

Concise Argument: Knowing who to trust: women and public health

In this issue of the JME, age-old questions around how to balance the interests of mother and foetus are revisited in two separate contexts: alcohol consumption during pregnancy, and maternal request caesarean sections. Both have been the subject of recent controversy in the UK, with March 2022 seeing the introduction of (contentious) new National Institute for Clinical Excellence (NICE) Quality Standards on combatting foetal alcohol spectrum disorder (FASD);¹ and the publication of the long-awaited Ockenden Review into a series of failures in NHS maternity care.² Both raise important questions about the role of healthcare professionals in policing women's choices during pregnancy and childbirth, and of the importance of deference to and trust in those choices.

In this issue's Feature Article, Rebecca Bennett and Catherine Bowden explore recent proposals to enhance the screening of pregnant women in order to prevent instances of fetal alcohol spectrum disorder through more accurately determining the true prevalence of alcohol consumption during pregnancy.³ Public Health England (PHE) has suggested research into tools such as blood biomarkers and meconium testing,⁴ which could better identify those women who are consuming alcohol 'covertly' and so make FASD diagnoses more straightforward. As Bennett and Bowden rightly suggest, such a move is unlikely to realise the kind of public health or welfare gains which would justify this level of interference with the women's autonomy, and may even result in more harm through discouraging engagement with antenatal care. However even absent these very intrusive methods of surveillance, the precautionary principle which underpins such policies – namely that in the absence of evidence that any alcohol is safe, women should be instructed to avoid it altogether – is itself difficult to justify.

The evidence on alcohol consumption during pregnancy is mixed. While it is widely accepted that heavy drinking in pregnancy can cause FASD,⁵ the position in respect of light or moderate drinking is less clear cut, with a lack of consistent evidence of adverse effects.⁶⁷ Indeed one study even found that light alcohol use could be associated with positive rather than negative outcomes,⁸ though this was likely the result of light alcohol consumption being associated with socio-economic advantage. Conversely, FASD is far more prevalent amongst those of lower socioeconomic status, with a study in the US indicating that the risk of bearing a child with FASD may be as much as 15.8 times higher for women of lower socioeconomic status, even if they engage in comparable levels of drinking.⁹¹⁰ There is also evidence that mothers of children with FASD are more likely to use other drugs or to smoke during pregnancy and to suffer from depression; meanwhile households into which children with FASD are born tend to be less stable and more chaotic.¹¹ The relationship between alcohol consumption and FASD is thus complicated by myriad other influences on child development and health; influences which are clearly heavily associated with socioeconomic factors.

It is against this evidence-base that NICE's new Quality Standards instruct healthcare professionals to advise pregnant women not to drink alcohol throughout their pregnancy, as well to repeatedly inquire about and record women's alcohol.¹² This replaced the previous guidance that one to two units not more than twice per week is safe; although it did not go as far as NICE's initial draft proposals which would have automatically included any reports of alcohol consumption into the child's medical records.¹³

There is much that could be said about such guidance: about the role of medical professionals in policing women's consumption of alcohol; about the implications for women's privacy; and about whether this kind of guidance will in fact result in lower instances of FASD or merely drive heavy drinkers underground. But they also raise broader questions about what standards we ought to be able to expect of bodies such as NICE (an executive non-departmental public body) or the Office for Health Improvement and Disparities (an executive agency of the Department of Health) when issuing public health advice, especially in areas of medical uncertainty. In their 2021-2026 Strategy, NICE identify their 'core purpose' as being 'to improve health and wellbeing by putting science and evidence at the heart of health and care decision making.'¹⁴ This, they achieve through three steps. The first, is by 'providing independent assessment of a wide range of complex evidence' to help practitioners, patients and the public 'make better informed decisions'; the second, by working with those at the forefront of scientific advances to recommend innovations and the third is to work with those in health and social care to encourage the uptake of effective treatments and interventions. It is the first of these -- helping the public make informed decisions through analysing the complex evidence involved -- which concerns us here; with this commitment to facilitating informed, evidence-based decisions reiterated throughout their website. The second of their four 'pillars', for example, is to create and maintain 'up-to-date guidance that integrates the latest evidence, practice and technologies in a useful and useable format';¹⁵ while their guidance is described as offering independent and 'evidence-based recommendations'.¹⁶

Given this stated aim, it might seem odd that NICE has chosen to do precisely the opposite in respect of alcohol consumption in pregnancy, where notwithstanding the lack of consistent evidence that light drinking causes any harm to foetal development, healthcare professionals are still being told to advise against even the lightest and very occasional drinking. Far from distilling the complex information to help women make informed decisions then, the effect is rather to conceal information about its apparent safety, thus depriving women of their opportunity to take the best decisions for them, informed by a proper understanding of all the known attenuated risks.

The rationale for such an approach has been made clear: a concern that the truth might confuse expectant mothers, and so, to avoid them inadvertently harming their children through a lack of understanding of what constitutes 'moderate' drinking, it is better to say no altogether. (It should, of course, be noted that it would be perfectly possible to produce guidance on this question – as indeed was the case prior to the new guidelines, with identified 1 to 2 glasses of wine up to twice a week as moderate drinking.) To some extent, whether this is true is an empirical assertion about how women will think and behave, which cannot be comprehensively negated here. But it is certainly the case that women are required to navigate a series of far more complex decisions in other aspects of their pregnancy and childbirth, that require them to comprehend and evaluate substantially more complex information than that required to decide whether to drink alcohol or not. Take the decision of whether to continue to take medication for epilepsy or anti-psychotic medication during pregnancy, weighing possible harm to the foetus against the serious implications for the health of the mother (and, consequently the foetus). Or the decision about when to opt for a caesarean delivery – some of the considerations about which are discussed by Chloe Romanis in her article on maternal request caesarean sections in this issue.¹⁷ And of course these pale in comparison to some of the complex choices parents have to make after their child is born. By contrast, the evidence in the context of alcohol consumption would seem relatively straightforward: heavy consumption can cause harm; light to moderate drinking may have the

potential to cause harm, but we do not currently have consistent evidence that it does. Given this, as Colin Gavaghan observes,

To continue preaching total abstinence because of a fear that women will misunderstand the truth, or regard a reassuring message about low-level consumption as a “green light” for unrestrained overindulgence, is patronising and paternalistic to a degree that is hard to reconcile with any real respect for autonomy and informed decision-making.¹⁸

This issue is especially pertinent in the context of a culture of shame surrounding women deemed to be making ‘sub-optimal’ choices for their children, and the ample evidence of pregnant women’s preferences or concerns being relegated in choices around gestation and childbirth, explored further in Romanis’ piece and demonstrated vividly by the Ockenden review. In this context in particular then, there is a need for much greater trust by healthcare professionals and officials in expectant mothers: trust that they will seek to inform themselves of the information; trust that they will use this information to make the right decisions for them *and their child*; and trust that they will then be honest and open with healthcare professionals about these choices. The latter, in turn, requires women to have faith in their ability to engage in such discussions without fear of judgement or reprimand, something which is militated against by NICE’s implicit suggestion that one glass of wine constitutes potential harm to the child. And this is only likely to get worst if the kinds of proposals considered by Bennett and Bowden ever come to fruition.

But it is also important beyond this context, since it goes to the legitimacy of such bodies in guiding the public’s healthcare choices. The public are entitled to expect transparency and openness in their handling of scientific evidence, and that any healthcare guidance is based on the best available evidence. A failure to do will result in public trust in our government’s health messaging diminishing, perhaps also in our medical profession who deliver such messaging. It is notable that in the ‘Maintaining Trust’ section of their guidance on ‘Good medical practice’, the General Medical Council stress the need to be ‘honest and trustworthy’ in all communications with patients, including making ‘clear the limits of your knowledge’ and making ‘reasonable checks to make sure any information you give is accurate.’¹⁹ Honesty and accuracy in the presentation of the information is key to maintaining trust in healthcare providers and institutions, yet as Patrick O’Brien has argued:

if we try to appeal to the lowest common denominator, most women will seek the evidence online and judge it for themselves. And if they perceive that we have been making value judgments on their behalf, or professing certainty where none exists, we are certain to lose their trust.²⁰

He is right, and the timing could scarcely be worse. The Covid 19 pandemic has already tested the credibility of public health experts, prompting increased distrust and scepticism in some quarters. Public trust is fragile, the fact that this NICE guideline rests upon the assumption that women cannot be trusted to tell the difference between light and heavy drinking will only damage it further.

Interestingly, in considering ways to restore public trust in the wake of the pandemic, Joshua Barocas and Monica Gandhi have stressed the need to evolve ‘non-judgmental, holistic, and patient focused styles of messaging around risk reduction and disease prevention’ which focus on harm reduction: ‘the principle of advising individuals how to mitigate risk, while acknowledging the real world conditions that may lead individuals to take some risks.’²¹ They give examples ranging from the management of HIV and addiction through to mitigating the risks of heart disease and diabetes in order to show that successful public health intervention involves advocating moderation, not abstention. The same principles

should guide messaging here: rather than insulating women from potentially harmful choices, they ought to be provided with the evidence in a clear and ambiguous way that enables them to make properly informed choices about the *extent* of risks that they wish to take. This is a crucial part of effective public health messaging, and of ensuring women's honest and open engagement with antenatal care, but it is also important to maintaining trust in health institutions, as vehicles for conveying complex factual information, and not mouthpieces of certain ideological views about motherhood.

¹ National Institute for Health Care and Clinical Excellence. Foetal alcohol spectrum disorder: Quality Standard 204. 2022 March 16. Available: <https://www.nice.org.uk/guidance/qs204>

² Findings, Conclusions and Essential Actions from the Independent Review of Maternity Services at The Shrewsbury and Telford Hospital NHS Trust. 30th March 2022. HC1219. Available: https://www.donnaockenden.com/wp-content/uploads/2022/03/FINAL_INDEPENDENT_MATERNITY_REVIEW_OF_MATERNITY_SERVICES_REPORT.pdf

³ Bennett R, Bowden C. Can routine screening for alcohol consumption in pregnancy be ethically and legally justified? *Journal of Medical Ethics* Published Online First: 23 March 2022. doi: 10.1136/medethics-2021-107996

⁴ Public Health England. Maternity high impact area: reducing the incidence of harms caused by alcohol in pregnancy. 2021:10. Available: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/942477/Maternity_high_impact_area_4_Reducing_the_incidence_of_harms_caused_by_alcohol_in_pregnancy.pdf

⁵ Jones KL, Smith DW, Ulleland CN, Streissfuth AP. Pattern of malformation in offspring of chronic alcoholic mothers. *Lancet* 1973; 301:1267-71. doi: [10.1016/s0140-6736\(73\)91291-9](https://doi.org/10.1016/s0140-6736(73)91291-9)

⁶ Gray R, Henderson J. Report to the Department of Health: Review of the Foetal Effects of Prenatal Alcohol Exposure. 2016 May. University of Oxford National Perinatal Epidemiology Unit. Available: [efaidnbmnnnibpajpegglefindmkaj/http://data.parliament.uk/DepositedPapers/Files/DEP2008-2368/DEP2008-2368.pdf](http://data.parliament.uk/DepositedPapers/Files/DEP2008-2368/DEP2008-2368.pdf)

⁷ Henderson J, Kesmodel U, Gray R. Systematic review of the fetal effects of prenatal binge-drinking. *J Epidemiol Community Health* 2007; 61: 1069-73. doi: [10.1136/jech.2006.054213](https://doi.org/10.1136/jech.2006.054213)

⁸ Kelly Y, Sacker A, Gray R et al. Light drinking in pregnancy, a risk for behavioural problems and cognitive deficits at 3 years of age? *J Epidemiol Int* 2009;38(1):129-140. doi: [10.1093/ije/dyn230](https://doi.org/10.1093/ije/dyn230)

⁹ Bingol N, Schuster C, Fuchs M et al. The influence of socioeconomic factors on the occurrence of fetal alcohol syndrome. *Advances in Alcohol & Substance Abuse* 1987;6:105-118. doi: [10.1300/J251v06n04_08](https://doi.org/10.1300/J251v06n04_08)

¹⁰ Abel EL, Hannigan JH. Maternal risk factors in fetal alcohol syndrome: Provocative and permissive influences. *Neurotoxicology and Teratology* 1995;17:445-462. doi: [10.1016/0892-0362\(95\)98055-6](https://doi.org/10.1016/0892-0362(95)98055-6)

¹¹ May PA and Gossage JP. Maternal risk factors for fetal alcohol spectrum disorders- not as simple as it might seem. *Alcohol Research & Health* 2011;34(1):15-26.

¹² National Institute for Health Care and Clinical Excellence. Fetal alcohol spectrum disorder: Quality standard [QS204]. Quality Statement 1 and 2.

¹³ National Institute for Health Care and Clinical Excellence. Foetal alcohol spectrum disorder NICE Quality Standard: Draft for Consultation. 2020 March 05. Available: <https://www.nice.org.uk/guidance/QS204/history>

¹⁴ National Institute for Health Care and Clinical Excellence. NICE Strategy 2021-2026: Dynamic, Collaborative, Excellent. 2021 April. Available: <https://static.nice.org.uk/NICE%20strategy%202021%20to%202026%20-%20Dynamic.%20Collaborative.%20Excellent.pdf>.

¹⁵ National Institute for Health Care and Clinical Excellence. The NICE strategy 2021 to 2026. Available: <https://www.nice.org.uk/about/who-we-are/corporate-publications/the-nice-strategy-2021-to-2026>.

¹⁶ National Institute for Health Care and Clinical Excellence. Home Page. Available: <https://www.nice.org.uk/>.

¹⁷ Romanis EC. Appropriately framing maternal request caesarean section. *Journal of Medical Ethics* Published Online First: 06 January 2022. doi: 10.1136/medethics-2021-107806

¹⁸ Gavaghan C. "You can't handle the truth"; medical paternalism and prenatal alcohol use. *J Med Ethics* 2009 35(5):300-3. doi: 10.1136/jme.2008.028662

¹⁹ General Medical Council. Good medical practice. GMC/GMP/1120. 2020.

²⁰ O'Brien P, Should women abstain from alcohol during pregnancy? No. BMJ 2015;351
doi: <https://doi.org/10.1136/bmj.h5232>.

²¹ Barocas J and Gandhi M. Harm reduction principles can help us restore trust in public health messaging on covid-19. The BMJ Opinion. 2020 Dec 15. Available: <https://blogs.bmj.com/bmj/2020/12/15/harm-reduction-principles-can-help-us-restore-trust-in-public-health-messaging-on-covid-19/>