whole document	Indicate number or 'general' if your comment relates to the whole document	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	Addendum	3.4.6	45	Our comments are as follows	
Proformas	that are not cor	rectly submit		ed in the example above may be returned to you.	
1			General	The draft guidelines appear to have been compiled with care and attention to the limits of the available evidence, in this complex area. We welcome this. Guidelines also mention personcentred care, which we understand means health professionals should take into account the context and circumstances of parents/carers and their infants, their needs and preferences, and personal choice – which we also welcome.  We believe that care of infants and the manner in	
				We believe that care of infants and the manner in which they are fed (breast, bottle, or a combination; solids also, once complementary feeding has begin) are inextricably linked. Both infant and carer behaviour are impacted upon by the manner in which a baby is fed; breastfed babies may wake more frequently at night but	

			breastfeeding mothers may cope with this by sleeping close to their babies, thus benefiting from the fact that they do not need to get up to prepare a bottle. Breastfeeding can also help mothers get back to sleep more quickly, due to the effect of oxytocin. Co-sleeping, if breastfeeding, appears to be less risky than if bottle-feeding (due to the protective effect of breastfeeding against SIDS), more beneficial in terms of maternal rest, and possibly harder to avoid. We understand that the guidance sought to address co-sleeping specifically, but find it somewhat problematic that breastfeeding is not mentioned (while parental smoking, for instance, is).
2	1.2	6/7	Recommendations – and likely implementation of the guidance In the absence of clear understanding of SIDS aetiology, it seems prudent to inform parents of the various factors associated with SIDS, and not to single-out co-sleeping. We are concerned that by restricting the addendum to co-sleeping, despite the careful wording of the guidance, media and public perceptions may be that co-sleeping is <i>the</i> main risk factor for SIDS - which is not the case.
			The guidance groups together co-sleeping and sleeping on a sofa or chair; and also, groups together accidental co-sleeping with intentional co-sleeping. This is perhaps the easiest way of analysing data from studies which used varied and sometimes unclear definitions (a major limitation in the available evidence). However, we suggest it limits the practical applicability of advice parents/carers would be given based on the recommendations.
			Despite the careful wording of the draft guidance, we are concerned that in practice, a simple 'no co-sleeping' message may be delivered by health professionals; or health professionals' advice may be interpreted this way by parents/carers, and also the media.
3			Furthermore we are concerned that implementation of the recommendations may have unintended consequences:  The draft guidelines implicitly assume that information given to parents will impact on

		their intentions, and that they will be able to put these intentions into practice. As early months with a new baby are often very tiring, falling asleep with the baby may occur unintentionally. We are concerned that parents, in an effort to abide by advice from their health professionals, may get out of bed at night and sit on a sofa/chair to feed their baby and get them back to sleep, and risk falling asleep unintentionally with their baby in this apparently more dangerous setting. Co-sleeping in bed could be a safer option if parents were prepared for this possibility, and could take adequate precautions to make the sleeping environment as safe as possible.  • We suggest that it is inappropriate simply to tell parents not to co-sleep, and that this should be clearly stated in the guidance.  • Particularly in relation to breastfeeding – the physiological norm that is important for lifelong health - we are concerned that the guidance does not inform parents about the protective effect of breastfeeding in relation to SIDS. That previous information parents may have received has mentioned that breastfeeding is protective, and this guidance does not, implies that the balance of evidence no longer favours breastfeeding over formula-feeding, yet this is not the case. That other factors related to SIDS, such as parental smoking, are mentioned, seems inconsistent.  • We request that the protective effect of breastfeeding should be mentioned.
4	General	Terms used The term 'bed-sharing' requires clarification, as to whether this is sharing a bed to sleep, or (e.g.)
		breastfeeding in bed while awake. It appears that NICE means 'co-sleeping in bed' but this is not clear. (Ditto, 'sofa-sharing').
		'Acknowledge that co-sleeping occurs' – it is unclear what this means: whether this is
		something health professionals are meant to say

			Might it better be rephrased as 'Tell parents/carers that co-sleeping sometimes occurs unintentionally – for instance falling asleep by accident; or deciding on the spur of the moment to bring the baby into bed with them to sleep on a night when they are very tired. Inform parents/carers of steps they can take to minimise risks in these situations. Inform parents that if they choose to co-sleep in bed regularly, they can also take steps to minimise risks.'
5	1.3	7	Person-centred care  Mothers need accurate information to weigh up
			how best to cope at night.
			The recommendations may push mothers to stop breastfeeding and switch to formula-feeding in the hope of gaining a better night's sleep causing <i>more harm</i> to overall infant health, than continuing exclusive breastfeeding for the first 6 months and co-sleeping with adequate precautions taken (see below: we believe breastfeeding, as a factor protective against SIDS, has been inadequately addressed in Carpenter et al.'s study).
			Yet a small study has shown that breastfeeding mothers get more sleep than bottle-feeding mothers when they co-sleep with their babies. The authors of this study called for the development of methods or devices that allow breastfeeding mothers and newborns to sleep next to each other in complete safety.
			This is a small study of 33 mothers and their 4-week-old infants but it indicates how individual preferences can include co-sleeping Quillin (2004).
			As many parents co-sleep, even when they had not intended to do so antenatally, all parents should be informed how make this choice fully informed by the evidence. So that, if the do co-sleep, they understand how to make the sleeping environment as safe as it can be in order to minimise risk of SIDS (as points 3,4,5 of the guidelines, and also mentioning breastfeeding).
			This would be in line with 'person-centred' care but currently is not addressed in the guidelines.

			Quillin SI and Glenn LL (2004). Interaction between feeding method and co-sleeping on maternal-newborn sleep. J Obstet Gynecol Neonatal Nurs 33:580-8.
6	2.1.2.3	11	Methodological issues We have not reviewed the evidence in detail but are concerned about over-reliance on Carpenter et al.'s analysis. We leave aside from our methodological criticisms the highly offensive analogy drawn between co-sleeping and being a 'sow' at risk of overlaying her 'piglets' – trusting that those creating NICE guidance are free from such prejudices (and, of course, aware that the setting and population is quite different from that to which NICE guideline will apply! We note, though, that mothers who breastfeed are subject to jokes and bullying that compare them to livestock, and that this has the potential to impact on their choices to breastfeed in public or at all.) We also understand SIDS to be distinct from deaths caused by suffocation or overlaying, so we question the relevance of the analogy.  Carpenter et al.'s analysis combined data from studies which used different and sometimes unclear definitions. Use of imputation of missing variables (including known associated factors such as drug and alcohol use) is highly questionable given likely variation in these factors between the constituent study settings, and limits the certainty of the findings (see response letter by Blair et al. to Carpenter et al.'s article – http://bmjopen.bmj.com/content/3/5/e002299. full.html#responses).  Between constituent study settings the prevalence of exclusive breastfeeding, mixed-feeding and formula feeding likely vary, but Carpenter et al's definition of 'breastfeeding' groups mixed-feeding (breast and bottle) together with exclusive breastfeeding. It would be surprising if the protective effect of breastfeeding applied uniformly irrespective of whether the infant was exclusively breastfed, or

		'mixed-fed' and receiving perhaps just one breastfeed per day. (It is also unclear whether expressed milk given in a bottle would 'count' as bottle-feeding). We believe that the known association of SIDS with formula-feeding has been inadequately addressed Carpenter et al.'s study design; and also that the protective association with breastfeeding has been 'diluted' by grouping mixed-feeding with exclusive breastfeeding. However we acknowledge that it difficult to establish how infant feeding should be controlled for in studies of SIDS and co-sleeping, since the mechanisms by which formula or bottle feeding contribute to an increased risk of SIDS (or conversely, breastfeeding protects against SIDS) are not well understood.  Interpretation of a p-value of 0.062 as statistically-significant is not considered best practice (Carpenter et al., Table 3). Many would not even consider this p-value as reaching 'borderline' statistical significance. An alternative interpretation of this particular result is that where the baby is aged over 3 months and the mother smokes but does not drink, there is no statistically-significant evidence of an increase in risk with bed-sharing vs. room-sharing.
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