

NICE guideline surveillance

Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy). (2007) NICE guideline CG53

10-year surveillance topic expert questionnaire

We are conducting a formal check of the need to update the guideline on chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy) to identify whether any recommendations need to be updated. As a member of the committee that developed this guideline we welcome your views on any areas that need updating. This document contains a questionnaire for you to record your views.

Your answers will be used to inform a decision as to whether an update of this guideline is needed at this time.

The NICE team performs robust literature searches in multiple electronic databases to identify studies which are relevant to the clinical guideline. Although extensive searches are performed, we would appreciate if you can highlight any important study which would impact on guideline recommendations and potentially change current practice. It would be helpful if you could also say how it impacts the guideline. Please provide enough information on the study for us to find it. The full reference is ideal, but if this is not possible, please include information such as:

- trial name
- lead author
- potential publication date of unpublished work.

If you provide details of any studies in your responses then these will be assessed to see if they were published within the search dates for the surveillance and whether they have already been identified in the literature searches.

Any new relevant studies identified by you or other members of the committee that meet the scope for the review will then be considered with the wider body of published evidence provided they meet the evidence type suggested in the protocol or used for that question in the guideline. Further details about the process for checking that published guidelines are current are available in chapter 13 of [Developing NICE guidelines: the manual](#).

In your answers, please consider possible inequalities in relation to age, disability (including learning disability and mental health), gender reassignment, marriage and civil partnership, pregnancy and maternity, race,

religion or belief, sex, and sexual orientation, as outlined in the [Equality Act 2010](#), as well as inequalities arising from socioeconomic factors and from the circumstances of certain population groups, such as looked after children and homeless people.

Please note that responses to this survey may be subject to a Freedom of Information request.

Please return the completed questionnaire by Monday 19 December 2016.

Any studies received after the deadline for return of this questionnaire will be considered where it is possible to do so, but may have to wait for the next surveillance check.

Thank you for your time.

Do you think the guideline needs to be updated?	No
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Please justify your rationale for the above decision by answering the following questions.

Topic expert questionnaire

	Response	References and supporting information
Is there new evidence in the following areas that may impact on current recommendations or address research recommendations in this guideline? How will it impact on the recommendations?		
Interventions (e.g. pharmacological, psychological treatments or prophylactic treatments)	No	Further evidence on the effectiveness of CBT has become available since the guideline was published (e.g. PACE trial, White et al, Psychological Medicine, vol 43 (2013), but this does not alter the recommendations made
Diagnostics (e.g. identification tools, physical examination, history-taking, or imaging tests)	No	No hard evidence on diagnostic testing or categorising has emerged.
Prognostics (e.g. clinical prediction rules or risk classification)	No	No good evidence on prognosis has emerged since the guideline was published.
Service user and carer experience Are you aware of any new published information, such as reports and policies, concerning the patient or service user experience or their information and support needs?	Unsure	I am not aware of any new information about service user and carer experience.
Referral, service delivery and other issues Are you aware of any new evidence concerning referral, service delivery or other issues?	No	
Inequalities Are there current inequalities in access to services or service provision that are not	No	

	Response	References and supporting information
addressed in the current guideline? ¹		
Costs Have costs changed for interventions or diagnostics (for example, drugs coming off patent, technologies becoming more affordable)?	No	Still a clinical diagnosis depending heavily on physicians' acumen.
Ongoing research Please provide details of ongoing research (e.g. randomised controlled trials and systematic reviews) that has not yet been published and that may impact on either the: 1. Guideline recommendations Or	None	
2. Research recommendations		
Research recommendations Are you aware of any new evidence that answers research recommendations in the guideline?	No	
Safety Are you aware of any harm or safety concerns about the practice, treatment/interventions or diagnostic strategy/tools recommended by the existing guideline?	No	

¹ Consider possible inequalities relating to age, disability (including learning disability and mental health), gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, and sexual orientation, as outlined in the [Equality Act 2010](#), as well as inequalities arising from socioeconomic factors and from the circumstances of certain population groups, such as looked after children and homeless people.

	Response	References and supporting information
Relevance Is the guideline still relevant to clinical practice and the organisation of care?	Yes	The guideline has stood the test of time well, and has been instrumental in shifting thinking about the common problem of CFS/ME and medically unexplained (functional) symptoms in general. I hope that a new guideline on management of functional disorders will extend this process further.