

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- potential publication date of unpublished work.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?	[Yes/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)	Yes	<p>Since the guidance was produced, the following trial describing the effectiveness of FITNET has been published. This trial suggested that internet delivered CBT was effective for children. Whilst CBT was covered in the guidance, delivering CBT using the internet was not.</p> <p>Effectiveness of internet-based cognitive behavioural treatment for adolescents with chronic fatigue syndrome (FITNET): a randomised controlled trial. Nijhof SL, Bleijenberg G, Uiterwaal CS, Kimpfen JL, van de Putte EM. Lancet. 2012 Apr 14;379(9824):1412-8.</p> <p>FITNET has not been trialled in the UK and there is currently no evidence on cost effectiveness. [REDACTED] [out of scope] started recruiting to conduct FITNET-NHS but the evidence [REDACTED] [out of scope] will not be available for 5 years.</p>
Diagnostics (e.g. identification tools, physical examination, history-taking, or imaging tests)	No	<p>[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> <p>There are some studies comparing diagnostic criteria but I think it is unlikely that these will impact on the recommendations.</p>
Prognostics (e.g. clinical prediction rules or risk classification)	No	<p>[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>

	Response	References and supporting information
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?	Yes	<p>██████ [out of scope] published papers on the experience of service users (patients and parents/carers) for children with CFS/ME.</p> <p>L Beasant, N Mills and E Crawley. Adolescents and mothers value referral to a specialist service for chronic fatigue syndrome or Myalgic Encephalopathy (CFS/ME). Primary Health Care Research & Development. Prim Health Care Res Dev. 2013 Apr 25:1-9.</p>
Referral, service delivery and other issues Are you aware of any new evidence concerning referral, service delivery or other issues?	Yes	See above and below
Inequalities Are there current inequalities in access to services or service provision that are not addressed in the current guideline? ¹	Yes	<p>██████ [out of scope] published on equity of access to specialist services:</p> <p>S Collin, J Sterne, W Hollingworth, M May, E Crawley. Equity of access to specialist chronic fatigue syndrome (CFS/ME) services in England (2008-2010): a national survey and cross-sectional study. BMJ Open. 2012 Aug 16;2(4). pii: e001417.</p>
Costs Have costs changed for interventions or diagnostics (for example, drugs coming off patent, technologies becoming more affordable)?	Yes	The money paid for services has been reduced by commissioners.

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
<p>Ongoing research</p> <p>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:</p> <p>1. Guideline recommendations</p> <p>Or</p>	Yes	<p>██████ [out of scope] data on health resource use from the CPRD that is not published describing health resource use before and after a diagnosis of CFS/ME. This will be submitted in the Winter/Spring of 2017</p> <p>██████ [out of scope] yet to publish the results from the SMILE trial</p> <p>E Crawley, N Mills, W Hollingworth, Z Deans, J Sterne, L Beasant, J Donovan, A Montgomery. Comparing specialist medical care with specialist medical care plus the Lightning Process® for Chronic Fatigue Syndrome or Myalgic Encephalopathy (CFS/ME): Study Protocol for a Randomised Controlled Trial. Trials. 2013 Dec 26;14:444. doi: 10.1186/1745-6215-14-444.</p> <p>██████ [out of scope] conducting to large trials:</p> <ol style="list-style-type: none"> 1. The MAGENTA trial is testing Graded Exercise Therapy in children with CFS/ME. ██████ [out of scope] will finish recruiting in 2018. 2. The FITNET-NHS trial is testing FITNET in the NHS. This will recruit for 5 years.
2. Research recommendations		[Please provide details – e.g. trial name, potential publication date and relevant area/question in the guideline]

<p>Research recommendations</p> <p>Are you aware of any new evidence that answers research recommendations in the guideline?</p>	<p>Yes</p>	<p>There is further research on the epidemiology of CFS/ME in children including:</p> <p>Epidemiological characteristics of chronic fatigue syndrome/myalgic encephalomyelitis in Australian patients. Johnston SC, Staines DR, Marshall-Gradisnik SM. Clin Epidemiol. 2016 May 17;8:97-107. doi: 10.2147/CLEP.S96797.</p> <p>Chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) is associated with pandemic influenza infection, but not with an adjuvanted pandemic influenza vaccine. Magnus P, Gunnes N, Tveito K, Bakken IJ, Ghaderi S, Stoltenberg C, Hornig M, Lipkin WI, Trogstad L, Håberg SE. Vaccine. 2015 Nov 17;33(46):6173-7. doi: 10.1016/j.vaccine.2015.10.018.</p> <p>Two age peaks in the incidence of chronic fatigue syndrome/myalgic encephalomyelitis: a population-based registry study from Norway 2008-2012. Bakken IJ, Tveito K, Gunnes N, Ghaderi S, Stoltenberg C, Trogstad L, Håberg SE, Magnus P. BMC Med. 2014 Oct 1;12:167. doi: 10.1186/s12916-014-0167-5.</p> <p>Adolescent chronic fatigue syndrome: prevalence, incidence, and morbidity. Nijhof SL, Maijer K, Bleijenberg G, Uiterwaal CS, Kimpfen JL, van de Putte EM. Pediatrics. 2011 May;127(5):e1169-75. doi: 10.1542/peds.2010-1147.</p> <p>S Collin, K Tilling, C Joinson, K Rimes, R Pearson, R Hughes, J Sterne, E Crawley. Maternal and childhood psychological factors predict chronic disabling fatigue at age 13: A UK birth cohort study, Journal of Adolescent Health 2015 56(2): 181-187 doi: 10.1016/j.jadohealth.2014.09.002.</p> <p>S Collin, R Nuevo, E Van De Putte, S Nijhof, E Crawley. Chronic fatigue syndrome (CFS) or myalgic encephalomyelitis (ME) is different in children compared to in adults: a study of UK and Dutch clinical cohorts. BMJ Open 2015 Oct 28;5(10):e008830. doi: 10.1136/bmjopen-2015-008830.</p> <p>S Collin, T Norris, R Nuevo, K Tilling, C Joinson, J Sterne, E Crawley. Chronic Fatigue Syndrome at Age 16 years. Pediatrics 2016 Jan 28. doi: 10.1542/peds.2008-1536).</p> <p>There is also further evidence of the prevalence of CFS/ME in adults The prevalence of chronic fatigue syndrome/myalgic encephalomyelitis: a meta-analysis.</p>
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	Response	References and supporting information
		Johnston S, Brenu EW, Staines D, Marshall-Gradisnik S. Clin Epidemiol. 2013;5:105-10. doi: 10.2147/CLEP.S39876.
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	Whilst the patient community remain concerned about safety, recent Cochrane reviews suggest exercise therapy is safe and patients are more likely to improve with treatment.
Relevance Is the guideline still relevant to clinical practice and the organisation of care?	Yes	[Please provide details]