

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- potential publication date of unpublished work.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?	Uncertain
--	------------------

Please justify your rationale for the above decision by answering the following questions.

Topic expert questionnaire

Response	References and supporting information
<p>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?</p>	

	Response	References and supporting information
Interventions (e.g. pharmacological, psychological treatments or prophylactic treatments)	Possibly	<p>1. Dr Sanne L Nijhof, MD  Press enter key for correspondence information  Press enter key to Email the author</p> <p>Effectiveness of internet-based cognitive behavioural treatment for adolescents with chronic fatigue syndrome (FITNET): a randomised controlled trial</p> <p>, Prof Gijs Bleijenberg, PhD , Cuno SPM Uiterwaal, PhD , Prof Jan LL Kimpen, PhD , Elise M van de Putte, PhD</p> <p>This study shows that CBT can be delivered to adolescents via the Internet. This does not change the guideline substantially, but it indicates an alternative mode of delivery for this treatment for this age group.</p> <p>2. Behav Res Ther. 2012 Nov;50(11):719-25. doi: 10.1016/j.brat.2012.08.005. Epub 2012 Aug 31.</p> <p>Family-focused cognitive behaviour therapy versus psycho-education for adolescents with chronic fatigue syndrome: long-term follow-up of an RCT.</p> <p>Lloyd S¹, Chalder T, Rimes KA.</p> <p>This study showed family focused CBT and psycho-education being comparably effective in the treatment of adolescent CFS, but family CBT was superior in terms of later emotional adjustment in young people. This is relevant because a number of young people with severe CFS develop emotional disorders on recovery.</p> <p>3. The PACE study (Sharpe et al, 2015) will be well known to reviewers already.</p>

	Response	References and supporting information
<p>Diagnostics</p> <p>(e.g. identification tools, physical examination, history-taking, or imaging tests)</p>	[Yes / No / Unsure]	[If yes, please indicate the areas in the guideline and how it will impact on recommendations – Please provide specific references to support your rationale]
<p>Prognostics</p> <p>(e.g. clinical prediction rules or risk classification)</p>	Possibly	<p>Helen Bould¹, Simon M Collin¹, Glyn Lewis¹, Katharine Rimes², Esther Crawley¹</p> <p><i>Arch Dis Child</i> 2013;98:425-428 doi:10.1136/archdischild-2012-303396</p> <p>Depression in paediatric chronic fatigue syndrome</p> <p>In this study of adolescents with CFS/ME depression was a common co-morbidity (29%) and present much more commonly than in the general population, and depression was associated with markers of disease severity, indicating that it is important to screen and if appropriate treat depression in this population.</p>
<p>Service user and carer experience</p> <p>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?</p>	[Yes / No / Unsure]	[If yes, please indicate the areas in the guideline and how it will impact on recommendations – Please provide specific references to support your rationale for example from patient surveys, qualitative research]
<p>Referral, service delivery and other issues</p> <p>Are you aware of any new evidence concerning referral, service delivery or other issues?</p>	[Yes / No / Unsure]	[If yes, please indicate the areas in the guideline and how it will impact on recommendations – Please provide specific references to support your rationale for example from observational studies]
<p>Inequalities</p> <p>Are there current inequalities in access to services or service provision that are not</p>	[Yes / No / Unsure]	[Please provide details]

	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)?	[Yes / No / Unsure]	[If yes, please indicate the areas in the guideline and how it will impact on recommendations – Please provide specific references to support your rationale]
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	[Yes / No / Unsure]	Professor Esther Crawley is conducting a replication national study in the UK of the use of internet accessed CBT for adolescent CFS/ME.
2. Research recommendations	[Yes / No / Unsure]	[Please provide details – e.g. trial name, potential publication date and relevant area/question in the guideline]
Research recommendations Are you aware of any new evidence that answers research recommendations in the guideline?	[Yes / No / Unsure]	Please provide specific information to support your rationale]
Safety Are you aware of any harm or safety concerns about the practice, treatment/interventions or diagnostic strategy/tools recommended by the existing guideline?	[Yes / No / Unsure]	[If yes, please indicate the areas in the guideline and how it will impact on recommendations – Please provide specific references to support your rationale]

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 / No / Unsure]	[Please provide details]