

National Institute for Health and Care Excellence

Fetal alcohol spectrum disorder

Consultation on draft quality standard – deadline for comments 5pm on 18/09/20

Please email your completed form to: QSconsultations@nice.org.uk

Note that this is an extension to the consultation exercise which was held from 6 March to 3 April 2020. The content of the quality standard remains unchanged. If your organisation commented previously, you do not need to resubmit your comments. However, if you have additional comments that you would like to submit, you are welcome to.

Organisation details

Organisation name – Stakeholder or respondent (if you are responding as an individual rather than a registered stakeholder please leave blank)	
Disclosure Please disclose any past or current, direct or indirect links to, or funding from, the tobacco industry.	
Name of person completing form	Dr Emma Milne Assistant Professor in Criminal Law and Criminal Justice Centre for Ethics and Law in the Life Sciences Durham Law School, Durham University, Palatine Centre, South Rd, Durham DH1 3LE
Supporting the quality standard	No

Would your organisation like to express an interest in formally supporting this quality standard? More information.	
Type	[Office use only]

Comments on the draft quality standard

Comment number	Section	Statement number	Comments Insert each comment in a new row. Do not paste other tables into this table because your comments could get lost – type directly into this table.
Example 1	Statement 1 (measure)	1	<i>This statement may be hard to measure because...</i>
1	Quality statement 1	1	The advice in this statement that women should not consume any alcohol while pregnant is based on limited evidence that a small amount of alcohol causes harm to a foetus (see Thom et al., 2020 for review of the data; Mamluk et al., 2017). Thus, the statement is not based on evidence, but on the simplicity of a message (abstinence). Such a response by the medical community is based on the principle that women cannot be trusted to make informed decisions about what is best for them and for their family. Presenting women with substantiated evidence and then allowing to make their own informed decisions would ensure an approach that is respectful of women and their choices.
2	Quality statement 1 and Quality statement 2	1 & 2	The quality statement documents fall back on popular tropes of the pregnant woman as mother, drawing on the notion and assumption that any 'good' mother would and should act in the best interests of the foetus. The impact of this is to encourage and promote notions of mother-blame and mother-guilt – the notion that anything that is 'wrong' with the 'baby' (used when referring to a foetus) must be the sole responsibility of the pregnant woman. Such attitudes are known to have substantial impact on the wellbeing and mental health of women, who end up feeling pressured to act in certain ways and 'to blame' for any possible negative outcome (Lupton, 2011; Harper & Rail, 2012; van Mulken et al., 2016; Ruhl, 1999). For discussion of how narratives around putting the foetus first are imbued with ideas of the 'good' motherhood, and mothering as natural to women see Milne (2020).

3	Quality statement 1 and Quality statement 2	1 & 2	<p>Intrusive questions into the lives of women who are pregnant will be counterintuitive to the intended outcome of reducing FAS and FASD. There is substantial evidence that when women are heavily policed in pregnancy by medical professionals they disengage from prenatal care. Lack of prenatal care is known to have a substantial impact on the health of both the pregnant woman and her foetus, far greater than the impact of alcohol, cigarette, and legal or illegal substance use (substantial evidence of negative consequences of policing comes from the USA, see Boudreax & Thompson, 2015; Kampschmidt, 2015; Ondersma et al., 2000). Thus, the impact of this policing policy is likely to drive women who need support and healthcare away from the medical system, thus subjecting them and their foetuses to greater risk of bad outcomes.</p>
4	Quality statement 2	2	<p>There is potential for this initiative to reignite attempts to hold women liable (criminally or civilly) for their actions while pregnant that are deemed to have a negative impact upon the health and welfare of the foetus post-birth. While this is not the intent of the quality standards, it must be remembered that by recording such information and transferring it to the health records of a child born alive then a record of behaviour will be created, which may be drawn upon as 'evidence'. Therefore, this policy has the potential to open the door to women facing legal consequences. Holding women legally liable for their actions (including inactions) while pregnant has significant implications for women's rights, resulting in a sex-based discrimination for all women due to the 'risk' of becoming pregnant (Brazier, 1999; see Milne, 2020 for a summary of the debate about foetal protection and women's rights).</p>
5	Quality statement 2	2	<p>There is no discussion of informed consent of pregnant women, nor that they are being told how the data collected about them is being used and will be used in the future. There is also no discussion of a woman's ability to opt-out of such intrusive questioning of her lifestyle and behaviour. If there is no intention to provide women with a reasonable level of information to allow them to make an informed decision as to whether or not they wish to opt-out of this data collection, then this intervention will be coercive in nature.</p>

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NICE reserves the right to summarise and edit comments received during consultations, or not to publish them at all, where in the reasonable opinion of NICE, the comments are voluminous, publication would be unlawful or publication would be otherwise inappropriate.

Comments received from registered stakeholders and respondents during our stakeholder engagements 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.

References

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