

Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management

(Oct 2020)

NICE National Institute for
Health and Care Excellence

Consultation on draft scope – deadline for comments by 5pm on 26 July 2018

email: CFSME@nice.org.uk

	<p>Please read the checklist for submitting comments at the end of this form. We cannot accept forms that are not filled in correctly or arrive after the deadline.</p> <p>We would like to hear your views on these questions:</p> <ol style="list-style-type: none">1. Which interventions or forms of practice might result in cost saving recommendations if included in the guideline? <p>Developing NICE guidance: how to get involved has a list of possible areas for comment on the draft scope.</p>
<p>Organisation name – Stakeholder or respondent (if you are responding as an individual rather than a registered stakeholder please leave blank):</p>	<p>Hope 4 ME & Fibro Northern Ireland</p>
<p>Disclosure Please disclose any past or current, direct or indirect links to, or funding from, the tobacco industry.</p>	<p>Nothing to disclose. No links of any type to the tobacco industry</p> <p>We would like to query why this disclosure is limited only to the tobacco industry? Surely disclosure should ask for all conflicts of interest; including but not limited to: links to drug companies, insurance companies, and/or financial gain from medical services.</p>

Name of person completing form:		Sally Burch	
Type		[for office use only]	
Comment No.	Page number or ' general ' for comments on the whole document	Line number or ' general ' for comments on the whole document	Comments Insert each comment in a new row. Do not paste other tables into this table, as your comments could get lost – type directly into this table.
Example	3	55	The draft scope currently excludes people who have already been diagnosed. We feel this group should be included because....

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1	1	4,5	<p>“Chronic Fatigue Syndrome” is a misnomer, that has caused harm to ME patients.</p> <p>“Chronic Fatigue Syndrome” as a name, gives the impression of simple ongoing tiredness. As a result, medical professionals are tempted to use the label too widely, and this neither helps the wrongly diagnosed individuals, nor those with a severe and complex presentation of ME. In short, the name Chronic Fatigue Syndrome causes the disease to be widely regarded as non-serious.</p> <p>In addition, the World Health Organisation (WHO) has a listing of Chronic Fatigue (ICD10-F48.0) and separately a listing of ME (ICD10-G93.3). The WHO recognises CF and ME as two separate entities, and we fear that maintaining the CFS name will perpetuate this problematical confusion.</p> <p>Therefore, we propose that the “Chronic Fatigue Syndrome” appendage to the name Myalgic Encephalomyelitis should be dropped entirely.</p> <p>Likewise “encephalopathy” as a variation on the ME name is unnecessary. “Myalgic Encephalopathy” was suggested at one point as a compromise, but it has not been well received by patients, and is not widely used in literature.</p> <p>Further the argument that the name Myalgic Encephalomyelitis does not perfectly equate with the disease presentation falls flat when considering other historic names, such as Malaria (which literally means “bad air”).</p> <p>A return to the name “Myalgic Encephalomyelitis” by NICE would be a positive step because:</p> <ul style="list-style-type: none"> a) Patients would appreciate this, b) NICE would be giving a strong message to the patient population that the disease is now being taken seriously and c) It would remove any doubt about this guide being applicable to patients presenting with simple long-term fatigue of unknown origin. <p><i>NOTE: For simplicity and clarity, the abbreviation ME will be used in this response to refer to the condition for which this guideline is being developed.</i></p>
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2	1	19	<p>The word “distressing” is a concern. If ME patients are “distressed” by their illness, this might suggest that ME is linked to the psychiatric construct of Bodily Distress Disorder or similar. We feel it goes without saying that any disabling disease is distressing, and therefore this word is misplaced within the description of ME and can be safely omitted.</p>
3	1	19-20	<p>The word “fatigue” despite being prefixed by “extreme and debilitating” is not a good word to describe ME. ME patients, are not simply experiencing fatigue, but instead they find they cannot function due to a plethora of disabling symptoms that occur, both as they try to perform normal daily tasks, and for an extended period afterwards. This is very different to “fatigue”.</p> <p>ME patients feel “ill” rather than tired or fatigued. In the same way that individuals off work with ‘flu would not say they were “tired”, so ME patients likewise do not regard their condition as primarily one of “tiredness” or “fatigue”. To be clear, our group feels that the word “fatigue” entirely misrepresents the condition.</p> <p>Descriptors that could replace the word “fatigue” could include: Lack of physical and cognitive stamina; Failure to function; Incapacity; Bodily weakness; ‘Flu-like symptoms; Inability to sustain effort; or even Rapid fatiguability.</p> <p>As a symptom, “fatigue” is much too common to be useful as a primary disease description.</p> <p>Suggestion for improving the sentence spanning lines 19 & 20:</p> <p>“ME is a disabling illness characterised by an extreme and debilitating lack of physical and cognitive stamina, particularly after exertion.”</p>

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4	1	21	<p>Illness Experiences: Whilst our group recognises that ME patients may not have a consistent presentation, we are concerned that the statement that ME is: “heterogeneous and multifactorial and people experience the illness differently”, takes away from any precision in attempting to properly describe the disease.</p> <p>Perhaps replace the sentence concerned with a much shorter one: “Clinically, ME may not present consistently at onset.”</p>
5	1	22 - 23	<p>Common symptoms: We would like to suggest that the following symptoms are added: Add: Post exertional exacerbation of all symptoms; noise and light sensitivity; muscle fatiguability; postural orthostatic intolerance; alcohol intolerance; and co-ordination issues.</p>
6	2	1 - 2	<p>Triggers: After stating that a virus is a commonly reported trigger, the scope says, “although the reasons for this being a trigger for ME/CFS are not understood.” Adding this phrase, completely negates the importance of the previous statement.</p> <p>We suggest the quoted words be deleted. The fact that the scope does not explain any link is sufficient to indicate the process is not yet fully understood.</p>

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7	2	2 – 4	<p>Aetiology: Whilst we agree that the aetiology of ME is not yet fully understood, it is not true that there is a complete “lack of understanding of the aetiology of the condition”, therefore this phrase is misleading.</p> <p>There are many aetiological factors currently described, to give just two examples: A clearly deficient 2nd day result on two-day cardiopulmonary exercise testing and Elevated levels of certain cytokines and other metabolites after exertion.</p> <p>It is of course true that current definitions of ME are mostly symptom based, and that these descriptive definitions are being used in both research and clinical care.</p> <p>We suggest the scope should note that the two definitions, most widely accepted for biomedical research, include the Canadian Consensus Criteria (CCC) and the International Consensus Criteria (ICC). We think it should also be noted that fatigue-orientated definitions such, as the Oxford criteria, are no longer regarded as appropriate for ME research.</p> <p>We suggest that this scoping document should mention the above 3 definitions by name, and perhaps also clarify that certain definitions, such as Oxford, have now fallen out of favour with medical scientists investigating ME aetiology because of their over inclusive and fatigue orientated nature.</p>
8	2	7	<p>Ongoing Research: Suggested additions: Gut biome, ATP synthesis, & muscle function.</p>

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9	2	11 - 13	<p>GPs: The scope states that “many GPs lack the confidence and knowledge to diagnose and manage ME/CFS”.</p> <p>Unfortunately, we find a number of local GPs think ME is a psychological condition undeserving of their time and effort. This is a major problem, which the CG53 guideline tends to encourage because of its huge emphasis on behavioural & rehabilitation type treatments.</p> <p>It is essential, in our view, that the new guideline should make a very strong statement to the effect that ME is an organic condition and that it has no underpinning psychological basis.</p> <p>We suggest that the scoping document include the following statement: “Many healthcare practitioners are operating under the false assumption that ME has no organic basis. This has led to an inappropriate attitude towards the care of ME patients”.</p> <p>Considering the massive impact of the biopsychosocial paradigm on ME care, and its capacity to ensure that many healthcare practitioners disregard the physical symptoms that their patients report, we feel it is important that the scope document should address these issues head on.</p> <p>Suggestions for the Guideline Committee to consider:</p> <ul style="list-style-type: none"> a) Adding ME to curriculum in medical schools* & also for trainee allied health professionals b) Continuous Professional Development modules to be offered to all existing practitioners c) Creating new posts for specialising in ME (GP specialists, Consultant specialists etc.) d) Removing from ME services, all clinics that specialise in behavioural rehabilitation. <p>However, it is vital that the individuals delivering educational services are aware of the full implications of the organic nature of ME, and of the extensive harms that can be caused by attempting to rehabilitate patients through psychological therapies or exercise regimes.</p> <p><i>*We surveyed 2nd year medical students in Queen’s University Belfast after a screening of UNREST, and they clearly stated the need for more information on ME during training.</i></p>
10	2	17	<p>Suggest replacing word “fatigue” on line 17 with “ill health”.</p>

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11	2	19 - 22	<p>Children: The issues in this section need to be more carefully described, so that a future guideline does not permit the problems that the previous CG53 guideline facilitated.</p> <p>Schooling: Without appropriate doctors' letters, schools are obliged to report long term pupil absences to social services, and if the doctor still does not properly explain the severity of ME, the parents get blamed for the children's absences. This can lead to child protection issues and the parents being effectively forced to send their children to school or risk facing court orders to remove their children.</p> <p>The dilemma is serious for parents: send the severely ill child to school thus worsening their condition, or risk losing custody of the child. No parent should have to face this on top of the issue of having a severely ill child. No child should be taken from his/her family at a time when they are most vulnerable. Yet it happens.</p> <p>This issue is one that the new guideline must specifically address in order to protect children from inappropriate removal from their family situations. The scope must allow for this.</p> <p>Treatments: When parents opt to refuse a NICE recommended treatment for their child, an issue can again arise with the medical establishment feeling that they know better. Parents should not have to accept NICE guidelines on marginally effective treatments. Medical professionals should not be allowed to over-rule parental discretion regarding treatments that are not in any way guaranteed to be effective.</p> <p>Again, this issue is one that the scope needs to specifically address in order to protect children from inappropriate and forced treatments.</p>
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<p>12</p> <p>Please add extra rows as needed</p> <p>Please return to: CFSME@nice.org.uk</p>	<p>2</p>	<p>23 - 28</p>	<p>CG53 Guideline: Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET)</p> <p>Our group is pleased to note that the scope states that “The evidence supporting these interventions has been challenged”. However, we suggest that the full extent of that challenge should also be recorded. Many highly respected scientists have declared the evidence base supporting these therapies, as effectively worthless due to the profound methodological flaws uncovered: not least the lack of blinding, alongside highly subjective outcome measures.</p> <p>We are pleased that the scope correctly notes that patients are “being pressured to participate in exercise programmes leading to a worsening of symptoms”. We believe this resulted from an over-confidence in these therapies, and a failure of the CG53 guideline to recognise that harm* may be caused.</p> <p>We suggest that the new guideline should detail the strength of the evidence supporting any treatment recommendations. This should include:</p> <ul style="list-style-type: none"> a) a proper description of the harms the treatment may cause, b) the degree of improvement that might on average be expected, and c) the “number needed to treat”. <p>This way patients can make a properly informed decision.</p> <p>*Note: We are concerned that CBT and GET were introduced without any means of officially recording adverse effects and that numerous charity complaints about therapy harms were dismissed, meaning that CBT & GET still remain as treatment recommendations to this day.</p> <p>Whilst we are pleased to note that the scope says: “There is therefore a need to review the evidence for these and other interventions”. We think “critically review” might be more appropriate, because there is much evidence to explore, both in terms of the complete papers themselves and the various critiques written by others.</p> <p>Considering the extensive harms from CBT and GET treatment practices reported by patient groups, we suggest that reviewing the place of these therapies in the current CG53 guideline, should be the urgent first task of the new guideline group.</p> <p>It is our view that these damaging therapies, based on the now completely de-bunked “fear avoidance and deconditioning” hypothesis for ME, should be urgently removed from clinical practice. Supportive counselling (to cope with lifestyle changes) and practical help (such as mobility aids) could be offered until such times as better treatment options become available.</p> <p>The adage “First do no harm” is paramount.</p>
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13	2	29	<p>Who is this Guideline for:</p> <p>Add: Benefit Agencies, e.g. Department of Work and Pensions</p>
14	3	20	<p>“Who is the Focus?”</p> <p>When considering ME as a whole, we suggest it is best to start with a consideration of Severe ME. It seems appropriate that ME guidelines should be written in with the aim of preventing those who have either Mild or Moderate ME from having their illness progress to Severe ME.</p> <p>This approach should be similar to how people presenting with minor symptoms of early cancer, are given appropriate treatment, and due respect, whilst their ongoing care is aimed at either curing the cancer or preventing the cancer from progressing.</p> <p>The potential for any ME patient to have their ME presentation progress to the severest form of ME should now be forefront in any discussion on ME care.</p> <p>Please can the draft scope include a statement such as the following:</p> <p>“The severest presentations of ME can result in patients existing in an almost comatose state for extended periods of time (sometimes years). These patients can: experience intermittent paralysis; unremitting pain; require tube-feeding; need 24-hour nursing care; be intolerant of light and sound; and generally, exist in a state described by many such patients as a “living death”. It is therefore essential that all ME patients are treated with the due respect, concern and care offered to patients with other similarly devastating diagnoses.”</p>
15	3	24	<p>Children and Young People:</p> <p>Please also see our comment #10</p>

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16	3	25	<p>People with Severe Symptoms: Please also see our comment #13</p>
17	5	5-6	<p>Related NICE guidance: Mental Health Problems We would like to query the addition of the NICE guideline CG123 for “Common Mental Health Problems: Identification and Pathways to care” in this list. Whilst we understand that people with ME may also present with mental health problems, we do not believe that this issue is specifically linked to ME, and thus this guideline is no more relevant to this scope than a guideline relating to cancer or heart disease.</p>
18	6	4	<p>Key Issues and Draft Questions Whilst we agree with all the questions listed in this section, we think that one crucial question must first be answered regarding ME. That question relates to the premise under which ME is to be treated.</p> <p>The CG53 guideline had a heavy emphasis on rehabilitative strategies. This approach to ME care strongly suggested to practitioners that an underlying psychological problem lay at the heart of ME aetiology.</p> <p>We think it is important that the scope adds a question that instructs the guideline committee to agree on the nature of the aetiology of ME before they proceed to making recommendations about ME care. It is not appropriate that the new guideline should have an approach that in any way confuses secondary or comorbid mental health issues, with the primary physiological issues faced by patients.</p> <p>Thus we suggest adding: Key Issue: The Nature of ME 1) Can it be agreed, that there is now sufficient evidence to declare ME an illness with an organic, physiologically based aetiology? 2) Can it also be agreed that ME should not be regarded as a psychosomatic disorder, treatable with therapies aimed at behavioural rehabilitation?</p>

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19	7	15 - 25	<p>Main Outcomes:</p> <p>If this section relates to the search for evidence published in medical and scientific journals regarding ME aetiology, treatment and care, then it seems that this guidance is rather lean.</p> <p>Surely there needs to be guidance relating to the type of evidence that is acceptable (or at least where the committee might find descriptions of acceptable evidence), and the sources from which that evidence should be obtained?</p> <p>We would expect that the guideline development committee will read extensively. We hope that when recommended therapies are to be based on the conclusions of any particular trial publication, that the full paper, along with any criticisms of the trial, are read and considered. This essential recommendation should be written into the scope.</p> <p>Our concern stems from the undue influence generated when the PACE trial (and its predecessors) used non-blinded trials with subjective outcomes to make CBT and GET appear more effective than they really are. Also, that critiques of this trial were effectively ignored.</p> <p>Regarding the various outcome measures listed, it is our view that objective outcome measures are of greatest importance in determining the success or otherwise of any potential treatment. Every trial considered as evidence should be critically reviewed to elucidate whether the methodology used, and the outcome measures recorded, might result in a bias that negates the stated conclusions. It is not sufficient to simply accept the authors' stated conclusions.</p>
20	7	18	<p>Quality of Life: We are concerned that subjective questionnaires should not be the only means of measuring life-quality outcomes. Objective measures should be explored.</p>
21	7	23	<p>Psychological Wellbeing: We are concerned that psychological wellbeing should not be one of the main outcomes for consideration. ME is not a psychologically based condition, thus psychological wellbeing should only be considered as secondary to the symptoms of ME.</p>

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22	General	General	<p>Specific question from NICE on this scope:</p> <p>“Which interventions or forms of practice might result in cost saving recommendations if included in the guideline?”</p> <p>Current guidance suggests CBT & GET are the most effective treatments. Both these therapies involve the significant cost of sending the patient to sessions with a specialist, and the result may, at best, only be a moderate improvement in functioning. Either therapy can also cause harm by persuading the patient to discount their symptoms. For many patients this has resulted in such harm, that they have had the course of their illness permanently worsened. This is not cost effective.</p> <p>Rest is Best. It would seem to us, that the best, and most economic, solution to this paradox would be to simply give new patients (after appropriate screening for other conditions) a period of prescribed rest. This might mean that, as soon as ME is suspected, a sick line for up to 6 weeks is written (or a shorter line offered, that can be updated by phone if required). Thus, the patient immediately starts a period of convalescence. The hope is that natural healing will avert the progression of the disease and allow the patient to self-heal.</p> <p>We think it is important to trust that patients are aiming to recover, and that this longer rest period will not be sought in as a means of evading work. It should also not be expected that this rest will necessarily be a curative process. If there has been no improvement after the six-week period of rest, it might then be appropriate to discuss with the patient how to adapt to a reduced lifestyle, and to offer counselling, and other support such as disability aids.</p> <p>Whilst no effective treatment for ME exists, and whilst the patient is remains unable to function due to the illness, no “rehabilitative” strategies should be considered. Many patients report that attempting to resume their previous lifestyle has lead to a permanent decline in their physical state. Rather the patient should be supported with the required assistance to obtain: appropriate benefits, insurance payouts, mobility aids and lifestyle adjustment advice.</p> <p>We would also like to suggest that Heart Rate (HR) monitoring of daily life activities is a useful practice, that can help patients to pace themselves. Heart rate monitoring was suggested in the old CG53 guideline but only for patients well on the way to recovery. We think it can help patients (except those with the the most extreme severity) to moderate what they attempt, and it will encourage appropriate rest periods when heart rate becomes elevated. The Workwell foundation suggested keeping HR below 60% of age calculated maximum heartrate. A number of our members have reported that HR monitoring has helped them to prevent further decline. A few have had a small degree of improvement which they attribute to heart rate monitoring.</p>
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23	General	General Suggestions for comments on a Scope taken from NICE website	<p>Take account of issues relating to treatment and care, or improving health and wellbeing, which are important for people affected by the guideline?</p> <p>We would like to point out again that it is important to our members that treatments on offer do not cause inadvertent harm. With that in mind we suggest:</p> <p>a) Immediate removal of CBT & GET from the treatment recommendations: The current therapies of CBT & GET are based on an outdated premise that ME patients are simply deconditioned, and over-sensitive to bodily symptoms. These therapies are also reported as harmful by a large percentage of patients. (See charity surveys from MEA and AfME)</p> <p>The urgent removal of these therapies is an issue of great importance for people affected by this guideline.</p> <p>We recommend that the scoping document ask that the new committee investigate these therapies immediately after convening for the first time.</p> <p>b) Investigate whether Anti-Depressants are less helpful than suggested. It has come to our attention that patients who are NOT feeling depressed are being asked to take anti-depressants because of a supposed benefit for ME.</p> <p>We suspect the reasoning is rather different and that these drugs are being prescribed on the basis that it is assumed that depression is the cause of the ME symptoms. Patients are also reporting that they are having extreme difficulty coming off these drugs once they have started.</p> <p>We suggest that the anti-depressants should not therefore be offered to patients when they present with ME. Should secondary depression occur then a new assessment can take place.</p>
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24	General	General Suggestions for comments on a Scope taken from NICE website	<p>Include medicines, procedures and other treatments or options for care (such as advice about lifestyle changes) that may be important for people affected by the guideline?</p> <p>Alongside a) Rest and b) Heart Rate monitoring (see point #21 above) we would also like to suggest:</p> <p>c) That the care of the most severely ill should be given prominence in the new guideline. A medical advisor to our group described these patients as equivalent to “a bed-bound quadriplegic” in their care needs. Examples of the extra care required could include: tube-feeding; sound and light proofing of living spaces; hoists; 24hour care; home visits and more if required. Currently the most severely affected ME patients have great difficulty accessing care.</p> <p>d) Moderately affected patients should not be discouraged from using mobility aids. Our members have often reported to us that their GP has told them not to use a wheelchair or mobility scooter as they will “become dependent”. Yet without mobility aids patients can become unable to leave their homes. We feel that appropriate support when discussing mobility aids would help patients to be more independent, thus reducing isolation and hopelessness.</p> <p>e) Dietary changes have helped some of our members. It seems that after ME onset, that some patients develop dietary intolerances eg to gluten. It would be useful if GPs could be supportive when a patient suggests that certain foods are now disagreeing with their digestive system.</p> <p>f) Drug intolerances. Patients often report that they react badly to new drugs. It might be useful for GPs to be aware that gradual introduction to a new drug is a good precaution.</p> <p>g) That, in the absence of realistic treatments, patients should be supported as they seek less conventional therapies. Thus, patients should be able to avail of nursing services such as having blood drawn to send for private tests. They should also not be criticised for attempting to find private treatments outside of the NHS. Patients should also be supported in seeking the benefits they require.</p>
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25	General	General Suggestions for comments on a Scope taken from NICE website	<p>Include treatments or other interventions that are currently used, but may not be effective, acceptable or tolerable to people using services?</p> <p>As already stated, it is our view that the currently offered treatments of CBT and GET, and the generalised advice from some GPs to “think positively” and “exercise more” are inappropriate.</p> <p>Also, as already mentioned, anti-depressants may not be appropriate.</p>
26	General	General Suggestions for comments on a Scope taken from NICE website	<p>Promote equality of opportunity regardless of age, disability, sex, gender identity, ethnicity, religion and belief, sexual orientation and socioeconomic status?</p> <p>We have noticed that patients who are of higher socioeconomic status (eg people working in a professional capacity, or attending University) have a better chance of being taken seriously by their GP. It is unfortunate that those of lower socioeconomic status (eg unemployed, or employed in a series of short term, or part time jobs) have a greater difficulty being heard by their GP.</p> <p>There seems to be an implicit assumption that those of lower socioeconomic status are more likely to be malingering or seeking benefits by exaggerating their physical impairments.</p> <p>Another bias we have noted is that those who are overweight or obese, are generally given less respect when they make observations about their physical health. They are often told that losing weight will reverse ME, when in fact there is no evidence to support this.</p> <p>The scope should ensure that these issues are considered, so that the guideline can advise GPs to set aside discriminatory biases when making an assessment of the patient’s condition.</p>

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27	General	General Suggestions for comments on a Scope taken from NICE website	<p>Identify other major projects related to this topic (such as promotional campaigns) that should be used when developing the guideline?</p> <p>Media: In recent years there have been a plethora of media articles suggesting that ME patients could recover if only they could “think positively” and “exercise more”. This has had a devastating effect on the patient/practitioner relationship. Many health care practitioners are swayed by this inaccurate media portrayal of ME patients.</p> <p>A promotional campaign to reframe ME as a serious and debilitating organic disease, would therefore seem appropriate. It is important that this campaign is directed not only at the general public, but also at all Health Care Practitioners.</p> <p>Research: Research into treatments for ME has been hampered over the past years by a lack of funding, and a tendency for UK funders to favour subjective studies based on psychosocial therapies. If NICE has any influence, then this needs to change.</p> <p>A campaign to promote increased funding for biomedical research into the physiology of ME should therefore be launched.</p>
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