

10 year surveillance (2017) – [Chronic fatigue syndrome/myalgic encephalomyelitis \(or encephalopathy\) \(2007\) NICE guideline CG53](#)

Stakeholder consultation comments form - proposal for ‘no update’

Consultation on the proposal for ‘no update’ opens on: 9am Monday, 10 July 2017

Comments on proposal to be submitted: no later than 9am Monday, 24 July 2017

Please enter the name of your registered stakeholder or respondent organisation below.	
Please use this form for submitting your comments to NICE.	
<ol style="list-style-type: none"> 1. Please put each new comment in a new row. 2. Please note – we cannot accept comments forms with attachments such as research articles, letters or leaflets. If we receive forms with attachments we will return them without reading the comments. If you resubmit the comments on a form without attachments, this must be by the consultation deadline. 3. If you wish to draw our attention to published studies, please supply the full reference. 4. NICE is unable to accept comments from non-registered organisations. If you wish your comments to be considered please register via the NICE website or contact the registered stakeholder organisation that most closely represents your interests and pass your comments to them. 	
Organisation name – Stakeholder or respondent	FORWARD-ME (forward-me.org.uk)
Disclosure Please disclose whether the organisation has any past or current, direct or indirect links to, or receives funding from, the tobacco industry.	NONE
Name of commentator:	COUNTESS OF MAR

[Developing NICE guidelines: the manual](#) gives an overview of the processes used in surveillance reviews of NICE clinical guidelines.

ID	Questions	Overall response yes / no	Comments Please insert each new comment in a new row
1	Do you agree with the proposal not to update the guideline?	NO	<p>We respect the authority of NICE to evaluate current evidence on its own terms, and we respect the authority that underlies its conclusion that recent research offers no substantial challenge to the current guideline. We suggest, however, that NICE exceeds its authority in assuming that patients, physicians and mental health practitioners need only be informed of its own evaluation of research. For this reason we request revisions of the current guideline so that it presents a truthful, neutral picture of debate among respected authorities about the nature and optimal management of CFS/ME.</p> <p>Our request is based on two central ethical considerations. (1) We submit the current guideline fails to respect “patient choice”, and “the right of individuals to make informed choices about healthcare (NICE – Social Value Judgments 2.1)</p> <p>No information is more important to any patient who pursues medical care for symptoms than the fact that their condition is understood by some respected health authorities to require biological testing, treatment and physician support. For this reason (barring unusual cases of therapeutic privilege) there is no situation in which this information is not of material importance to a patient with CFS/ME. Similarly, while we respect NICE’s interpretation of recent research on CBT and graded exercise therapy (GET), no reasonable person would imagine that a patient gives informed consent to these interventions without knowledge that some respected health authorities conclude (a) that there is “insufficient evidence to determine the effectiveness of CBT on the outcome of global improvement” (AHRQ, 2016 Addendum) and (b) that GET involves “potential harms” (HHS Chronic Fatigue Syndrome Advisory Committee 2015).</p> <p>(2) We point out the “legislation on human rights, discrimination</p>

ID	Questions	Overall response yes / no	Comments Please insert each new comment in a new row
			<p>and equality requires that patients are not denied access, or have different or restricted access, to NHS care because of their disabilityor other status” (NICE – Social Value Judgments 6.0). Failure to inform physicians and mental health practitioners of the US conclusion that CFS/ME is a biological medical condition that requires biological care obstructs patients’ access to biological care. This obstruction singles out CFS/ME patients as somehow uniquely undeserving of access when facing a demonstrable possibility of need.</p>
2	Do you agree with the proposal to remove the guideline from the static list?	YES	<p>In 2007, NICE guidelines for the management of CFS/ME reflected a global consensus among researchers and health authorities about the nature and optimal management of the condition. In 2017, however, that is no longer the case. Given the unanimous reversal of opinion towards biological management of CFS/ME by US health authorities, it is ethically concerning that NICE could entertain the possibility of not only maintaining the guideline as it stands, but keeping it on the static list.</p> <p>First, to allow for these possibilities is to fail to respect NICE’s commitment to evidence-based practice. While policy makers at NICE have every right to a professional evaluation of current research that is opposed to the evaluation made by their counterparts in the US, the US interpretation of the research is itself evidence of which patients, physicians and mental health providers in the UK must be informed.</p> <p>Second, to allow for these possibilities is to fail to respect NICE’s commitment to ethical practice as specified in the Social Value Judgements document. While we respect NICE’s concern to avoid questions of aetiology, that concern in no way frees NICE, or the NHS, from the ethical obligation to inform patients and providers of a substantial difference in orientation</p>

ID	Questions	Overall response yes / no	Comments Please insert each new comment in a new row
			to this condition by respected health authorities elsewhere.
3	Do you have any comments on areas excluded from the scope of the guideline?	YES	<p>The surveillance report considers and resolves the question of whether the guideline should be changed to align with the conclusions in the US about diagnosis and management of CFS/ME. Our request, however, is not that the guideline be revised to reflect a change of opinion in the UK, but rather that it is revised to present a truthful, neutral picture of the difference of opinion between UK and US health authorities about the nature and management of this condition.</p> <p>For this reason, the surveillance report fails to address, or even consider, the heart of the matter, the question of whether the guideline as it stands is ethical with respect to (1) informed consent, and (2) the obligation never to obstruct access to biological medical care for any patient group that faces a significant possibility of biological need.</p> <p>We request that either the guideline be revised to include vital information now excluded, or that NICE develops a new surveillance report that directly addresses these ethical considerations in a way that reflects the organisation's commitments to the ethical practices described in the Social Value Judgements document.</p>
4	Do you have any comments on equalities issues?	YES	<p>In the context of well-understood conditions of cancer, a significant possibility of need for biological medical care is immediately understood as sufficient to secure a right of access to that care. Based purely on the possibility of need, policy makers are clear that any patient group who might well suffer from cancer has a right to access to biological testing, treatment and support.</p> <p>Stigma about CFS/ME has made it difficult for policy makers to recognise the profound importance of their obligation to continue to protect that right in the context of this condition.</p>

ID	Questions	Overall response yes / no	Comments Please insert each new comment in a new row
			<p>Given the conclusion among US health authorities that CFS/ME is a biological condition for which patients require biological testing, treatment and support, a significant possibility of biological need is a scientific fact for this patient group.</p> <p>Because the need for biological medical care is a possibility rather than a proven fact, it is unclear at this time whether policy makers have an obligation to proactively ensure that all patients in this group receive medical care. Still, the possibility of need is sufficient to establish that it is unethical for policy makers to knowingly obstruct access to biological testing, treatment and support for this patient group.</p> <p>Because the current guideline directs patients squarely towards behavioural management, it clearly does obstruct patients' access to biological testing, treatment and support. To avoid this ethical violation, we request that the guideline be revised to present a truthful, neutral picture of the current debate about the nature and management of CFS/ME.</p>

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

Closing date: 9am, 24 July 2017

PLEASE NOTE:

NICE reserves the right to summarise and edit comments received during consultations, or not to publish them at all, if NICE's reasonable opinion is that the comments are voluminous, publication would be unlawful or publication would be otherwise inappropriate.