National Institute for Health and Clinical Excellence
CFS/ME consultation draft
29 September – 24 November 2006
Comments on chapter 5

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SH	25% ME Group	132	FULL	88	1-25	The diagnostic criteria are something of a dustbin: with fatigue plus one other symptom. This will therefore include such conditions as burn-out, stress and somatisation disorders. Actual M.E. may well be a minority condition within this umbrella. Bear in mind that fatigue is often one of the lesser symptoms of the condition – the main symptoms are usually muscle pain, severe headaches, cognitive problems and sleep disturbance. These criteria are therefore totally naïve and unacceptable and must have been compiled without reference to qualified researchers in the bio-medical field. The GDG need to highlight the	Issue 1 – Diagnostic criteria:The intention is to raise awareness that the individual may have CFS/ME to manage symptoms at an early stage prior to a diagnosis. We have redrafted this section in order to make this clearer. Issue 2 – Lack of clear definition:

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						difficulty posed by the lack of clear definition in research and other papers between 'chronic fatigue, Chronic Fatigue Syndrome, and ME.' This must be recognised as an important block in accepting the findings of research in to CBT and GET. While we know that there is not as yet a diagnostic test for M.E., there are objective tests that fit a diagnostic signature and provide good circumstantial evidence. One such test may be a SPECT scan. For MS diagnoses, MRI scans are used, even though it is known that these are not definitive. So, where there is a serious doubt by a clinician over a diagnosis of M.E,. I feel the guidelines should suggest the use of SPECT scans to assist in	This section has been revised. Issue 3 – SPECT scans: No evidence was found for the use of scans. If evidence arises, it will be considered in the revision of the guideline. Issue 4 Patient Access - The publication and implementation of a national guideline on CFS/ME with the accompanying document 'Understanding NICE guidance' will raise awareness of the condition and give both patients and health care

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						diagnosis. M.E.-friendly paediatricians are currently reporting a worrying trend in diagnosing Munchausen's by Proxy. In such circumstances the parents/carers of sufferers ought to have access to equipment and tests that may vindicate them.	professionals access to information on recognising and managing CFS/ME.
SH	25% ME Group	133	FULL	88	1-25	http://www.investinme.org/Documents/PDFdocuments/Byron%20Hyde%20Little%20Red%20Book%20for%20www.investinme.org.pdf SEE PAGE 2-3 **A new and simple definition of Myalgic Encephalomyelitis and a new simple definition of Chronic Fatigue Syndrome** As presented at the Invest in ME London Conference of May 12,	We have revised the relevant chapter and recommendations to clarify the diagnosis process. The submitted evidence, however, does not meet our inclusion criteria, so although considered, has not been added to the evidence review.

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						2006 by Byron Hyde MD: ME/ ICD-CFS is a multi-system disorder, one form of which can be associated with enteroviruses related to the poliomyelitis virus. Virally-induced ME used to be known as "atypical poliomyelitis". There are acknowledged similarities and overlaps between ME and the post-polio syndrome (PPS), particularly concerning the nature and source of the pathophysiology, including virological evidence that enteroviruses persist in the human central nervous system. Specifically, the mechanism of the incapacitating exhaustion is identical in the two conditions (ie. in ME and PPS). In ME there are chronic sequelae and the effects may be neurological, hormonal,	

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						autoimmune and myalgic, which may include the myocardium.	
SH	25% ME Group	134	FULL	88	4	Myalgic Encephal**opathy** is not a terminology that is acceptable or registered with WHO.	The title of the guideline was amended to 'Chronic fatigue syndrome/myalgic encephalomyelitis (encephalopathy)' in response to the scope consultation with stakeholders.
SH	25% ME Group	135	FULL	88	5	*"Reaching a diagnosis can be a particular problem*" According to Professor Rachel Jenkins, Principal Medical Officer, Department of Health and herself a psychiatrist, this is not necessarily so. It will be recalled that in 1991 she stated: *"Once one is familiar with (the disorder), such patients are in practice not too difficult to differentiate from those with true psychiatric illness such as depressive illnesses, anxiety,*	Issue 1 – Reaching a diagnosis: This section has been revised.

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						hypochondriasis or hysteria. The physical symptoms should be an aid to diagnosis, although they may be wrongly attributed to primary psychological illness unless care is taken in eliciting them" (Assessment and Diagnosis of ME in the Psychiatric Clinic. Rachel Jenkins. BMB 1991:47:4:241-246) Further, correct diagnosis would be less difficult if the international research evidence were to be made available to UK physicians in the UK medical journals instead of being deliberately suppressed, dismissed and misrepresented by the psychiatric lobby (as has been shown to be the case for the last two decades).	Issue 2 – Research evidence: The international research literature was searched. Please refer to Appendix 1.
SH	25% ME Group	136	FULL	88	18	*"CFS/ME cannot be diagnosed by*	No evidence was found for a definitive

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						any test currently available" That may be true for "CFS/ME" but it is not true for ME/CFS: although there is as yet no single, definitive and specific test, there is a recognised pattern of reproducible abnormality on the appropriate testing that, if positive, is virtually diagnostic.	set of tests.
SH	25% ME Group	137	FULL	88	25	The phrase 'will also share' implies that the clinician will understand the patient's worries, whereas with CFS/M.E. misunderstandings are common e.g. the doctor may think that it is a relief if the patient is found not to have cancer, but for someone who is severely affected they may be more worried about having CFS/M.E.	This has been reworded to reflect these concerns.

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SH	25% ME Group	138	FULL	90	Box	*"Evidence Statements: there is limited evidence for a wide range of risk factors including higher social class in childhood"* This is untrue: there is ample published evidence that ME/CFS affects all social classes	This is an evidence statement which is a statement that synthesises the evidence findings. However, because of the lack of utility of this evidence statement, this has been deleted.
SH	25% ME Group	139	FULL	104	5.3.8	**Myalgic Encephalomyelitis has nothing to do with 'fatigue'** If you are tired all the time, you do not have ME. The terms 'fatigue' and 'chronic fatigue' were not associated with this illness at all until the name Chronic Fatigue Syndrome was coined in 1988 (this despite the fact the illness had already been legitimately named Myalgic Encephalomyelitis in 1956) (Hyde 2005, [online]). The 'f' word was selected in 1988 entirely for	The GDG considered that we should accept that ' Chronic Fatigue Syndrome', rightly or wrongly, is now well established in the medical and scientific vocabulary, as well as in common English usage. A pragmatic decision was taken therefore to use CFS/ME as there seemed little point in departing from the accepted 'CFS/ME' terminology (also supported by use in many other reports}.

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						what it could achieve politically: it was never intended to be a genuine medical description of the symptomatology of the illness. In reality having M.E. is like having parts of Multiple Sclerosis, AIDS, Alzheimers, Arthritis and Epilepsy all mixed together at once, with some extra horrific symptoms thrown in that are entirely its own. M.E. is a neurological illness of extraordinarily incapacitating dimensions that affects virtually every bodily system – not a problem of 'chronic fatigue.' **Fatigue is a symptom common to hundreds of diseases and to normal life, but is not a distinguishing feature of Myalgic Encephalomyelitis.**	

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						The most apparent features are extreme post-exertional muscle fatiguability, which is quite distinct from chronic "fatigue" or tiredness, together with recurrent nausea and profound, incapacitating malaise. It is striking how consistent are the symptoms that characterize this condition. The exhaustion experienced by patients is extreme: "the disabling weakness and exhaustion a patient with ME / ICD-CFS experiences is so profound that "fatigue" is probably an insult".	
SH	25% ME Group	140	FULL	105	Box	*"The following should be regarded as 'red flags', indicating suspicion of serious underlying pathology: abnormal neurological signs (and) features of cardiovascular problems"*	The 'red flags' are to alert clinicians to other serious conditions that may have similar presenting symptoms.

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						There is abundant published evidence of substantial neurological deficit in the ME/CFS literature. Both neurological signs and cardiovascular abnormalities are well-documented features of ME/CFS and the Draft Guideline acknowledges on page 112, lines 2/3/4 that the Canadian definition requires such features to be present. *"before diagnosis of CFS/ME, assessment of mental health should be carried out"* ME/CFS is just as much a physical disorder as cancer, lupus or multiple sclerosis, in none of which is a mental health assessment obligatory before diagnosis, so why is there special pleading for	We have recommended that an assessment of psychological wellbeing be targeted to symptoms, so is not an obligatory assessment, but is targeted as appropriate.

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						ME/CFS?	
SH	25% ME Group	141	FULL	106	2nd box	Instinctively, all patients yearn to get back to a previous (better) level. To say that 'advice should focus on …a gradual return to a normal daily routine' belittles the severity of the condition and implies that setting the goal of recovery is sufficient to induce it.	Noted. This wording has been changed.
SH	25% ME Group	142	FULL	107	5.2.8	The evidence is there, and to deny it is to deny reality. However, it is easier to deny the evidence if the tests necessary to prove these anomalies are proscribed. For example, the Draft Guideline specifically recommends (5.2.8, page 107) that serology testing for viral or bacterial infections (including other chronic and latent infections) should not be carried	We have revised the recommendations to emphasise the role of investigations in diagnosis, including the role of serology testing.

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						out, yet Professor Maes et al (see above) recommend that all patients with ME/CFS should be checked by means of the IgA panel, which is another test that is not approved in the Draft Guideline. Equally, in cases of suspected ME/CFS, informed clinicians believe that patients should be tested for borreliosis, one of most important differential diagnoses, yet this, too is proscribed, despite the fact that a leading UK microbiologist recognises that some people who are thought to have ME/CFS may actually have borreliosis. As BADA (Borreliosis & Associated Diseases Awareness: www.bada-uk.org) points out, it is recognised by the scientific establishment that Borrelia is able to evade immune	

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						surveillance. Lyme Disease (LD) may be misdiagnosed as multiple sclerosis, ME/CFS or other autoimmune disorders. The symptom list for ME/CFS and for borreliosis has considerable overlap, for example: fatigue, myalgia, migratory joint pain, neuropathy (including numbness, tingling, burning and itching, hypersensitivity), tremor, muscle twitching, vision problems such as double vision, photophobia, hyperacusis, balance problems and vertigo, severe startle factor, NICE-term memory loss, sleep disturbance, cardiac arrhythmia, tachycardia, nausea / vomiting, adrenal dysfunction and immune system disturbances.	

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						To reiterate: the longer the tests that reveal serious (but sometimes treatable) organic pathology continue to be disallowed, the longer the psychiatric paradigm will prevail and patients will continue to be neglected and abused by some members of the medical profession. There are many illustrations of the biomedical problems in ME.Please see [my comments elsewhere]	
SH	25% ME Group	143	FULL	111	27-28	It is widely accepted in the ME community and researchers looking at ME, that the Canadian criteria are much more reliable in diagnosing true ME	The evidence review concluded that no current case definitions are established as being superior to the others. The Canadian criteria are based on expert opinion, and not research evidence.
SH	25% ME Group	144	FULL	124	Box	*"some will recover FULLy"* This is misleading, as the statistics show that only 4% had FULL	Noted and reworded.

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						remission (not recovery) at 24 months (US CDC statistics	
SH	25% ME Group	145	FULL	124	12-16	It must be remembered that NICEis preparing Guidelines for ME, not a broad spectrum of chronic fatigue conditions. So it is important that a more precise diagnostic tool; like the Canadian criteria is used to diagnose true ME	The diagnosis recommendations have been revised. The evidence review concluded that no current case definitions are established as being superior to the others. The Canadian criteria are based on expert opinion, and not research evidence.
SH	25% ME Group	146	FULL	124	4-16	Taken from: Handbook of Chronic Fatigue Syndrome by Leonard A. Jason, Patricia A. Fennell and Renée R. Taylor) The physician and patient alike should remember that CFS is *not* a disease. It is a chronic fatigue state as described in four definitions	Noted.

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						starting with that published by Dr. Gary Holmes of the CDC and others in 1988 (Holmes, Kaplan, Gantz, et al., 1988; Holmes, Kaplan, Schonberger, et .al., 1988). The definition created by Lloyd, Hickie, Boughton, Spencer, and Wakefield (1990) is also widely used in Australia. There are two subsequent definitions. The Oxford definition of 1991 (Sharpe et al., 1991) and the 1994 NIH/CDC definitions (Fukuda et al., 1994) are basically, with a few modifications, copies of the first definition. Whereas the one essential characteristic of ME is acquired CNS dysfunction, that of CFS is primarily chronic fatigue. By assumption, this CFS fatigue can be acquired abruptly or gradually.	

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						Secondary symptoms and signs were then added to this primary fatigue anomaly. None of these secondary symptoms is individually essential for the definition and few are scientifically testable. Despite the list of signs and symptoms and test exclusions in these definitions, patients who conform to any of these four CFS definitions may still have an undiagnosed major illness, certain of which are potentially treatable. Although the authors of these definitions have repeatedly stated that they are defining a syndrome and not a specific disease, patient, physician, and insurer alike have tended to treat this syndrome as a specific disease or illness, with at times a potentially specific	

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						treatment and a specific outcome. This has resulted in much confusion, and many physicians are now diagnosing CFS as though it were a specific illness. They either refer the patient to pharmaceutical, psychiatric, psychological, or social treatment or simply say, "You have CFS and nothing can be done about it."	
SH	25% ME Group	147	FULL	126	1	*"Spatial disorientation is not Generally characteristic of CFS/ME and is indicative of brain damage"* Spatial disorientation is documented in the ME/CFS literature: see, for example: □ Neuropsychological Deficits in CFS. Sheila Bastien. CFIDS Chronicle Fall 1989:24-26	Noted but is not characteristic.

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						(abnormalities consistent with organic brain syndrome) □ Alteration of spatial-temporal parameters of gait in CFS. Saggini R et al. J Neurol Sci 1998:154:1:18-25 (abnormalities consistent with involvement of the central nervous system) □ Patterns of Neuropsychological Abnormalities and Cognitive Impairment in Adults and Children. Sheila Bastien. In: the Clinical and Scientific Basis of ME/CFS; ed. BM Hyde, J Levy and Paul Levine; pub. The Nightingale Research Foundation, Ottawa, 1992: 453-460 □ Neuropsychological Function in	

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						Patients with Chronic Fatigue Syndrome, Multiple Sclerosis and Depression. Ella Daly, Anthony Komaroff et al. Applied Neuropsychology 2001:8(1):12-22 (spatial abnormalities consistent with brain alteration in ME/CFS	
SH	25% ME Group	148	FULL	126	1-3	In Moderate and severe ME spatial disorientation is a problem. Many cannot drive, walk through door ways etc properly because of this symptom	Noted but is not characteristic.
SH	25% ME Group	149	FULL	126	20	'… dependant **on** the …'	Revised.
SH	25% ME Group	150	FULL	133	16	*"There is little understanding of the nature of the disease"* This is an astonishing statement, as there is a significant body of scientific literature that documents	We have followed the findings of the Gibson Inquiry, which has concluded that no current theory of causation is supported by sufficient evidence to gain general acceptance. We agree that

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						the multi-system, multi-organ dysfunction that over the last 50 years has been demonstrated in ME/CFS (for example, the vascular abnormalities that have demonstrated a novel finding not seen in any other known disorder.)	more high quality biomedical research is required.
SH	25% ME Group	151	FULL	133	17	*'A view held by a few individuals on the GDG was that CFS/ ME could not be identified or managed unless a broader view was taken, This perspective is put forward below.'* Why are the views of only a 'few' (which is a vague number) allowed to dominate this document? What about other views?	The framework has been revised in the light of the comments received.
SH	25% ME Group	152	FULL	133	20	Line 20 onwards refers again only to CFS. , not to ME. Are we to believe that not all the document actually is referring to and therefore	This has been revised.

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						aimed at helping people with ME? If this is so, it needs to be made clear. Also, if only a broad view is taken, then the real needs of people with ME are in danger of being dismissed or overlooked or not seen. By taking a wide view and a limited criteria to define the illness, this is almost certainly what will happen.	The GDG wants to encourage the provision of services to all who could benefit. Current understanding of the nature of CFS/ME is insufficient to justify tight criteria that exclude some people from potentially helpful therapies.
SH	25% ME Group	153	FULL	133	24-25	*"there are no objective abnormalities to account for the illness experienced"* This is untrue: there are numerous indisputable abnormalities, but these are seen only on appropriate testing, not on basic screening (which is the only permitted level of investigation on ME/CFS patients in	This issue is now clarified in the text.

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						the UK NHS).	
SH	25% ME Group	154	FULL	133	16 & 24-25	These statements are absolutely not true. NICEGDG need to read the research, see the biomedical evidence for this illness. There is overwhelming research to show the abnormalities in MYALGIC ENCEPHALOMYELITIS, unless the majority of the group is only reading and accepting the mis-information from the psychiatrists and the very weak 'evidence based medicine' that they present? It is critical to the issue that the people making up these guidelines only reflect one viewpoint which is held and promoted by a few very vociferous people who have a lot to gain by promoting this and a lot to lose when the truth is finally	In considering the explanation for CFS/ME, we have followed the report of the Gibson Inquiry, which accepts that there is insufficient evidence to fully substantiate any of the current theories of causation, and that more high quality biomedical research is needed. The framework has been revised to make this clear.

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						accepted. And that time is surely getting close.	
SH	25% ME Group	155	FULL	134	14-16	*"CFS has been described as part of a broader condition that includes a range of disorders including fibromyalgia, irritable bowel syndrome…."* There is no doubt that this statement is here intended to refer to somatisation disorder but there is no credible evidence to support such an assertion: it is singularly unscientific and is merely the belief of the Wessely School psychiatrists. There is, however, a school of thought that believes such disorders may all be metabolic or neuro-immune in origin.	This section has been revised. We seek to acknowledge that different people hold different views on causation, and sometimes these views are strongly held. Since we do not know what the cause of CFS/ME is, the GDG cannot accept any of the current theories, but must instead encourage more basic research and encourage those who hold strong views to take a more tolerant, open-minded attitude to ensure that patients who may benefit from various interventions do have access to those interventions.

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SH	25% ME Group	156	FULL	134	25-26	*"Terminology used by doctors such as 'functional syndrome' and 'medically unexplained symptoms' are part of common usage in clinical practice today".* Such terms are used in relation to perceived psychiatric disorders only, never to medical disorders	See response above.
SH	25% ME Group	157	FULL	134	27	*"The terms have arisen to describe non-conventional diseases"* ME is not a 'non-conventional' disease: it is a formally classified neurological disease and has been so since 1969.	The wording has been revised.
SH	25% ME Group	158	FULL	135	1-5	ME is a distinct disease from the 'medically unexplained' conditions that are referred to by psychiatrists and often show clear medical problems that have been recorded	The GDG accepts the Gibson Inquiry's conclusion that no current theory on the causes of CFS/ME is, as yet, supported by sufficient evidence, and that further biomedical research is necessary. This section has been revised and is

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						In a separate response to NICEsome of these anomalies were laid out. **Problem: Continued refusal to heed the biomedical evidence that disproves the biopsychosocial model of ME/CFS pages 5-8** No matter how much biomedical evidence about ME/CFS is submitted to UK official bodies, it is ignored, even when sent by Recorded Delivery. For illustrations of what has been submitted to various official bodies over the years, see the www.meactionuk.org.uk website. The only feasible conclusion is that no biomedical evidence, however relevant to ME/CFS patients'	intended to recognise that different people hold different views about the cause(s) of CFS/ME, and to encourage more biomedical research.

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						wellbeing, will be allowed to displace the pre-determined agenda of imposing CBT/GET on patients diagnosed with "CFS/ME", nor will biomedical evidence be allowed to displace the determination of the influential psychiatric lobby to re-classify ME as a behavioural disorder by subsuming it within the heterogeneous term "CFS/ME", the intention being to drop the term "ME" as soon as expediently possible, thereby achieving the long-held goal of "eradicating" ME (see page 20 below). There can be no acceptable rationale for this continued ignoring by Government bodies of the evidence that ME/CFS is a multi-system, multi-organ disorder at endothelial level ie. that it is an	

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						inflammatory-mediated response causing endothelial swelling and arterial stiffness with hard evidence of raised isoprostanes not seen in any other known disorder. Although the precise cause is yet to be determined, the symptoms of ME/CFS are not, as stated in the Draft Guideline (page 135, line 1), "medically unexplained": as noted in our article "ME Exists: True or False?", it remains beyond reason that the existence of so many documented abnormalities in people with ME/CFS should simply be disregarded and denied, including the following: □ abnormalities of the central nervous system include abnormalities of brain cognition,	

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						brain perfusion, brain metabolism and brain chemistry; there is evidence of low blood flow in multiple areas of the brain; neuro-imaging has revealed lesions in the brain of approximately 80% of those tested and according to the researchers, these lesions are probably caused by inflammation: there is a correlation between the areas involved and the symptoms experienced; abnormalities on SPECT scans provide objective evidence of central nervous system dysfunction; there is evidence of a chronic inflammatory process of the CNS, with oedema or demyelination in 78% of patients tested; there is evidence of a significant and irreversible reduction in grey matter volume (especially in Brodmann's	

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						area 9) which is related to physical impairment and may indicate major trauma to the brain (which could also explain the low recovery rate); there is evidence of seizures; a positive Romberg is frequently seen in authentic ME/CFS patients.	
SH	25% ME Group	159	FULL	135	1	There can be no acceptable rationale for this continued ignoring by Government bodies of the evidence that ME/CFS is a multi-system, multi-organ disorder at endothelial level ie. that it is an inflammatory-mediated response causing endothelial swelling and arterial stiffness with hard evidence of raised isoprostanes not seen in any other known disorder. Although the precise cause is yet to be determined, the symptoms of	Review of evidence about the cause of CFS/ME was outside the scope of the guideline. We follow the report of the recent Gibson Inquiry, which has looked at this question in some detail.

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						ME/CFS are not, as stated in the Draft Guideline (page 135, line 1), "medically unexplained": as noted in our article "ME Exists: True or False?", it remains beyond reason that the existence of so many documented abnormalities in people with ME/CFS should simply be disregarded and denied, including the following:	
SH	25% ME Group	160	FULL	135	4	"*The mental or physical condition debate predominates in the clinical encounter undermining the doctor patient relationship."* This debate is important because the psychiatric lobby has introduced confusion by its involvement in a neurological illness and thus of course the relationship will be undermined if a patient is being	We hope the revised wording in this section is helpful.

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						seen by someone who actually believes the underlying reason for the illness is 'misguided illness belief.' This seems quite reasonable to me.	
SH	25% ME Group	161	FULL	135	16	*'The definition and concept of CFS through a biopsychosocial model acknowledges the role of both external and internal influences on the development of and recovery from CFS. The Biopsychosocial model negates the duality of mind and body and a significant cause of conflict between the patient and the healthcare professional.* The biopschosocial model negates the true neurological illness that ME is and the complexity of symptoms.It implies it does not matter what the cause is. If doctors	This section has been revised. We follow the Gibson Inquiry's conclusion on the causes of CFS/ME.

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						believe that ME is purely psychiatric this will impact negatively on the relationship. It cannot be covered over. Also this reference only refers to CFS not ME. It has not even said CFS/ME. So who exactly is this document for? Not, it appears for people with neurological Ramsay defined ME?	It should have been CFS/ME – this has now been corrected.
SH	25% ME Group	162	FULL	135	1-24	P135 lines 1 - 24 are again only referring to CFS. Is this because it is actually inappropriate recommendation for ME? The changing from CFS to CFS/ME is confusing and inconsistent and needs addressing.	This was an error, and should have been CFS/ME as elsewhere in the guideline.
SH	Action for M.E.	29	FULL	104	5.2.8	"Primary healthcare professionals should be familiar with the	The aim of the recommendation is to encourage training in this area to avoid

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						presenting features of CFS/ME..." recent research indicates that this is not the case. Some reference to primary healthcare training would be helpful. (Ref: Primary healthcare provision and Chronic Fatigue Syndrome: a survey of patients' and General Practitioners' beliefs. BMC Family Practice. 6:49, 2005) The list of symptoms does not delineate all of those which can be experienced by people with M.E./CFS, particularly by those with severe M.E. Pain is a significant problem for many people with M.E./CFS and this needs to be noted (in both sets	this happening in future. We have given guidance on broad criteria to alert the clinician to the possibility of CFS/ME, not for use as diagnostic criteria specifically. This has been clarified in the guideline. Re pain – we have added a recommendation on the need for appropriate pain management

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						of guidelines). We would like to see the healthcare provider be required to direct the patient to an appropriate form of pain management.	
SH	Action for M.E.	30	FULL	106	5.2.8	Risks of prolonged bed rest: while this is accepted wisdom, constituents, particularly those with severe M.E., felt this was unhelpful, if not dangerous, to their condition. Indeed, some constituents with milder forms of M.E. have also expressed concern that the guidelines emphasise the need for exercise without necessary provisos (in relation to need, appropriately qualified practitioners etc.). In response to our online survey, 34.3% strongly agreed and 37.2% agreed that rest and minimal activity	Prolonged bed rest: This section has been changed to make it clear that this area of the guideline refers to pre-diagnosis.

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						- at levels well below FULL capacity - help people with severe M.E./CFS to manage their illness. And when asked, during a setback, Activity Management should be maintained but not include prolonged rest unless absolutely necessary, 46.3% strongly disagreed and 27.8% disagreed with this statement. These differing views need to be addressed.	
SH	Action for M.E.	31	FULL	107		The number of recommended tests is limited. For example, it seems illogical that the test for Creatinine Kinase is limited to children only.	Noted, but the list is not intended as a definitive, complete list, as clinical judgment should be exercised.
SH	Action for M.E.	32	FULL	110	5.3.1.1-5.3.1.3	Criteria: The guidelines state "No studies have established the superiority of one case definition over another". Given this, there is patient support for the Canadian	Noted and we have revised the diagnosis recommendations to clarify.

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						Guidelines; and many have felt dismayed at the wider definition of M.E./CFS used. While we acknowledged an understandable desire to ensure no one falls through the net, there is a need for clearer case definition. Given that recent research has indicated that GPs are not confident about making a diagnosis, greater detail re. diagnosis would seem logical. It would also be helpful if there were a recommendation for research into case definition.	The GDG have made research recommendations according to the NICE methods (see the Guidelines Manual for details)
SH	Action for M.E.	33	FULL	116	5.3.4 ln7	The assumption that the patient can refuse treatment without compromising the therapeutic relationship needs to be stated as a	Noted and we will pass the information on to NICE.

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						requirement in all guidelines.	
SH	Action for M.E.	34	FULL	124	5.3.6	We appreciate the concerns of the GDG re. ensuring an early diagnosis and the accompanying problem of a false diagnosis. This would lead one to presume that a recommendation of biomedical research and research into subsets would be appropriate (see P28 FULL guidelines).	The GDG have made research recommendations according to the NICE methods (see the Guidelines Manual for details)
SH	Action for M.E.	35	FULL	126	4-6	Sleep apnoea merits prompt investigation and referral - This is not expressed as clearly or with the same urgency in the NICEer guidelines (see NICEguidelines P27, 1.3.2.4)	The investigation and referral of sleep apnoea is outside the scope of this guideline.
SH	Action for M.E.	36	FULL	132	5.4.5.1	The partnership approach between patients and healthcare	Thank you.

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						professionals is welcomed.	
SH	Action for M.E.	37	FULL	132	5.4.5.2	These recommended timeframes for referral were Generally well received. Our survey found that 44.3% strongly agreed, and 35.9% agreed, that adults and children with mild M.E./CFS should be referred within 6 months. This rose to 58% strongly agreeing and 29.3% agreeing that the moderately affected should be referred within 3-4 months; and increased to 69.8% strongly agreeing and 19.1% agreeing that the severely affected should be referred immediately.	Thank you.
SH	Action for M.E.	38	FULL	133 – 135	5.5	We expected reference to the WHO definition, or the Department of Health's classification of M.E. as a long-term, neurological illness to be made.	We have revised this section and hope the changes make the views of the GDG clearer.

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						NICE's implicit rejection - given here - of the psychosomatic viewpoint is extremely important. This position needs to be made crystal clear and included in the NICEguidelines. The emphasis on using appropriate language and sensitivity in dealing with patients is welcomed. Feedback we have received, however, indicates that there are still major problems in terms of how health practitioners relate to people with M.E/CFS. Some reference to training in relation to this would be helpful. Our constituents would welcome a clearer acknowledgement by health professionals that: a) the illness is a real, physical illness; and b)	

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						M.E./CFS is not a somatic condition. Again, a clear statement by NICEis required here.	
SH	Association for Psychoanalytic Psychotherapy in the NHS (APP)	13	FULL	115	table	because the costs of counsellors have not been included - even though elsewhere (p. 269) a study is quoted which analyses these costs - the wrong conclusion has been arrived at - that specialist care is as cost effective (for all cases) as primary care - why is this stated when it is not true?	This section in the consultation draft did not state that specialist care was cost-effective. However, it was felt that this crude estimate of cost implications was not conclusive and this section has consequently been revised.
SH	Association for Psychoanalytic Psychotherapy in the NHS (APP)	15	FULL	135	6-20	given the emphasis on the importance of establishing a good therapeutic relationship, it is surprising that no reference is included here to the role of the practice counsellor - why is this?	The potential of counselling in supporting patients was considered in the reviews of evidence about the effectiveness of different interventions, discussed elsewhere in the guideline.
SH	Association of	9	FULL	88	9-10	By definition, fatigue is always the	The sentence relates to fatigue and

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	British Neurologists					hallmark feature of CFS/ME (major criteria): can the GDG offer appropriate citation to their claim that "fatigue and pain are not always the prominent features"? Perhaps they are talking about a different condition rather than CFS/ME	pain at onset of the condition. The sentence has been reworded so that this is now clear.
SH	Association of British Neurologists	10	FULL	90	5	Preceding infection is a clear risk factor for CFS/ME and there are epidemiological studies showing clear link of CFS/ME to infections other than just infectious mononucleosis	The GDG did not consider that the evidence of a link of CFS/ME to specific infections was convincing.
SH	Association of British Neurologists	11	FULL	104		GDG is neither competent nor empowered to redefine CFS/ME by using only one of all the minor criteria: by doing so, the group is tactically promoting Oxford criteria over the more widely used and	The GDG have not attempted to define CFS/ME, e.g. for research purposes, but instead have provided clinical indicators which should raise suspicion of the condition.

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						recognised international (modified CDC) criteria-again, a clear evidence of psychiatrists' influence on this group.	
SH	Association of British Neurologists	12	FULL	104		Specifically, why the symptoms of "dizziness, nausea and palpitations" (last bullet point) have been included as one of the criteria and what is the research evidence to do so?	The experience of the members of the GDG were that these symptoms were common.
SH	Association of British Neurologists	13	FULL	106		Ferritin level should be routinely measured in all women of child bearing age as recent iron-deficiency may present without hypochromic anaemia	The GDG did not consider that estimation of serum ferritin provided information over and above that provided by full blood count in adults and therefore did not include it as a recommended screening test (though it could be undertaken at the discretion of the diagnosing physician).
SH	Association of	14	FULL	107		Creatinine Kinase should be	Noted and revised.

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	British Neurologists					routinely done both in the adults and in children, as it is an important biochemical test to identify primary and metabolic muscle disease presenting as fatigue, post-exertional malaise and myalgia from CFS/ME.	
SH	Association of British Neurologists	15	FULL	109		In selected cases, neurological opinion and formal brain imaging (MRI) may be required to exclude multiple sclerosis which may present with fatigue, pain and related symptoms very similar to CFS/ME	Abnormal neurological signs are stipulated as requiring further investigation. The GDG did not consider that fatigue or muscle pain in the absence of abnormal neurological signs or a history suggestive of MS merited a recommendation for brain imaging.
SH	Association of British Neurologists	16	FULL	126	19 -23	Given that a proper neurological examination is mandatory for patients with suspected CFS/ME and relatively few non-specialist GPs are competent in doing so, the	The GDG did not consider that the diagnosis of CFS/ME required a neurologist, but stipulates that where there is doubt about the diagnosis specialist opinion and investigation may

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						threshold for referral to a neurologist should be low	be required.
SH	Association of British Neurologists	17	FULL	134	14-24	This paragraph deals with a publication (Wessely et al, Lancet 1999) which was published as a HYPOTHESIS and which remains to be proven. However, the GDG seems to have taken it as a matter of fact. Please refer to the criticisms of this article in the subsequent correspondence in the Lancet. By the same logic, one can argue that fatigue in CFS/ME is very similar to fatigue in other medical diseases, multiple sclerosis and cancer. This particular paragraph, being only a hypothesis, is totally irrelevant for the purpose of a dedicated guideline on CFS/ME.	This paragraph does not reflect any opinion published in the literature but rather summarises the consensus view of the GDG.
SH	Association of	18	FULL	134	14 -24	I would advise the GDG to read	The literature review searched for

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	British Neurologists					[the] Lancet article (Fatigue in neurological disorders), which has been widely cited as the most definitive work in this area, to understand fatigue and its inter-relationship with physical, cognitive an d psychiatric symptoms. Indeed, nowhere in this document there has been any conscious attempt to explain the multi-dimensional nature of fatigue succinctly.	evidence on CFS/ME exclusively, not for evidence of management of fatigue. The GDG recognise that some concepts in the paper are useful.
SH	Association of British Neurologists	19	FULL	134	25-29	The GDG should also be criticised for its total lack of reference to the neurological aspect of fatigue and its overemphasis and over-reliance on the psychiatric literature from a group of psychiatrists	The literature review searched for evidence on CFS/ME exclusively, not for evidence of management of fatigue, and the GDG reviewed all the relevant published literature impartially. Representatives were drawn from a variety of stakeholders; psychiatrists did not have a disproportionate representation on the GDG and the

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							views expressed a consensus.
SH	Association of British Neurologists	22	FULL	88 onwards		With possible exception of some psychiatrists, most specialists prefer the international criteria in order to diagnose CFS/ME. Clearly therefore, there is very little compelling evidence at present that these patients benefit from CBT and GET	The intention is to raise awareness that the individual may have CFS/ME to manage symptoms at an early stage prior to a diagnosis. We have redrafted this section in order to make this clearer.
SH	Association of British Neurologists	23	FULL	88 onwards		The GDG must acknowledge that difference in the selection criteria for diagnosing patients is an important factor for predicting outcome	Noted.
SH	Association of British Neurologists	40	FULL	106		There is selective omission of research literature on reproducible neuroendocrine tests (e.g. buspirone test), brain imaging (MR spectroscopy), cognitive disability	Research in these aspects was not considered convincing by the GDG

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						with an overemphasis on research data from certain psychiatrists	
SH	Association of Medical Microbiologists	1	FULL	107 (table)		The AMM welcomes the opportunity to comment on the guidelines with respect to microbiological investigations. The Association agrees that serology for General or chronic virus infections and serology for chronic bacterial infections (e.g. borelliosis) should not be undertaken in the absence of any indicative history (i.e. should not be done routinely)	Thank you.
SH	Association of Young People with ME	5	FULL	106		Children and Young People AYME recognises that CFS/ME is the same illness for children and adults. However, the impact of the illness is very different for children and this has not been sufficiently addressed. More reference needs	We have made some additional recommendations on the need for specific management principles for children.

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						to be made to the NSF 'ME exemplar' and to the RCPCH Guidance 2004, particularly with reference to the very small child needing constant vigilance (Pg 38 3.1.3 RCPCH) and the General relationship with the family (page 43 management of CFS/ME RCPCH 2004). In addition, diagnosis of children and young people could be enhanced by referencing the RCPCH Guidance on P106.	
SH	BRAME Blue Ribbon for the Awareness of ME	81	FULL	88	9-10	5.1: We are pleased that you acknowledge that whilst fatigue may be a symptom, that for many, other symptoms are far more debilitating and dominating eg pain, and that when patients first approach the doctors, and throughout their	Thank you. This section you mention serves as an introduction to the evidence found rather than an endorsement of set of one criteria over another. This has been revised to include other criteria as

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						illness, fatigue may be the last thing they mention, if at all. This just shows why the Oxford criteria are completely inappropriate – as can be seen in your quote by Wessely and Sharpe about their Oxford Criteria (p111 4-8) about it being a syndrome around fatigue, and other symptoms may be present. This is not appropriate for ME/CFS. The fatigue experienced may also only be down to the body's reaction to the other symptoms eg. sleep dysfunction and pain, so therefore the fatigue is a secondary/reactive symptom, rather than a primary/core symptom.	highlighted in the comments.
SH	BRAME Blue Ribbon for the Awareness of ME	82	FULL	88	18	5.1: At present there is no specific definitive test to diagnose ME/CFS but there are tests that, along with a	The guideline recommends a full history and examination. If evidence of testing is published, it will be considered in the

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						FULL history of illness, and FULL physical examination, that can help support the diagnosis. (see the Canadian Clinical Guidelines previously referred to). There is also research showing that possible testing may be soon, especially given the recent research by Kerr and Gow on genetics.	revision of this guideline.
SH	BRAME Blue Ribbon for the Awareness of ME	83	FULL	89	13	5.2.2.1: These tests would prove useful as a secondary line of testing and should be included. Orthostatic intolerance is a real problem for most ME/CFS patients, and the GDG did see a number of papers showing the usefulness of the tilt-test, so why were these dismissed? The 5 lab tests for fibrinogen prothrombin platelets etc should definitely be tested at regular intervals on the severely affected	We have noted only that they are not to be used routinely, but that clinical indications should guide investigations. Issue 2 - The 5 lab tests: This section is about investigations to diagnose the condition. It is not about management of the condition.

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						who are often bedbound and the risk of blood clots/DVT forming, especially as those with ME/CFS, are thought by many doctors/researchers, including the work of Dr Les Simpson, to have 'sticky blood'. Dr Les Simpson showed a changed in the shape of red blood cells, causing difficulty in micro-circulation and leading to tissues not receiving sufficient oxygen and nutrients to sustain normal functioning.	
SH	BRAME Blue Ribbon for the Awareness of ME	84	FULL	89	14	5.2.2.2: This illness is the same disease whether you are an adult or a child, the disease process does not change as soon as you become 16 or 18, and tests should be done if needed to help with diagnosis. Obviously clinicians should be sensitive to their age, if tests were	This is an evidence statement which is intended to reflect the quality of research evidence pertaining to children in this area.

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						of a more invasive nature, or when thinking of medication or treatments, and to the effects of some drugs or therapies, when a child is still growing and developing.	
SH	BRAME Blue Ribbon for the Awareness of ME	85	FULL	90	5	5.2.4.1: We feel there are some clear risk factors of someone developing ME/CFS eg viral infection like glandular fever, multiple insults to the body with repeated infections, environmental factors such as exposure to organo-phosphates and other chemicals, vaccinations/immunisations, and as research is now confirming a genetic susceptibility (as shown by separate studies by Dr J Kerr and Dr J Gow), or, of course a combination of multiple risk factors coming together.	This section has now been removed.

National Institute for Health and Clinical Excellence
CFS/ME consultation draft
29 September – 24 November 2006
Comments on chapter 5

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SH	BRAME Blue Ribbon for the Awareness of ME	86	FULL	90	5	5.2.4.2: We cannot agree with some of these, and they certainly need further explanation. Feel this is an unhelpful evidence statement in its current form.	This is an evidence statement which is a statement that synthesises the evidence findings. However, because of the lack of utility of this evidence statement, this has been deleted.
SH	BRAME Blue Ribbon for the Awareness of ME	87	FULL	90	5	5.2.4.3: This illness is the same whether you are a child or an adult and so the risk factors are basically the same – trying to continue with education is similar to an adult trying to continue with work. The added risk for children is being forced to attend school, being classed as school phobic, being misdiagnosed with Munchausens by proxy, or if social workers are involved, the risk and fear of children being taken into care, forced into treatments or at worst physically removed from their home by medical professionals, social	This is an evidence statement which is a statement that synthesises the evidence findings.

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						workers, and police, who fail to comprehend the true physical nature of the illness ME/CFS.	
SH	BRAME Blue Ribbon for the Awareness of ME	88	FULL	91	7-13	5.2.5.1: See responses already made in 5.2.2.1. These tests may be very helpful, certainly with the moderate and severely affected. If electrodermal analysis is useful in differentiating a diagnosis between ME/CFS and depression, then it should be considered if appropriate. No mention anywhere of Tony Cleare's research which shows a difference in serotonin levels between those with ME/CFS and depression, and also shows why a difference in Serotonin levels indicate those who did not respond well to GET. If sub-groups were identified it would help in offering	The evidence reviewed in this guideline does not allow us to distinguish between these groups when making recommendations. However, we have stressed the need to consider both preferences and needs of the individual throughout the recommendations.

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						appropriate management.	
SH	BRAME Blue Ribbon for the Awareness of ME	89	FULL	92	6-7	5.2.6. Patients do not find it a negative experience to have numerous tests, as they feel so ill and want a correct diagnosis, and even if they do not get a positive answer, it can be a relief and reassuring to know what illness it is not. Unfortunately many doctors consider comprehensive testing as 'reinforcing the patient's belief in an organic cause to their illness' – this is disgraceful, ME is a physical organic illness – comprehensive testing is necessary – no wonder so many people are being misdiagnosed in this country.	Point well taken. It should be noted that diagnostic testing, especially invasive tools, will incur immediate disutility due to an impact on quality of life or risk of adverse events. However, following the diagnostic procedure, there may be benefit from increased certainty that a condition is confirmed or ruled out. The correct valuation of all benefits and harms to patients will make appropriate decisions for patients and doctors possible.
SH	BRAME Blue Ribbon for the Awareness of ME	90	FULL	92	12-17	5.2.6. Investigations are cost effective as they enable an earlier accurate diagnosis, and appropriate	It should be noted that "the same [effectiveness] outcome" means per definition that items such as 'diagnostic

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						advice and management, rather than perhaps months or years of ill-health, the cost of multiple doctor/hospital visits and cost of symptom management, apart from the cost of the personal impact on the patient of being so unwell, and having no real understanding of what is wrong with them - that does have a negative impact on a patient. How is it cost-effective to not do the tests and to possibly misdiagnose a patient as having ME/CFS, when in actuality they may have another chronic/fatal condition which could be appropriately treated? There have been many instances of this, most recently that of a young man being diagnosed as ME/CFS when it was actually CJD, and one of our	precision' will not be compromised by an alternative programme. For the evaluation of cost-effectiveness, both costs and consequences of an intervention are examined. Therefore, the quoted paragraph has to be viewed in context of the prior section. It can be assumed that patients accrue disutility over time while they go through multiple investigative procedures until a final diagnosis is made. This means that the longer this period is, the greater the quality of life loss in absolute terms. Necessary staff time is directly linked to the costs of a test, and with the disutility to the patient over time, less time intensive interventions are expected to be more cost-effective. We have also recommended that appropriate investigations should be

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						respondents highlighted a recent case of someone with Alzheimers being misdiagnosed as having MECFS.	done as indicated by clinical signs and symptoms.
SH	BRAME Blue Ribbon for the Awareness of ME	91	FULL	94 -103		5.2.7: See comments made in previous line – tests can help to make an effective diagnosis, or help to pick up any co-morbid illnesses, and to enable good management There is also a danger of valuable epidemiological data being lost by certain tests not being included – especially tests for viruses in early stages of the illness, allowing risk factors to be identified eg. EBV.	This table documents the questions and responses to the questionnaire for transparency. They cannot be changed now.
SH	BRAME Blue Ribbon for the Awareness of ME	92	FULL	104	1	5.2.8: Delayed onset of fatigue is a characteristic of this illness. The CMO Report (2001) 4.2.1.1 states clearly that "*other fatigue states do not present with the characteristic*	We have given guidance on broad criteria to alert the clinician to the possibility of CFS/ME, not for use as diagnostic criteria specifically.

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						delayed fatigue seen in CFS/ME. Another distinguishing feature of the illness, in comparison with other 'fatigue states', is its prolonged relapsing and remitting course over months or years." The Canadian Clinical Case Definition and Guideline states "*Chronic fatigue must not be confused with ME/CFS because the 'fatigue' of ME/CFS represents pathophysiological exhaustion and is only one of many symptoms. Compelling research evidence of physiological and biochemical abnormalities identifies ME/CFS as a distinct, biological, clinical disorder*." This recommendation reads as a new diagnostic criterion for	This has been clarified in the guideline.

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						ME/CFS. We cannot agree with fatigue and 'one or more of the following symptoms' as a diagnostic criteria, ME/CFs should not even be considered if there is only fatigue and one other symptom present. This, like the Oxford Criteria, will lead to many people being misdiagnosed and mismanaged. In comparison to the 'NICEcriteria', these are the other criteria, for all of which symptoms must be new onset and present for 6 months:- The Canadian Criteria – patient must have fatigue, post-exertional malaise and/or fatigue, sleep dysfunction, and pain, plus 2 or more neurological/cognitive manifestations, and one or more symptoms from two of the	

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						categories autonomic, neuroendocrine and immune manifestations. These criteria include an alternative diagnosis of Idiopathic Chronic Fatigue for those who do not fulfil the criteria for ME/CFS, allowing those patients to still receive advice and management and be monitored. From the CMO Report (2002) CDC – Holmes (1988) requires fatigue of 6 months plus 6-8 symptoms CDC – Fukuda (1994) requires fatigue of 6 months plus at least 4 other core symptoms. London (1990) derived from Dowsett and Ramsey – includes General or local muscular fatigue	

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						following minimal exertion with prolonged recovery time. Neurological disturbance of cognitive, autonomic and sensory functions, with involvement of cardiac, endocrine and other systems with a prolonged relapsing course. Whereas the Oxford Criteria (Sharpe) 1991 and the Australian Criteria (Lloyd) 1990 only mention fatigue of 6 months with disabling functional impairment, cognitive or neuropsychiatric symptoms. No other symptoms are specified and neurological symptoms, suffered by all ME patients, are specifically excluded. The other major problem with the Oxford and Australian criteria is that	

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						neither has psychiatric diagnosis as an excluding condition eg. Depressive illness and anxiety disorders (there is multiple research papers showing that ME and ME/CFS are not depression or a psychiatric condition). Therefore the group comprised of those diagnosed using either of these criteria only need to have chronic fatigue for more than six months. This means that they could have multiple causes, and alternative diagnoses, as well as those whose fatigue is due to psychiatric conditions – therefore these criteria are totally useless for diagnosing ME/CFS, and all research based on groups selected using either of these diagnostic criteria are flawed/invalid, because the results	

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						are unable to be extrapolated for use on the ME/CFS population. Many ME/CFS specialists both in the UK and around the world, along with patient groups, and patients themselves, strongly believe that the Canadian Clinical Criteria is currently the criteria which best fits their symptoms and illness experience of ME/CFS. We strongly recommend the use of the Canadian Clinical Diagnostic Criteria. Recommendation of the use of the Canadian Clinical Criteria by the NICEGuideline would have been very constructive and positive for patients with ME/CFS – enabling a more accurate diagnosis, and helping to exclude or differentiate ME/CFS from other illnesses.	

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						The CDC states that ME and CFS are similar but different illnesses. To really help patients and medical professionals care for patients with ME/CFS, they have to be identified from the larger spectrum of patients with chronic fatigue states.	
SH	BRAME Blue Ribbon for the Awareness of ME	93	FULL	106	Box 1	When using symptom management, the clinician must be alerted to the fact that, if the patient does have ME/CFS they may well be more sensitive to medication and to use considerable caution on dosage	There does not appear to be evidence to support this. Many drugs will not be effective if not given at least the minimum advised dosage. However, we have made a recommendation on this issue.
SH	BRAME Blue Ribbon for the Awareness of ME	94	FULL	106	Box 2	Sleep dysfunction is a core symptom of ME/CFS and most patients have tried everything to try and improve sleep and to have quality sleep. Prolonged bed rest in an acute phase or severe relapse is not an option; it is a necessity, as	Noted: this wording has been changed to clarify this.

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						patients are frequently just too ill to even lift their head off the pillow. Everyone with ME/CFS, including the long-term severely affected, still live with the hope that one day they will be able to return to life which bears some semblance to normality. This statement is an insult to patients, as it does not acknowledge the severity of the illness, and with all the talk of behavioural therapies, this can have a very negative impact on patients making them feel that they have not tried hard enough to get better.	
SH	BRAME Blue Ribbon for the Awareness of ME	95	FULL	106	Box 4 /5	5.2.8 (Please also refer to responses already given on 5.2.2.1, 5.2.5.1, 5.2.6, and 5.2.7.) FULL and thorough investigations should be done to enable an accurate diagnosis of ME/CFS, whilst also	The GDG considered that ferritin should only be done routinely in children, but that clinical judgment should be used.

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						identifying any other underlying or co-morbid condition eg ferritin levels only to be done in children, when it should be included for adults as well. We feel that cholesterol should also be included, as this is often found to be slightly raised in ME/CFS patients, but also as most ME/CFS patients have dietary problems, 'sticky blood' and many have cardiovascular problems, the baseline should be found and monitored at intervals.	Regarding cholesterol, the investigations listed here are to aid diagnosis, not ongoing management.
SH	BRAME Blue Ribbon for the Awareness of ME	96	FULL	107	Box2	We feel that these tests are important to also be included in order to give an accurate diagnosis of ME/CFS. The serology for infections, and along with Folate levels, B12 should also be included.	There are clearly many tests that should be carried out to assist with management in individual cases. The GDG did not, however, find sufficient evidence for any test which diagnoses CFS/ME. The tests listed are those

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						Orthostatic intolerance is a major problem for most patients, the moderately, and especially, the severely affected. This should be identified and monitored, and has been shown in some studies to be a diagnostic marker.	which would assist in ruling out other conditions
SH	BRAME Blue Ribbon for the Awareness of ME	97	FULL	108 109	25-29 1-4	You say 4 times as many women as men get ME/CFS. There is a known endocrine involvement in ME, and for many women, any iron deficiency may be exacerbated, as the CMO Report clearly acknowledges. With many women having menstrual difficulties, prolonged and heavy menstruation, as well as co-morbid gynaecological conditions. It has also been found in ME/CFS clinics, and is well documented by	There are clearly many tests that should be carried out to assist with management in individual cases. The GDG did not, ,however, find sufficient evidence for any test which diagnoses CFS/ME. The tests listed are those which would assist in ruling out other conditions.

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						haematologists, that adults may show an 'acceptable' blood picture on normal testing, not immediately alerting the clinician to the presence of an underlying abnormality/deficiency eg very low ferritin, folic acid or B12 levels (B12 would help to diagnose/eliminate Pernicious Anaemia.) The symptoms for these deficiencies are similar to those experienced with ME/CFS. Ferritin levels should be recommended for both adults and children, and continually monitored throughout the patient's illness, especially for the long term severely affected.	
SH	BRAME Blue Ribbon for the Awareness of ME	98	FULL	107 109	Box 1 5-6	Again why is creatinine kinase only recommended for being tested in children when it could help to	Changed.

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						identify muscle disease in adults. Creatinine kinase should be recommended for both adults and children.	
SH	BRAME Blue Ribbon for the Awareness of ME	99	FULL	107 108	Box 2 3-9	Blood serology is important to be included to test for bacterial (eg borelliosis) and viral infections (Enteroviruses eg Coxsackie A & B, Herpes viruses eg EBV, CMV, HHV6 and Hepatitis B, C). There are also papers that show viruses cause neurological damage. Testing would mean that apart from helping to manage the patient's illness, it could help by collating important epidemiological evidence for potential viral triggers, and along with patient's history, why some patients go on to develop ME/CFS, as well as helping to identify	Issue 1 – Serology testing: Testing is only not recommended when there is no indication that the individual previously had an infection. Therefore patients who have had symptoms of an infection will be appropriately tested.

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						possible sub-groups of ME/CFS, and to explain why some groups of patients respond differently to existing management of the illness, and have different recovery rates. Even the Oxford Textbook of Medicine Vol I and II (1987) states clearly that "*Viruses invade and damage the central nervous system in two ways; directly, by infecting the leptomeninges, brain, and spinal cord, and indirectly, by inducing an immunological reaction resulting in para- and post-infectious syndromes*."	

National Institute for Health and Clinical Excellence
CFS/ME consultation draft
29 September – 24 November 2006
Comments on chapter 5

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							Issue 2 : The term 'should' is standard in all NICE guidelines.
SH	BRAME Blue Ribbon for the Awareness of ME	100	FULL	108	10-16	Should be some reference, even if not used as a diagnostic tool, to make clinicians aware that research has shown that there is a reduced blood flow, in particular to the brain of ME/CFS patients. Many of our respondents are bewildered at the lack of inclusion of research produced by SPECT scans, and mentioned the work of	No evidence was found for the use of these tests as diagnostic tools. If evidence arises, it will be considered in the revision of the guideline.

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						Durval Costa.	
SH	BRAME Blue Ribbon for the Awareness of ME	101	FULL	110	1–Box 1	5.3.1.1 We would challenge this statement saying that there is no evidence to say that one case definition is better than another. This has been articulately debated for years. The York review itself showed that the Canadian Guidelines, Holmes et al 1988 and the London/Dowsett criteria are all better accurate diagnosis and at creating more homogeneous groups than the Fukuda et al 1994 criteria.	This comment refers to an evidence statement which is a statement that synthesises the evidence findings. The GDG discussed the evidence and agreed this statement.
SH	BRAME Blue Ribbon for the Awareness of ME	102	FULL	110	1-Box 2	5.3.1.2 The CDC Holmes 1988 criteria requires patients to have fatigue of at least 6 months duration, at least 50% reduction in function, and 6 to 8 core symptoms. This criteria therefore identifies a	The recommendations on diagnosis have been revised and clarified. However, as stated in the evidence review, there is no clear research evidence on the most appropriate case

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						more homogenous group of patients presenting with a larger number of core symptoms. The CDC Fukuda 1994 criteria require patients to have 6 months of fatigue with substantial functional impairment with at least 4 other core symptoms. These therefore open the criteria up to embrace a larger and more heterogenous group of patients.	definitions to be used.
SH	BRAME Blue Ribbon for the Awareness of ME	103	FULL	110	1-Box 3	5.3.1.3 As explained above the CDC 94 criteria requires fewer symptoms, whereas the Dowsett ME and Canadian Criteria have much more precise and targeted clinical criteria allowing for those with the illness to be properly, and correctly diagnosed, creating the homogeneous group that is needed	The recommendations on diagnosis have been revised and clarified. However, as stated in the evidence review, there is no clear research evidence on the most appropriate case definitions to be used.

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						for correct diagnosis, management and research.	
SH	BRAME Blue Ribbon for the Awareness of ME	104	FULL	110	2-Box 1	5.3.1.4: Why is there a need for a separate case definition for children? This illness, and its symptoms, are the same whether you are a child or an adult. The only difference to be acknowledged is the sensitivity needed for management and education, and the need for diagnosis to occur earlier than in adults.	Noted, but there may be different patterns of presentation in children
SH	BRAME Blue Ribbon for the Awareness of ME	105	FULL	110	2-Box 2	5.3.1.5: Why do guidelines, recommendations, management and research always take on the more psychiatric/psychological approach with children? This is neither acceptable nor helpful. If the study listed here is true, we would question more whether the	This is an evidence statement which is intended to reflect the quality of research evidence pertaining to children in this area.

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						diagnosis was correct, or whether the children were being brought down by multitudes of medical professionals/educationalists who are trying to convince the child that their problems are not physical – you try having no-one believe or support you and see how you feel.	
SH	BRAME Blue Ribbon for the Awareness of ME	106	FULL	111	1-26	We have already given our reasons why we find even the mention of the Oxford criteria within this document unacceptable, but mentioning it first – words fail us! If the intention is to include all research and diagnostic criteria in chronological order – where are the Ramsay criteria for ME which were the first created in this country? Why is there no mention of the Holmes et al CDC criteria from 1988? This predates the Oxford and were found in the	The evidence review applied agreed inclusion and exclusion criteria, and in the full guideline, we have reported details of some of the most commonly cited criteria in chronological order – detailed critiques can be found in the full evidence review (Appendix in the full guideline).

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						research review to more accurately identify those with ME than the Fukuda criteria, and to show those that are more severely affected. To include the Oxford criteria, which have never been held up to research scrutiny and has never been peer-reviewed and are based on a flawed and erroneous hypothesis in the first place, is perverse to say the least. The Oxford Criteria (Wessely/Sharpe) 1991 along with the Australian Criteria (Lloyd) 1990 only mention fatigue of 6 months with disabling functional impairment, cognitive or neuropsychiatric symptoms. No other symptoms are specified – this is not ME/CFS this is describing a chronic fatigue state – not the	

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						illness/condition that this document is supposed to be addressing and providing advice on. The other reason for the unacceptability of the Oxford criteria is that they do not have a psychiatric diagnosis as an excluding condition eg. Depressive illness and anxiety disorders (there are multiple research papers showing that ME/CFS is not depression), Therefore any group comprising of those diagnosed using either of these criteria only need to have chronic fatigue for more than six months. This means that they could have multiple causes and alternative diagnoses, as well as those whose fatigue is due to psychiatric conditions. These criteria are totally useless as a diagnostic tool for ME/CFS, and all	

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						research based on groups selected using either of these diagnostic criteria is flawed, and the results are unsuitable for extrapolation to the ME/CFS population.	
SH	BRAME Blue Ribbon for the Awareness of ME	107	FULL	111-112	27-4	The Canadian clinical criteria are the only clinical diagnostic criteria available. All others are for research purposes only. Those who fit these criteria are those, who we believe, truly have the illness of ME/CFS. These criteria have been acknowledged to create an homogeneous group, which is vital as they identify the true illness ME/CFS. The core neurological, immune and neuroendocrine manifestations are central to the illness and are not optional. The Canadian criteria also allow clinics/GPs to treat everyone as	The evidence review concluded that no current case definitions are established as being superior to the others. The Canadian criteria are based on expert opinion, and not research evidence.

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						they allow those who do not fulfil the criteria to be given the diagnosis of Idiopathic Chronic Fatigue Syndrome. This alternative group can be diagnosed, managed and continually assessed, as they may go on to develop ME/CFS, or they may naturally improve, or may develop/be diagnosed with alternative illnesses.	
SH	BRAME Blue Ribbon for the Awareness of ME	108	FULL	112	16-18	5.3.2.2 Summary of evidence: ME AND ME/CFS ARE NOT 'TYPES' OF CHRONIC FATIGUE!! Chronic Fatigue is listed by WHO under psychiatric conditions, whereas ME and ME/CFS are listed under ICD10-G93.3 as neurological illnesses alongside PVFS. This guideline is for ME and ME/CFS not chronic fatigue states therefore all research relating to chronic fatigue	Noted and deleted.

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						should be removed.	
SH	BRAME Blue Ribbon for the Awareness of ME	109	FULL	112	12-30	The York review was based on a flawed remit, as it did not allow for research into the true illness ME/CFS, of which there is copious good quality strong evidence to be looked at – perhaps that is why you came up with so many 'weak and inconsistent' studies.	The York review was conducted using recognised and validated methods in accordance with NICE methodology. Details of the methods are reported in the full guideline.
SH	BRAME Blue Ribbon for the Awareness of ME	110	FULL	114	11-Table	Costs attached to false diagnoses: there is no mention here of the financial and social costs that are incurred from misdiagnosis, and subsequent management of these conditions, if thorough exclusionary/exploratory testing is not done to start with. The correct use of the Canadian diagnostic criteria, along with proper testing, would lead to correct	Any implications from correct and false diagnosis relate here to the diagnosis of CFS/ME (instead of diagnosis of other conditions).

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						diagnoses being made sooner, making it more cost effective and less distressing for the patient.	
SH	BRAME Blue Ribbon for the Awareness of ME	111	FULL	114 115	16-18 Table 1	Why is the cost per hour for a hospital consultant/specialist not included in this table, as we know it is considerably less than for a GP who costs £143ph? GPs are often ill-informed and misunderstanding of ME/CFS. Specialist clinics following a bio-medical approach, using a well trained multi-disciplinary team, headed up by a consultant would be more cost-effective and far more helpful for the patients.	Thank you. This section has been revised.
SH	BRAME Blue Ribbon for the Awareness of ME	112	FULL	124	5.3.5.1	Recommendations: For the mild/moderately affected 4 months is too soon for making a diagnosis as all diagnostic criteria say that	The GDG considered the time frames to be appropriate.

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						symptoms must be present in adults for 6 months before a diagnosis can be made. This does not mean that a provisional diagnosis of ME/CFS cannot be made, and appropriate advice and management given, before 6 months.	
SH	BRAME Blue Ribbon for the Awareness of ME	113	FULL	124	5.3.5.3	Some patients may make some, or, for a minority, considerable improvement, it is well recognised that there is no cure for ME/CFS, as repeatedly stated throughout the CMO report, yet strangely this vital information is not present in the guidelines. A very small minority may go into long remission – but it must be stressed that this is a relapsing condition, so no-one recovers – and certainly not FULLy. There is no mention that some	Noted and this recommendation has been revised.

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						patients may deteriorate, and that for some it may be fatal.	
SH	BRAME Blue Ribbon for the Awareness of ME	114	FULL	124	5-7	Amazed by this statement, as the Canadian Clinical Criteria would enable clinicians to make a definitive diagnosis of ME/CFS, and they also have helpful, informative and constructive advice for managing the condition. We note that you identify that the research case definitions are not necessarily helpful in clinical practice and yet ignore the clinical criteria.	The evidence review concluded that no current case definitions are established as being superior to the others. The Canadian criteria are based on expert opinion, and not research evidence.
SH	BRAME Blue Ribbon for the Awareness of ME	115	FULL	124	12-16	This is a guideline for ME/CFS not for a range of conditions with chronic fatigue, and the Canadian Guidelines would enable clinicians to make a reliable and accurate diagnosis of ME/CFS. As the	The diagnosis recommendations have been revised. The evidence review concluded that no current case definitions are established as being superior to the others. The

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						NICEevidence has shown, studies comparing other broader diagnostic criteria, led to a very large and heterogeneous group, creating more confusion for medical professionals and patients alike regarding diagnosis and management.	Canadian criteria are based on expert opinion, and not research evidence.
SH	BRAME Blue Ribbon for the Awareness of ME	116	FULL	125	2-7	Good health care professionals should always be vigilant and observant in monitoring their patients condition and symptoms, and be ready to reconsider a diagnosis or be aware of a co-morbid condition.	Noted. These are covered in the recommendations on review.
SH	BRAME Blue Ribbon for the Awareness of ME	117	FULL	125	18-22	The statement 'health care professionals should be aware of some of the symptoms frequently presented to raise awareness' is meaningless. What is a guideline	We have recommended that the reality and impact of the condition and symptoms should be acknowledged in order to address such concerns.

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						like this for, if it is not to give health care professionals the information and skills they need to help them to diagnose and manage an illness? Health care professionals should be aware of all the core symptoms, and the range of other symptoms, to enable them to make a diagnosis, offer symptom management and support. There is no mention of empathy with the patient. It is even more essential for good, quality and accurate information to be in a guideline for an illness like ME/CFS, where there are such strongly controversial views. The patient experience of a clinical consultation is that their GP, far too often, totally disbelieves in ME/CFS, or takes the psychiatric/psychological approach	

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						to the illness, instead of offering understanding of the overwhelming complex and debilitating illness that the patients endure 24/7.	
SH	BRAME Blue Ribbon for the Awareness of ME	118	FULL	126	1-3	Spatial disorientation is recognised as being a problem for many moderate and most severely affected ME/CFS patients.	Noted but is not characteristic.
SH	BRAME Blue Ribbon for the Awareness of ME	119	FULL	126	14	5.4.1 Referral to Specialist CFS/ME Care We know of one long standing ME/CFS clinic, which takes the bio-medical approach, that has completed surveys of its patients over the years. It has shown that the patients have found the clinic, and the understanding and knowledgeable consultant, an absolute lifeline over the years to help them understand and manage	Thank you for this information.

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						their illness.	
SH	BRAME Blue Ribbon for the Awareness of ME	120	FULL	133	16-19	5.5 A Conceptual Framework If the wealth of biomedical and patient evidence had been thoroughly looked at by the GDG there would have been a substantial understanding of the reality of the illness ME/CFS. It is of great concern to the patient population, and those clinicians and researchers who are truly understanding of this chronic and debilitating illness, that "a view held by a few individuals on the GDG was that CFS/ME could not be identified or managed unless a broader view was taken". If they had no real understanding of the illness ME/CFS as listed by WHO, why were they invited to be on the	The views of a few members of the GDG did not dominate the guideline. Great care was taken during development to ensure all views were identified and a balanced guideline produced. The framework has been revised to take account of the comments received through the consultation. We hope that the revised version helps patients and professionals work together to improve care and services, despite the differences in the views people hold about the nature of the condition. In considering the explanation for CFS/ME, we have followed the report of the Gibson Inquiry, which accepts that there is insufficient evidence to fully substantiate any of the current theories

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						GDG? If it was a 'few members' then why was their view able to dominate the format and content of the guideline? ME/CFS is not chronic fatigue – it has been stated that "*the disabling weakness and exhaustion a patient with ME/CFS experiences is so profound that 'fatigue' is an insult*". ME/CFS is not a behavioural disorder, a psychiatric illness, somatic/functional disorder, an illness belief, depression or anxiety disorder. By taking such a broad view, and by introducing diagnostic criteria, like those created within this guideline, which are just one symptom away from the unacceptable and	of causation, and that more high quality biomedical research is needed. Specifically, the GDG does not state that MM/CFS is a behavioural disorder, a psychiatric illness, a somatic/functional disorder, an illness belief, depression or anxiety disorder.

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						discredited Oxford Criteria, is of no help to anyone. They create a 'dustbin of illnesses' which leaves patients misdiagnosed and mismanaged, with potentially fatal consequences. By accommodating this broad brush approach, NICEhas failed, in this guideline, to offer an constructive advice or information to those medical professionals who truly wish to understand ME/CFS in order to help their patients and are in danger of doing grievous damage to ME/CFS patients. There is nothing here to give doctors any view of the reality of the illness apart from the patient testimonials.	
SH	BRAME Blue Ribbon for the	121	FULL	133-134		Is this deliberate here to only mention CFS or an oversight? If this section refers to ME/CFS, even	This was an error, and has been corrected. It should have been CFS/ME. The GDG accepts the Gibson Inquiry's

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	Awareness of ME					though we still need much more research into the aetiology and pathogenesis of ME/CFS, there is a wealth of good biomedical evidence and research showing abnormalities, along with surveys of thousands of patients to give invaluable information on the reality of this illness and the patient experience of ME/CFS. Much of this information has been forwarded to NICE by ourselves and other ME groups and researchers.	conclusion that no current theory on the causes of CFS/ME is, as yet, supported by sufficient evidence, and that further biomedical research is necessary.
SH	BRAME Blue Ribbon for the Awareness of ME	122	FULL	133	27-28	To state there is a 'lack of an objective definition of CFS as a discrete disease entity' is misleading if this is also referring to ME or ME/CFS.	The text has been revised.
SH	BRAME Blue Ribbon for the	123	FULL	133-134		Adoption of the Canadian Clinical Guidelines by NICEwould have	We hope the revised guideline is an advance. Whilst the GDG felt the

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	Awareness of ME					really helped medical professionals, not only to have the information they need to make a more precise and accurate diagnosis of ME/CFS, but would also give them constructive information and skills to help manage their patient's chronic illness.	Canadian guidelines had virtues, they also thought there were weaknesses which we had tried to overcome.
SH	BRAME Blue Ribbon for the Awareness of ME	124	FULL	134	5-6	'Entrenchment and polarisation of viewpoints about a physical or psychological origin of CFS'. ME/CFS is a physical illness, but whilst psychiatrists, particularly of the 'Wessely school', continue to influence, at the highest level, their views on ME/CFS being a mental/behavioural disorder, neurasthenia or illness beliefs. In a recent book on Clinical Medicine: 5th edition: Kumar and Clark 2004 psychiatrists White and Clare, in	The guideline accepts the Gibson Inquiry's conclusions on the current evidence about the cause of CFS/ME and the need for more biomedical research.

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						their section on psychological medicine, list CFS/ME under functional or psychosomatic disorders – medically unexplained symptoms, and deem CFS/ME to be a somatoform disorder. Compare this to the Canadian Clinical Guidelines which patients know to be the reality of this overwhelming, complex, debilitating and chronic illness ME/CFS, and you can not fail to comprehend why there is such a strong difference of opinions. By taking the behavioural approach to managing this illness, instead of addressing the real physical illness affecting the central nervous system, immunological and neuroendocrine systems, which for	The guideline seeks to promote access to interventions that may help alleviate some symptoms as well as encourage more research to identify the cause.

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						the severely affected becomes a multi-system, multi-organ illness, these NICEguidelines are not going to improve the situation for patients.	
SH	BRAME Blue Ribbon for the Awareness of ME	125	FULL	135	6-20	Any doctor should aim to have a good therapeutic relationship with their patient, and acknowledge their symptoms, suffering and disability and the impact that has on their lives. When patients visit their doctor, they need information and advice. For example 'is it safe for me to have a vaccination?' or 'what type of anaesthetic can you recommend, if any, for my dentist to use?' Patients will have a wealth of questions to ask their doctor about their complex medical condition, and these may seem unusual questions to ask, but if you truly understand ME/CFS, then they are	Noted and this is a principle of care (see also the Introduction to the NICE guideline). Also please see the Understanding NICE Guidance for suggested questions that patients may wish to ask their doctor or healthcare practitioner.

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						very important, in order to avoid adverse and possible severe reactions. Definition and concept of this illness through a biopsychosocial model shows no concept of ME/CFS, is of no real help to patients, and as is shown in patient evidence, is found by the majority to be unhelpful or harmful.	The GDG accepts the Gibson Inquiry's conclusion that no current theory on the causes of CFS/ME is, as yet, supported by sufficient evidence, and that further biomedical research is necessary.
SH	British Paediatric Mental Health Group of the Royal College of Paediatrics and Child Health	2	FULL	122		Diagnosis in children. This is given a definite time frame of 3 months. Why? The RCPCH document chose not to give a definite time frame, rather using the definition of 'severe persistent fatigue not explained by	The 3-month time frame was recommended in the CMO report and is used in many of the papers. The GDG supported this time-frame.

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						other disorders'. We recognise that it probably takes about 3 months to work through the system but do not agree with a restrictive time frame.	
SH	British Paediatric Mental Health Group of the Royal College of Paediatrics and Child Health	3	FULL	130		The graphs of the consensus documents are confusing if there have been disagreements at various stages of the consultation process.	Noted, but we have included such detail to allow transparency.
SH	British Paediatric Mental Health Group of the Royal College of Paediatrics and Child Health	4	FULL	132		Why do all children with mild CFS/ME need referral to specialist care after 4-6 months. As I read it from the table, it is appropriate to refer those who wish for a referral or who are not doing so well, but in the recommendations of the guideline it comes out as a 'should'. Many General paediatricians are competent to oversee the	The recommendation has been changed and an alteration has been made to the flow chart.

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						management of these children, leaving specialist care for those who really need this scarce resource.	
SH	Cambridgeshire Neurological Alliance	32	FULL	104	All 5.2.8	"Primary healthcare professionals should be familiar with the presenting features of CFS/ME" ➢ The reality is that they are not. There are still horror stories of GPs/others mocking, or just ignoring the person's remarks, or just appears evasive and/or quite rude.	The aim of the recommendation is to encourage training in this area to avoid this happening in future.
SH	Cambridgeshire Neurological Alliance	33	FULL	106	All	The five bullet points listed are often seen in the severe CFS/ME stages and must be seen as part of the CFS/ME symptom list	Noted and this is recognised, but are also listed here as 'red flags' where additional investigation may be needed at any stage of the illness.
SH	Cambridgeshire Neurological	34	FULL	107	All	➢ The head-up tilt test should be carried out and that would	Issue 1 – Tilt test: The GDG did not find sufficient evidence that this was helpful

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	Alliance			Page 125 Page 126 Page 126 Page 126 Page 126 Page 127	25. All 1. 4. 7. 5.4 All	prove the level of disability ➢ Serology testing should be done as many people who have had tick bites, were in fact diagnosed with CFS/ME	in diagnosis. We have noted only that they are not to be used routinely, but that clinical indications should guide investigations Issue 2 – Borreliosis: The statistics on borreliosis from the National Reference Laboratory (England & Wales) in Southampton are that about 600 cases of borreliosis are diagnosed annually, of which only two to three have brain involvement. The lab has tested several hundred CFS patients using a validated and sensitive serological test and has found only one positive. This patient had evidence of prior infection - but the patient had had a tick bite and a feverish illness i.e. 'an indicative history'. Therefore, routine testing is not warranted. Issue 3 – Folate levels: The GDG did

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				Page 128 Page 132 Page 133	5.4.4 All All And 3.	➢ Foliate levels can be added as well NICE should recognised that extreme weight loss is also a feature of M.E. and can be due to the hormone disruption impact, severe confusion (i.e. not remembering to eat), unable to self-care, through level of disability, or severe allergies and food intolerances.	not find sufficient evidence that this was helpful in diagnosis as a routine test, but may be done if indicated. Issue 4: This section is with regard to excluding other conditions, for which extreme weight loss may be a symptom. The concern of the GDG is that many potentially life threatening conditions are not identified as the symptoms the patient experiences are attributed to the CFS/ME.
SH	CFS/ME Clinical Network Coordinating	5	FULL	107		Should the EBV/infectious mononucleosis be in the routinely	This is a list of tests which should not be done routinely.

National Institute for Health and Clinical Excellence
CFS/ME consultation draft
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	Centre					INCLUDED section?	
SH	Chronic Fatigue Research Unit at King's College London	5	FULL	91	5.2.5,2	Page 91 (5.2.5,2) draws attention to the conclusions of the Hickie et al 2006 BMJ paper on the predictors of post infective fatigue. There is no mention of our larger UK primary care based prospective study of the predictors of post infective fatigue in the larger cohort study carried out in UK primary care (Wessely S, Chalder T et al. Post Infectious Fatigue: A Prospective Study in Primary Care. Lancet 1995;345:1333-1338) which identified the role of pre exposure depression on the development of post infectious fatigue. That study showed a different pattern of predictors between acute and chronic post infectious fatigue, a	We have removed the recommendation on post-viral management. Regarding the evidence for post-infectious fatigue, that is outside the scope of this guideline. Note also we have clarified management in the early stages of the condition.

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						finding replicated in the subsequent albeit smaller King's EBV primary care study. The latter concluded that "In the univariate analysis, increased baseline levels of immune activation were associated with and predictive of fatigue at 3 months. Cortisol levels were not associated with, or predictive of fatigue. Using multivariate models of clinical and psycho-social baseline factors, severity of symptoms and illness perceptions were found to best predict fatigue 3 months later. At 6 months, fatigue was best predicted by female gender and illness perceptions, and at 12 months by female gender and a symptoms-disability factor" (Candy et al. Predictors of fatigue following the onset of infectious	

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						mononucleosis. Psychological Medicine 2003;33:847-853). That study is of particular interest since it concluded with a small randomised trial that showed that a single session of activity counselling decreased subsequent fatigue Given that it is accepted that EBV is an established risk factor for the development of CFS, then we believe that this finding is of clinical relevance – we note also that the ME Association in their submission , already published on the internet, appeal for more guidance on what to do in the early stages of illness, this might also speak to that issue (Candy et al A randomised controlled trial of a psycho-educational intervention to aid recovery in infectious	

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						mononucleosis. Journal of Psychosomatic Research 2004;57:89-94). NICEmight also note another new paper from New Zealand that is a prospective study of chronic fatigue and CFS after infection – in that paper EBV was a risk factor for chronic fatigue at 3 months, but not for CFS at 6 months- on the other hand depression and anxiety were associated with the onset of both (Moss-Morris R, Spence M. To "lump" or to "split" the functional somatic syndromes: Can infectious and emotional factors differentiate between the onset of chronic fatigue syndrome and irritable bowel syndrome? Psychosomatic Medicine 2006;68:463-469. 9).	

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SH	Chronic Fatigue Research Unit at King's College London	10	FULL	134	14-16	Page 134, lines 14 – 16: "CFS has been described as part of a broader condition that includes a range of disorders including fibromyalgia, irritable bowel syndrome…." True, and this will be well received by many doctors, since it reflects their views, and emphasises the way in which we can increase our knowledge of one "syndrome" by drawing on relevant information from another. The considerable literature now on fibromyalgia and its management, the literature on chronic pain, and so on and so forth, is directly relevant to many CFS patients in whom Generalised or muscle pain can be such a prominent feature. We think that this section could be strengthened by firstly making it clear that the	Thank you for these references. The cause of CFS/ME was outside the scope of the guideline, and it is not possible at this stage to review all the evidence on this issue. The GDG is aware of the Gibson Inquiry report and generally accepts the conclusions.

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						statement "has been described" is actually rather more evidence based – there are far too many primary studies to cite, but useful quantitative reviews are found in Aaron L, Burke M, Buchwald D. Overlapping Conditions Among Patients with Chronic Fatigue Syndrome, Fibromyalgia, and Temporomandibular Disorder. Arch Intern Med 2000;160:221-227 and elsewhere, and General reviews in Barsky A, Borus J. Functional somatic syndromes. Annals of Internal Medicine 1999;130:910-921. Wessely S, Nimnuan C, Sharpe M. Functional somatic syndromes: one or many? Lancet 1999;354:936-939. and there are also many systematic reviews of treatments	

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SH	College of Occupational Therapists	36	FULL	116	7	*"All treatments are offered allowing the person with the CFS/ME to refuse without compromising the future therapeutic relationship".* This is an ideal principle and one that we'd all like to assume but I'm concerned that it might be unworkable in reality. There are times when a patient's preoccupations etc may severely interfere with them making progress, snookering opportunities for the therapist to assist them with moving forward with any type of treatment. (In some of these circumstances we cannot continue to offer intervention at that time but would certainly be pleased to offer intervention without prejudice at a later stage if the person has progressed). Please could we have	The view of the GDG is that this an abiding principle.

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						more clarity here?	
SH	College of Occupational Therapists	41	FULL	88	25	"*disease*" is CFS a disease? A better word may be 'illness' or 'syndrome'.	Noted and consistent language has been applied throughout.
SH	College of Occupational Therapists	42	FULL	89	1, 2	Sentence appears out of context.	Thank you for pointing this out. This has been revised.
SH	College of Occupational Therapists	43	FULL	104		Only one other symptom in addition to fatigue. Are we now saying that all patients have chronic fatigue rather than chronic fatigue syndrome? In clinical experience there is a difference between those with a primary fatigue state, which is always likely to impact on mental functioning as well, and those who have a distinct range of symptoms with a number of features, as described in current criteria.	We have given guidance on broad criteria to alert the clinician to the possibility of CFS/ME, not for use as diagnostic criteria specifically. This has been clarified in the guideline.

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						There does not seem to be sufficient evidence presented to contravene current practice and clinical experience that there is a distinct syndrome.	
SH	College of Occupational Therapists	44	FULL	105	3rd box	Words "adult or" missing only, refers to child.	Noted and revised.
SH	College of Occupational Therapists	45	FULL	111	4, 5	Multiple authors – Sharpe et al – not just Wessely & Sharpe.	Noted and revised.
SH	College of Occupational Therapists	46	FULL	113	5	Is the *International CFS Study Group* the Canadian definition? If so, it needs to be referenced for cross-referencing.	Reference added.
SH	College of Occupational Therapists	47	FULL	125	25	Perhaps the possibility of anorexia nervosa and other eating disorders should be specifically mentioned in	The GDG considered that the cause of the weight loss was then to be explored, rather than suggesting causes in this

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						relation to weight loss.	guideline.
SH	College of Occupational Therapists	48	FULL	125	28	Add 'food intolerances and bowel problems.'	Noted, but this refers to difficulty eating as a key concern for the GDG. We have recognised elsewhere the symptoms of food intolerances and bowel problems.
SH	College of Occupational Therapists	49	FULL	127	7 / 8, 11/12, 13	Ethically, statement 2 is sound in terms of respecting an individual's choice. However, clients need to be aware that resources are limited and interventions are based on evidence, as stated elsewhere in this document. So, in essence, the therapeutic relationship may be compromised if the patient refuses an intervention because there may be no other intervention on offer and the therapeutic relationship ends. We must be honest from the outset as to what our services can	Noted.

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						offer and not raise unrealistic expectations. Statements 4 and 5 emphasise this.	
SH	College of Occupational Therapists	50	FULL	134	1	There would be a consequent adverse impact on both the therapeutic relationship and healing process.	We hope the revised text addresses this issue.
SH	College of Occupational Therapists	51	FULL	134	11	Doctor / healthcare professional.	This has been revised.
SH	Department of Health, Peninsula Medical School	21	FULL	88 -89	1- ..8	See above comments on p36, line 27. While the content of this section is largely apposite, it is unhelpful to start by saying it can be a problem! It should start by empowering clinicians to be more confident in the pattern recognition process that enables diagnosis. The problems can follow. The diagnosis depends	Noted and revised.

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						on recognition of the characteristic set of symptoms, appropriately characterised in type/range and by what factors affect them. NB it is important to explore the nature of the tiredness/fatigue just as we do pain, because the patient will then be able to clarify how different this experience is from everyday fatigue or fatigue associated with some other conditions (eg depression). The presence of malaise, worsened by exercise/activity is important as is cognitive change. Notably this has been reinforced by a recent study showing the symptoms that can help differentiate CFS/ME from depression (*Hawk C et al. Int J Behav Med 2006. 13: 244-251*). It is important to emphasise that a positive provisional diagnosis is	

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						most likely to be achieved by setting aside sufficient time to characterise the history upon which diagnosis depends, and to recognise characteristic features, such as delayed setbacks after over-activity. There should also be reference to the undoubted therapeutic benefit of the narrative history, as well as its valued role in diagnosis.	
SH	Department of Health, Peninsula Medical School	22	FULL	89	1, 7	"Red Flags" must be explained either here, or in the glossary of terms or both. Not everyone will know what these are.	Thank you for pointing this out. This has been revised.
SH	Department of Health, Peninsula Medical School	23	FULL	95	Table 9c	Here and throughout all text: The term is Creatine KInase. Creatinine is different. I am not sure if this is the reason for the confused statements on this test in the later sections (see below).	Noted and clarified for adults and children. We have revised the term.

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				95 107 109	Table 9c Box l. 2 5-6	At p 95, 9c, the statement is that CK is agreed as an appropriate test, but later and in the summary of recommendations it is stated as only agreed for children, but without any explanation for why and how this conclusion was reached. The recommendation is bizarre. One of the differential diagnoses for CFS/ME (adults and children) with prominent muscular pain or weakness is a primary muscle disorder (various myopathies) or a multi-system disorder affecting muscle (eg poly-/dermato-myositis, polymyalgia rheumatica, vasculitis). CK is a valuable screening marker for such muscle disorders, and is simply and cheaply done.	
SH	Department of Health, Peninsula	24	FULL	111	9-10	See comments above (P 36 line 12)	Thank you. This has been revised.

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	Medical School					re CDC. And spelling is "Centers"	
SH	Department of Health, Peninsula Medical School	25	FULL	111- 112	27-… -4 Sections 5.3.2.2/3	It may be worth pointing out that the Canadian definition has not (to my knowledge) been tested or validated as a set of criteria, in view of its popularity in some quarters.	Noted.
SH	Department of Health, Peninsula Medical School	26	FULL	114 - 115	16-.. -5	The text and the tabulation imply that the health professionals mentioned are all equally capable of making a diagnosis. Yet, apart from a hospital physician (not mentioned in the table – see below), most of these other professionals, although capable of contributing to treatment and assessment, are not trained or skilled to make diagnosis, especially not in the setting of complex differential diagnosis and co-morbidity. This section needs to be substantially re-thought and	Thank you for this comment. This section has been revised.

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						rewritten to reflect the actual roles, training and capability of different health professionals.	
SH	Department of Health, Peninsula Medical School	27	FULL	115	Table	Hospital consultant physician must be added, as this is probably the most common, and most expensive, health care professional, to whom patients are referred for diagnosis.	Thank you. This section has been revised.
SH	Department of Health, Peninsula Medical School	28	FULL	124	1: Box	Recommendations: Strongly agreed.	Thank you.
SH	Department of Health, Peninsula Medical School	29	FULL	125- 126	23- … -6	Are these the only "red flags" referred to above (89: 1,7)? What about suicidal ideation; extreme agitation/anxiety, for example, severe angina-like chest pain, niceness of breath on exertion, and numerous other symptoms that could signify other disease? It is	Noted, and the recommendation on this and the process of diagnosis have been revised,

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						important to be clear on what grounds any particular differential diagnoses are specifically promoted to be red flags as opposed to differential diagnostic clues. Whilst NICEwill not wish to write a medical textbook, it is important that its specific mention of "red flag" conditions are justified by some explicit criterion, and be explained to avoid diversion of attention away from the FULL range of differential diagnoses.	
SH	Department of Health, Peninsula Medical School	30	FULL	126	21	Add: co-morbidities that render diagnosis and/or treatment more complex. This, in my wide clinical experience, is the most important discriminant for referral to specialist care apart from severity.	Noted and revised.
SH	Department of	31	FULL	132	5.4.5	See also comments above on p 27	We have revised the process of

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	Health, Peninsula Medical School					algorithm. There is a serious problem with the phrasing of these three recommendations. Despite the first recommendation, the other two are written in a way to imply/encourage specialist referral rather than saying that, if referral is needed, these are the timings. The need for referral to a specialist unit is covered in the earlier text, but this needs to be restated or explicitly cross-referred to, so that primary care clinicians are enabled to care for patients within their competence and expertise.	diagnosis and management to clarify which interventions can be delivered in a generalist setting, and which interventions need specialised input.
SH	Department of Health, Peninsula Medical School	32	FULL	133	24-25	This statement ("no objective abnormalities") is very misleading. The research literature on the pathophysiology and manifestations of this illness, using a wide variety of techniques (eg blood changes,	This is now clarified in the text.

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						CNS imaging changes), shows that there are very many objective changes associated with the illness, some of which may be highly pertinent to the experience of illness (eg cytokine levels, fMRI changes). That is different from the use of "objective tests" in clinical diagnosis, which I think is what is being conflated here, and for which none have been shown to have the necessary specificity or positive predictive value.. This sentence needs to be rephrased, as it is currently manifestly incompatible with a substantial research literature.	
SH	Department of Health, Peninsula Medical School	33	FULL	133-5	Section 5.5	This is really valuable and Generally well stated. My specific comments below do not undermine the value that I attach for this, and	Thank you.

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						the need for its essence to be sufficiently replicated in the NICEversion.	
SH	Department of Health, Peninsula Medical School	34	FULL	133	27	A case definition can be "objective", as can a clinical diagnosis by a skilled clinician, even in the absence of "objective tests". I think the word needed here is "validated". Moreover, it is the very fact that a skilled and experienced clinician can convey a high level of diagnostic certainty that can make this transaction a powerful tool for re-enablement. If a primary care physician is unable to have that confidence to convey that level of conviction, then that is a basis for specialist referral.	The text has been amended.
SH	Department of Health, Peninsula	35	FULL	134-5	25 - .. -5	Agreed. However, the term "medically unexplained syndrome"	We hope the revised wording helps.

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	Medical School					merits a similar statement to that given on 135, lines 2-4. The fact that medicine cannot currently explain something neither makes it any less valid, nor a singular entity. It is simply a statement of the limitations of contemporary medicine and science, and has absolutely no relevance as a nosological entity in clinical discourse.	
SH	Invest in ME	103	FULL	88	1	- *Making a diagnosis of CFS/ME* "5.1 Introduction CFS/ME (Chronic Fatigue Syndrome/Myalgic Encephalomyelitis or Myalgic Encephalopathy) is a condition for which causation is uncertain and diagnostic criteria variable. "	The title of the guideline was amended to 'Chronic fatigue syndrome/myalgic encephalomyelitis (encephalopathy)' in response to the scope consultation with stakeholders.

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						IiME Comment: It is not encephalopathy – see WHO ICD 10 G93.3.	
SH	Invest in ME	104	FULL	88	9 onwards	• The range of presenting symptoms is wide, and fatigue and pain are not always the prominent features. IiME Comment: So why is fatigue so heavily emphasised and used to influence elsewhere in this document?	Noted and this sentence has been revised.
SH	Invest in ME	105	FULL	88	11onwards	• Patients may have been investigated extensively, but fruitlessly, for varied physical symptoms and may feel frustrated by the lack of help they have received from the medical profession by the time the diagnosis is made.	The guideline advises a full medical examination and makes research recommendations.

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						IiME Comment: The lack of a proper medical examination and lack of funding by MRC for biomedical research needs to be emphasized as a cause also.	
SH	Invest in ME	106	FULL	88	*18 onwards*	• CFS/ME cannot be diagnosed by any test currently available. IiME Comment: But there are markers (see Dr. Byron Hyde - Appendix 6 - 14).	Please refer to the section in this chapter on investigations for a discussion of this.
SH	Invest in ME	107	FULL	88	*23 onwards*	'Red flags' in the history and examination indicate the need for urgent specialised investigation. IiME Comment: They also indicate the urgent need for biomedical research to find a diagnostic test for ME.	This is beyond the scope of the guideline.
SH	Invest in ME	108	FULL	89	13	- 5.2.2.1	

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					onwards	There is insufficient evidence to show that potential diagnostic tests for CFS/ME are useful diagnostically for adults and children. 1 IiME Comment: Potential diagnostic tests will be useful in allowing a patient to become prepared early with a diagnosis of ME. 2 Specific diagnostic tests reviewed are: − the head up tilt test(2/3) − five laboratory blood tests (fibrinogen, prothrombin fragment 1+2, thrombin-anti-thrombin complexes, soluble fibrin monomer (SFM) and platelet activation (CD62P, ADP)) (3)	Issue 1: This comment refers to an evidence statement which is a statement that synthesises the evidence findings. The GDG discussed the evidence and agreed this statement. Issue 2: No evidence was found to support this. If evidence arises, it will be considered in the revision of the guideline.

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						− auditory brainstem responses (3) − electrodermal conductivity (3). IiME Comment: These tests may, however, identify subgroups of CFS/ME.	
SH	Invest in ME	109	FULL	90	1 onwards	- *5.2.4 Evidence Statements* *5.2.4.1* Clear risk factors for CFS/ME have not been identified. (2-) *5.2.4.2* There is low grade or limited evidence for a wide range of risk factors including: − sick certification after viral illness, IiME Comment: What about the viral illness itself? − presence of fatigue at time of viral	This is an evidence statement which is a statement that synthesises the evidence findings. However, because of the lack of utility of this evidence statement, this has been deleted.

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						illness, IiME Comment: Is this implying that the fatigue is the causative factor rather than the viral illness? − lower physical functioning, IiME Comment: This must be really low grade evidence if it exists? − higher pain and fatigue scores at baseline, older age (adults and children), IiME Comment: We fail to see what evidence this can refer to. − exhaustion, − being female, − low educational level, IiME Comment: Well, this puts the	

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						end to the idea of "yuppie flu"!!!! Are NICEreally stating that people of lesser education are now the suspects for ME? − visits to the GP, IiME Comment: This we find ridiculous! Are NICEstating that people who need to visit their GP are more inclined to get ME? Maybe the frequency of visits might have something to do with being disbelieved? It might have something to do with symptoms persisting despite 'standard' treatment? Is NICEattempting to portray ME patients as hypochondriacs? − longstanding limiting medical condition aged 10 years,	

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						− higher social class in childhood, IiME Comment: And yet lower educational level earlier! − psychological distress prior to presentation, IiME Comment: Where is the evidence for this? It does NICEno credit to list these 'risk factors' without supplying evidence. − presence of infectious mononucleosis, − positive Monospot tests at time of onset, − time in bed at onset, − exercise power, − mood disorder. (-2)	

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						IiME Comment: We do not believe this is worthy of a document purporting to assist diagnosis or treatment of ME. It is widely accepted that ME follows viral or bacterial infections, vaccinations, chemical exposure. Yet these risk factors are not mentioned at all. There is no mention of the pressure on returning to work or school prematurely after infection as a cause for long term ME. What is low grade is the research funding and epidemiological studies. *5.2.4.3* Clear risk factors for development of CFS/ME in children and young people have not been	

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						identified (2-) IiME Comment: How about pressure to return to school too early?	
SH	Invest in ME	110	FULL	91	18-23	- 5.2.5.2 *Additional Clinical Evidence* No new evidence was found in the update searches. However, a recent paper in the BMJ concluded that 'prolonged fatigue states after infections are common and disabling' and that post-infective fatigue syndrome was predicted 'largely by the severity of the acute illness, rather than by demographic, psychological, or microbiological factors'. This strengthened the recommendation regarding post viral management.	We have removed the recommendation on post-viral management.

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						IiME Comment: What about research from Dr. Vance Spence and oxidative stress? This is due, perhaps, to the make up of the NICE group which seems to have nobody qualified to analyse this data.	
SH	Invest in ME	111	FULL	91	25	- *5.2.6 Health Economics Evidence Summary* The investigations needed to rule out other significant disease before making a positive diagnosis of CFS have a number of components which are of importance from an economic perspective. IiME Comment: Are we still discussing ME or is it just now CFS? These are very lax standards of precision in this document.	Noted with thanks, this has been changed.

National Institute for Health and Clinical Excellence
CFS/ME consultation draft
29 September – 24 November 2006
Comments on chapter 5

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SH	Invest in ME	112	FULL	92	*12-17*	"Any approach which produces the same outcome for less healthcare provider time will improve the cost-effectiveness of the overall process." IiME Comment: This last sentence is so risky as it will inevitably lead to short-cuts, lack of precision in diagnosis and almost inevitable degradation in treatment.	For the evaluation of cost-effectiveness, both costs and consequences of an intervention are examined. Therefore, the quoted paragraph has to be viewed in context of the prior section. It can be assumed that patients accrue disutility over time while they go through multiple investigative procedures until a final diagnosis is made. This means that the longer this period is, the greater the quality of life loss in absolute terms. Necessary staff time is directly linked to the costs of a test, and with the disutility to the patient over time, less time intensive interventions are expected to be more cost-effective. It should be noted that "the same [effectiveness] outcome" means per definition that items such as 'diagnostic precision' will not be compromised by

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							an alternative programme.
SH	Invest in ME	113	FULL	92	18 onwards	"Regarding the role of investigations after a positive diagnosis of CFS has been made, the likelihood of the result of the investigation changing management should be considered, together with the improvement in quality of life that change might bring, and contrasted with the cost of the investigation and the disutility of the investigation to the individual " IiME Comment: Are we still discussing ME or is it just now CFS? These are very lax standards of precision in this document.	Noted with thanks, this has been changed.
SH	Invest in ME	114	FULL	93	1 onwards	*5.2.7 Clinical Scenario Questionnaire to GDG and Wider Group*	In accordance with the methodology for clinical scenarios, the assumptions that form the basis for answering the questions must be explicit. So that

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						1. The person with the CFS/ME and health care professionals involved in their care will make decisions in partnership. These are directed by the patient's personal preferences and builds on the existing experience and skills of the professional. IiME Comment: Elsewhere it is the patient who is in control yet here it is partnership. It should be consistent throughout these guidelines that the patient is always in control. Decisions cannot be based on existing experience of the 'professional' if they are biased or lacking in appropriate knowledge. This very much depends on the healthcare professional associated with the patient.	respondents have a common understanding of the factors which influence the appropriateness of treatment. These statements were agreed as assumptions for the questionnaire. They are not guideline recommendations. A fuller explanation is in the methodology chapter.

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						2. All treatments are offered allowing the person with the CFS/ME to refuse without compromising the further therapeutic relationship. IiME Comment: Yes – this is extremely important 4. Treatment is provided by the NHS in the context of availability of adequate numbers of competent, appropriately trained health care professionals. IiME Comment: This is important but who decides 'appropriately trained'?	
SH	Invest in ME	115	FULL	104	1 onwards	*5.2.8 Recommendations* Primary healthcare professionals should be familiar with the presenting features of CFS/ME, and	We have given guidance on broad criteria to alert the clinician to the possibility of CFS/ME, not for use as diagnostic criteria specifically.

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						be able to identify these features when adults and children consult. CFS/ME should be considered if an adult or child has fatigue that is all of the following: • persistent and/or recurrent, and • unexplained by other conditions, and • results in substantial reduction in previous activity level, and • characterised by post-exertion malaise and/or fatigue (often delayed with slow recovery), AND one or more of the following symptoms: • difficulty with sleeping (for	This has been clarified in the guideline.

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						example,, insomnia, hypersomnia, unrefreshing sleep, disturbed sleep/wake cycle) • muscles and/or joint pain(multi-site without evidence of inflammation) • significant headaches of new type, pattern or severity • painful lymph nodes without pathological enlargement • sore throat • cognitive dysfunction, for example difficulty thinking, inability to concentrate, impairment of NICE-term memory, word-finding difficulty, difficulty to plan/organise thoughts,	

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						difficulty with information processing • physical or mental exertion making symptoms worse • recurrent flu-like symptoms • dizziness, nausea and palpitations. IiME Comment: This is too broad a definition. The Canadian Guidelines is more specific and should be used. Many tests exist in aiding a diagnosis for ME. Therefore, using psychological therapies for 'unexplained fatigue' is inappropriate. Although diagnostic tests for ME are still being worked upon with promise, nevertheless many tests	Re investigations – No evidence was found for the use of scans and other tests. If evidence arises, it will be considered in the revision of the guideline.

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						and procedures can be administered in aiding a diagnosis of ME. These include the use of SPECT, MRI and PET scans, test for NK cell activity and endocrine abnormalities, Tilt Table Test, viral tests and many more (Appendix 6 – 13). Although these tests aren't always offered by the NHS for ME, they have nevertheless shown evidence of physical abnormalities. Head-up tilt test is used in research for examination of ME patients. Serology for chronic bacterial infections e.g. borelliosis – this ought to be present as standard. It is unbelievable that serology testing for latent infections (toxoplasma, EBV (Epstein Barr virus), CMV (cytomegalovirus)) "in	Re mycoplasma: We have stated that serological tests for past infection, with any agent, cannot establish aetiology. Acute illness caused by mycoplasma infection may of course trigger CFS/ME, but there is no evidence to suggest that

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						the absence of any indicative history," is not performed. Where is the test for mycoplasma which is implicated in many ME cases?	mycoplasma has any role in the maintenance of the disease.
SH	Invest in ME	116	FULL	*105*		*"similar symptoms and signs as CFS/ME"* IiME Comment: The biomedical community have listed a number of contraindicative conditions that need to be considered in isolating a diagnosis of ME These could be proposed for inclusion here to replace the existing text. "Primary healthcare professionals should listen careFULLy to parents' and/or carers' concerns and be willing to reassess their initial opinion, or to seek a second opinion	Issue 1 – Signs and symptoms : Noted with thanks.

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						from a 'colleague if a child fails to recover as expected. " IiME Comment: who is 'qualified' and who is a 'colleague'? This is a very interesting formulation of expression, as this could come from the discredited MSBP diagnosis criteria, and is obviously biased towards the psychosocial model. Biomedical experience of ME professionals confirm that it is quite a common occurrence that patients do not recover in the traditionally anticipated manner. However, this does not indicate psychological intervention, rather a lack of understanding of the aetiology and treatment attempted. Surely a referral to a paediatrician with expertise in ME should be	Issue 2 – Second opinion:The wording

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						made to ensure that ME is correctly assessed, rather than a General paediatrician? Shouldn't a referral be made more rapidly than "within 6 weeks"? "As with other potentially chronic conditions, before progressing to a diagnosis of CFS/ME, medical examination and assessment of mental health (both targeted according to the presenting symptoms) should be carried out. " IiME Comment: Why mental health – is this applicable to all other illnesses – such as cancer, MS, IBS? This is quite shocking. Is it usual to have psychiatric assessments of patients presenting	is taken from the Referral for Suspected Cancer guideline. As with CFS/ME, cancer is rare in children and is not the first thing that may be suspected. This aims to encourage healthcare professionals to listen to parents/carers, 'think outside the box' and to seek a relevant second opinion. It would be difficult to dictate from whom the opinion would be sought as this would depend on the symptoms. We have revised the recommendation on mental health…

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						with "*potentially chronic conditions*"? This, again, indicates bias towards the psychosocial model.	
SH	Invest in ME	117	FULL	*106*		"In the absence of a definite diagnosis and/or while waiting for referral, advice and symptom management should not be delayed until a diagnosis is made." IiME Comment: This statement again goes in direct contravention of the biomedical model, where treatment requires a specific diagnosis. "When an acute infection is followed by excessive fatigue, the adult or child should receive advice on how to promote recovery. The advice should focus on sleep management, risks of prolonged	Issue 1: The view of the GDG was that symptoms should be managed while waiting for a diagnosis. Issue 2: This recommendation has been removed.

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						bed rest (for example, deterioration in muscle function), and a gradual return to a normal daily routine. " IiME Comment: Surely the promotion of adequate rest is more important. The testimonies in this document alone detail the risk of returning to activity too soon. You are not listening to the patients. How about the risks of GET and CBT and other psychological therapies? The benefits of adequate rest need to be emphasised along with adequate supplies of current, accurate information about ME and the research which is underway. "Investigations should be tailored to the history, and signs and symptoms of the adult or child, taking into account other possible	Issue 3: The GDG considered this to be an appropriate recommendation.

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						diagnoses. " IiME Comment: What does this mean? It is so loose that it is an irrelevant comment. "Before progressing to a diagnosis of CFS/ME, investigations should be carried out to exclude other diagnoses that would explain the symptoms. Such tests could include the following, but clinical judgment should be used. • Urinalysis for protein, blood, glucose. • FULL blood count. • Assessment of blood ferritin levels (children only). • Urea & electrolytes.	

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						• Liver function tests. • Thyroid function tests. • Erythrocyte sedimentation rate / plasma viscosity. • C-reactive protein. • Random blood glucose. • Serum creatinine. • Screening blood tests for gluten sensitivity. • Serum calcium. • Creatinine kinase (children only). " IiME Comment: What is the physical biological/biomedical basis for defining these clinical tests in relation to the aetiology of ME? This list needs to be modified, at a	Issue 4: No evidence was found for the use of these tests as diagnostic tools. If evidence arises, it will be considered in the revision of the guideline.

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						minimum. Prof Puri has identified raised levels of Choline along with other chemicals in the brain blood interface in ME patients, and Drs Kerr and Gow have identified modified gene expressions unique to ME patients. If we look at the gene array we do find some abnormalities, but if patients with ME/CFS, exercise then we find a lot more abnormalities. The standard NHS blood and thyroid function tests have been shown not to address specific expressions in ME patients and, therefore, cannot provide reliable results. There is still debate about specific thyroid function tests being implicated in ME, e.g. maladjustment of T3 and T4 levels that do not provide the expected results.	

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SH	Invest in ME	118	FULL	*107*		The following tests should not be done routinely. • Serology testing for chronic bacterial infections (for example, borelliosis) in the absence of any indicative history. IiME Comment: It is an odd assessment to ignore this with current evidence available. The potential of misdiagnosis is great. This test needs to be considered. • Serology for General viruses (for example, heterophile antibody tests for infectious mononucleosis) in the absence of any indicative history. • Serology testing for latent infections: toxoplasma, EBV (Epstein Barr virus), CMV	Issue 1 The statistics borreliosis from the National Reference Laboratory (England & Wales) in Southampton are that about 600 cases of borreliosis are diagnosed annually, of which only two to three have brain involvement. The lab has tested several hundred CFS patients using a validated and sensitive serological test and has found only one positive. This patient had evidence of prior infection - but the patient had had a tick bite and a feverish illness i.e. 'an indicative history'. Therefore, routine testing is not warranted. Issue 2 Mycoplasmal infections. We have stated that serological tests for past infection, with any agent, cannot establish aetiology. Acute illness caused by mycoplasma infection may of

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						(cytomegalovirus) in the absence of any indicative history. IiME Comment: Mycoplasmal infections need to be found early as it is implicated in CFS/ME cases and can be treated with antibiotics. Some of the infectious agents which have been associated with development of CFS/ME and for which an established treatment exists are Enteroviruses, Epstein-Barr virus, Cytomegalovirus, Human herpes virus-6, Parvovirus B 19, Hepatitis C, Chlamydia pneumoniae and Coxiella burnetii (Appendix 6 - 18) and whether elevated levels of Choline can be used as a "fingerprint test" for ME, as suggested by Prof Puri.	course trigger CFS/ME, but there is no evidence to suggest that mycoplasma has any role in the maintenance of the disease.

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SH	Invest in ME	119	FULL	107	*3-6*	5.2.9 Deriving Recommendations The GDG decided that certain investigations should be carried out to rule out other diseases and conditions, but it was impossible to recommend a definitive, comprehensive list IiME Comment: which surely shows a failing in these guidelines. We need to have a list, which can be added to as more research becomes available. These guidelines already rule out necessary testing of known mis-diagnoses.	The GDG has given general guidance but tests must be based on the presenting symptoms. The GDG discussed this but it would be impossible to be inclusive re-writing a medical textbook..
SH	Invest in ME	120	FULL	108	*3 onwards*	As stated above, viral serology, in the absence of a recent history suggesting viral infection, should not be carried out. In reviewing the results from the wider survey, the	We have revised the recommendations to emphasise the role of investigations in diagnosis, including the role of serology testing.

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						GDG decided that it was difficult to establish a link between CFS/ME and serology indicating past viral infection and that serological evidence of past infection would not alter the patient's management IiME Comment: But it might give earlier diagnosis- what about antimicrobials used early? (Appendix 6 - 18). See earlier response re Devanur and Kerr.	
SH	Invest in ME	121	FULL	110	*1*	- *5.3 Arriving at a Diagnosis* *5.3.1.1* Evidence to substantiate existing case definitions of CFS or ME is limited. No studies have established the superiority of one case definition over another IiME Comment: Why are the Canadian Guidelines Criteria not	We have added a synthesis of criteria used in other guidelines (from the New Zealand Guidelines Group) for information. We have also revised the recommendations on diagnosis for clarification.

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						referenced here, since they are becoming more widely accepted around the world by the biomedical community of ME experts, rather than inventing a further set of criteria that are not agreed outside the psychosocial model practitioners? *5.3.1.2* Community based studies have indicated that patients meeting CDC 1994 criteria form a more heterogeneous group than patients meeting CDC 1988 criteria (2-) IiME Comment: So shouldn't Canadian guidelines ("even more stringent" according to NICE) now be used ?	
SH	Invest in ME	122	FULL	110	7 onwards	- *5.3.2 Clinical Evidence Summary* The definition of CFS/ME is based	The York review was conducted using recognised and validated methods in accordance with NICE methodology.

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						upon its classification as a 'syndrome,' that is, a pathological condition characterized by its symptoms rather than its cause. The systematic review conducted by the Centre for Reviews and Dissemination (CRD) at the University of York forms the primary evidence base for adult-onset CSF/ME in this guideline IiME Comment: Isn't this then putting the whole guidelines document at risk as that York review was limited and unrepresentative?	Details of the methods are reported in the full guideline.
SH	Invest in ME	123	FULL	111	*4-8*	The Oxford Criteria of CFS/ME, developed in 1991 by British psychiatrists Simon Wessely and Michael Sharpe defined CFS/ME as a "syndrome in which fatigue has	Have revised this statement.

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						been present for at least six months, during which time it has been present more than 50 per cent of the time." Other symptoms may also be present such as myalgia, mood and sleep disturbance. . IiME Comment: These are psychiatrists and cannot represent a pathological illness. The Oxford criteria are far too broad to be of any use.	
SH	Invest in ME	124	FULL	111	*27*	The 2003 Canadian definition is more stringent and was developed by an international CFS clinical team. IiME Comment: So why not recommend the use of the Canadian Guidelines if they are more stringent.	The evidence review concluded that no current case definitions are established as being superior to the others. The Canadian criteria are based on expert opinion, and not research evidence.

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SH	Invest in ME	125	FULL	113	*17 onwards*	*Health Economics Evidence Summary* IiME Comment: The economics of diagnosis are of little interest. Accurate diagnosis is the requirement and will likely lead in the long term to economies. We believe it is a false economy to attempt to quantify at the outset which line of diagnosis is to be used based on this ROC curve model.	There are necessary decisions to make when it comes to diagnosis and the all consequences to the NHS and its patients need to be included in this process. Please see Nicola Crichton's article (J Clin Nur 2002;11:134) for an introduction to ROC curves.
SH	Invest in ME	126	FULL	116	*4 onwards*	1. The person with the CFS/ME and health care professionals involved in their care will make decisions in partnership. These are directed by the patient's personal preferences and builds on the existing experience and skills of the professional. IiME Comment: Patient must be in	Issue 1: We have recommended throughout the need for partnership, working with individuals as they prefer. It should also be noted that this relationship may change over time as people become more expert in self-management if appropriate.

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						control, not just partnership. Will this model then support a patient who refuses CBT and GET, in the knowledge that these therapies are either unhelpful or harmful, when insurance companies demand that they be used? 2. All treatments are offered allowing the person with the CFS/ME to refuse without compromising the further therapeutic relationship. IiME Comment: Agreed. We welcome this. 3. There is a good rapport in which the patient and their families/carers feel believed and validated. IiME Comment: Do NICEapply similar comments to other biological	Issue 2: Thank you. Issue 3: We have recommended this to address concerns that people are not being believed, and have also recommended that the reality and impact of the condition and symptoms should be acknowledged.

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						illnesses – cancer, MS, HIV/AIDS? Do these patients have to be 'believed' and 'validated'? Isn't this indicative of the current environment where ME patients are treated as having a somatoform condition? 4. Treatment is provided by the NHS in the context of availability of adequate numbers of competent, appropriately trained health care professionals. IiME Comment: Who decides which 'professionals' are competently trained. These should be specified.	Issue 4: Details of training are outside the scope of a clinical guideline. However, it is anticipated that appropriate professional bodies will ensure that healthcare professionals are adequately trained.
SH	Invest in ME	127	FULL	124	*1*	- *5.3.5 Recommendations* 5.3.5.1 A diagnosis of CFS/ME in an adult should be made after symptoms have persisted for 4	Issues 1 and 2: The diagnosis recommendations have been revised to clarify. Regarding the time frames, these are guides to allow for appropriate investigation and to ensure

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						months, and after other likely causes of the symptoms have been ruled out IiME Comment What are the agreed criteria for diagnosis? Shouldn't the international Canadian Guidelines be used for such a diagnosis, and what is the reason for the proposed 4 months delay? This again flouts accepted international wisdom that early diagnosis and intervention can help prevent the onset of severe ME and provide evidence for refinement of diagnostic tools. *5.3.5.2* The diagnosis of a child should be made by a General paediatrician after symptoms have persisted for 3 months and other likely causes of the symptoms have been ruled out	that people are not left without a diagnosis after a prolonged period. However, where a diagnosis <u>can</u> be made earlier, then there is no requirement to wait for the time points stated.

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						IiME Comment Again, a paediatrician with expertise in ME would, surely, be more appropriate. Also, why wait 3 months for a diagnosis, as a different time period from an adult? Early diagnosis is even more important for children. *5.3.5.3* When a diagnosis is made, a prognosis of cautious optimism should be conveyed. With appropriate management, most children and adults, but not all, will have some improvement and some will recover fully. IiME Comment: What is the scientific basis for this statement? Why single out this illness from others. Where is the basis for this statement? 'Some' adults, 'some' children, 'some' will and 'some'	Issue 3: Noted and revised to reflect Centres for Disease Control and Prevention data on prognosis

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						won't. Define or quantify 'some'. Otherwise this is a totally pointless statement. Patients want honesty – even children – so it is better to be realistic and factual rather than woolly and unspecific Has there ever been any scientific research published in the international community to base such a prosaic statement for cautious optimism. Has there been a scientific or rigorous assessment of the outcomes of ME patients? This paragraph/statement raises a number of major questions that need to be answered before the statement could be accepted, such as: how many patients were involved; what was the patient selection criteria; what were the	

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						diagnostic tools used to confirm the cohort was purely suffering ME; were there other medical or clinical influences; over what period of time did the study follow individual patients progress; what happened to the severe ME sufferers; what were the demographics; what were the statistical analysis results; what appropriate management techniques were trialled; what were the statistical samples of age and gender; what definition of "most" was employed, e.g. simple majority of all participants over/under a defined age; what percentage recovered FULLy; how was "some improvement defined"; who performed the research; was more than one medical research centre involved in the research; was the	

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						research approved by the Medical Ethics Committee; what clinical and research qualifications did the researchers possess; where were the study results published; who were the independent academic referees who assessed the academic and scientific rigorousness; and, who funded the study to be conducted? If any of the above questions can not be answered with adequate academic probity, then the statement must be removed.	
SH	Invest in ME	128	FULL	124	*5*	- *5.3.6 Deriving Recommendations* Diagnostic Criteria The GDG reviewed the current diagnostic criteria, but did not find any one of them particularly helpful in managing the condition or in	The evidence review concluded that no current case definitions are established as being superior to the others. The Canadian criteria are based on expert opinion, and not research evidence.

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						making a definitive diagnosis. IiME Comment: This cannot be correct. The Canadian guidelines give specific expertise on diagnosis. Other specialists (Dr. Byron Hyde) also have good diagnostic criteria.	
SH	Invest in ME	129	FULL	124	*7*	The case definitions used in research papers are not necessarily helpful in clinical practice, especially in a condition whose symptoms evolve gradually and where early recognition and treatment is probably beneficial. IiME Comment: Acute onset ME is not gradual. Most ME cases are acute onset.	This section has been revised.
SH	Invest in ME	130	FULL	124	*12*	The GDG was concerned that the application of narrow diagnostic criteria may make it less likely that	The diagnosis recommendations have been revised.

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						advice and treatment is given early in the course of the illness. On the other hand, the GDG were also concerned that if broader criteria were used, people would be falsely diagnosed and other serious conditions missed. IiME Comment: Exactly - which is why the Oxford criteria are unfit for ME. Why does NICEcontinue using these criteria and not come out in favour of the Canadian guidelines which are more stringent? There is no point in having Generalised and inaccurate criteria – such as the Oxford – if it means including other conditions due to the range allowed. This document is supposed to be for a neurological illness.	The evidence review concluded that no current case definitions are established as being superior to the others. The Canadian criteria are based on expert opinion, and not research evidence.
SH	Invest in ME	131	FULL	125	*12*	- *Making a diagnosis*	Noted and revised (see also the

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						However, the GDG decided that a diagnosis was crucial to the patient and their families in understanding their symptoms and receiving appropriate treatment. It must however, be considered a working diagnosis and regularly reviewed IiME Comment: Shouldn't it be based on a thorough medical examination? Patients should be treated as individuals and not be the object of labelling. CFS/ME should not be seen as a dead end diagnosis where all investigations stop and patients are only called in for note taking.	recommendations on assessment and investigation).
SH	Invest in ME	132	FULL	125	*18*	Signs and Symptoms There was strong agreement that persistent, debilitating, post exertional fatigue characterised the	The recommendations are based on evidence for such interventions; however, patient preference and need is paramount throughout.

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						condition IiME Comment: So why is GET recommended?	
SH	Invest in ME	133	FULL	132	*1*	5.4.5.1 IiME Comment: [*Referral to specialised care* …] A referral of a patient diagnosed with ME should follow agreed diagnostic criteria that have been developed by gaining an understanding of the aetiology of the illness. Is there a "fingerprint test" that can differentiate Chronic Fatigue states from the neurological condition defined by the WHO ICD-10 93.3 definition? If not referral should be based on "cautious best practice approach", noting that patients suffering with severe ME may be damaged by the application of GET and that there is no proof	As noted throughout, management should be agreed with the patient and should be guided by the patient's preferences and needs.

The comments made by registered stakeholders during consultation, and responses from the guideline development group (GDG), are now available in the following tables. The comments received from stakeholders are not endorsed by the GDG or the Institute and appear here only as record of the comments that the GDG received. (Please note that where a particular comment has not been responded to directly by GDG, this should not be taken to mean that the GDG agrees with that comment.)
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						that CBT can assist such conditions. In fact, the "drop-out" rate of severe ME patients from the CNNC centres would suggest that CBT provides no positive outcomes. The CNNC should be able to provide statistics for their operation. However, it is noted that without scientifically rigorous statistical analysis this response statement is purely anecdotal, like much of the content of the proposed NICEguidelines. [*Referral* …] In addition to previous comments about timescale delays for referrals, what criteria are to be used to select the "moderate" or "severe" ME symptoms to instigate accelerated or immediate referral action? This statement seems to contradict a previously stated (and	Regarding timeframes, definitions of severity can be found at the beginning of the guidelines, and earlier referral/diagnosis can be made if appropriate, for example for people with severe/disabling symptoms.

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						challenged) need for a diagnosis after 4 months for an adult and 3 months for a child.	
SH	Invest in ME	134	FULL	132	1 onwards	5.4.5.3 "The GDG considered that when seen in the early stages of illness, it is reasonable to observe adult patients for a few weeks before specialist referral as some patients will improve spontaneously. The view of the GDG is that no adult should wait for more than 6 months for a referral. " IiME Comment: In the early stages of illness it is important to identify viral or bacterial causes and treat them early with relevant antimicrobials. What are the statistics relating to	However, patients may present with symptoms which then improve spontaneously, in which case they probably did not have CFS/ME. We refer to symptoms improving, not spontaneous remission of CFS/ME.

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						this (wonderful event of) spontaneous improvement? From which clinical study are the published and peer-reviewed results available? The Guideline Development Group and the Independent Guideline Review Panel established with the National Collaborating Centre should have reported the significant findings to support this statement. Without the scientific basis to support this statement, this statement should be removed or reworded to - "Some patients who are not found to have ME will improve spontaneously".	
SH	Invest in ME	135	FULL	133	*7 onwards*	"Referral to a multi-disciplinary team specialising in CFS/ME The GDG decided that a referral should be made following a	The statistics on borreliosis from the National Reference Laboratory (England & Wales) in Southampton are that about 600 cases of borreliosis are diagnosed annually, of which only two

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						diagnosis. However, this may be a provisional diagnosis rather than a certainty. The view of the GDG was that 3-6 weeks following the onset of symptoms was Generally too short a time but that 6 months is too long. The GDG decided that 3-4 months following the onset of symptoms, once exclusion tests were completed and following a provisional diagnosis, was Generally the appropriate time to refer patients to a multi-disciplinary team specialising in CFS/ME. However, this needed to be based on the individual, as people with severe symptoms needed to be referred immediately. " IiME Comment: Infectious agents (such as Mycoplasma pneuomoniae), which are implicated	to three have brain involvement. The lab has tested several hundred CFS patients using a validated and sensitive serological test and has found only one positive. This patient had evidence of prior infection - but the patient had had a tick bite and a feverish illness i.e. 'an indicative history'. Therefore, routine testing is not warranted.

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						in ME, may not be picked up by the test recommended to be performed by a GP. It is no point in waiting 3-4 months before prescribing antibiotics. Lyme Disease needs to be treated early so the diagnostic test (preferably the more precise US or Euro version) needs to be made. It is not only patients with severe symptoms who need to be treated early.	
SH	Invest in ME	136	FULL	133	*16 onwards*	5.5 A Conceptual Framework There is little understanding of the nature of the disease and there were differing views on the GDG about this with lengthy discussions. A view held by a few individuals on the GDG was that CFS/ME could	The framework has been revised. We recognise that there are different views on the nature of the disease, including whether CFS and ME are distinct entities. We accept the Gibson Inquiry's view that the origins and nature of CFS/ME are poorly understood and that more high quality biomedical research

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						not be identified or managed unless a broader view was taken. This perspective is put forward below. IiME Comment: Views by ME support groups show that ME must be seen as a distinct and separate illness from CFS. This is part of the problem with healthcare staff and others – by broadening the view inevitably the requirements for diagnosing and treating ME patients will be diluted.	is required. We have revised the framework in an attempt to account for the different views and level of knowledge in a way that encourages professionals and patients to work together to improve care and services.
SH	Invest in ME	137	FULL	133	*20 onwards*	A conceptual framework for patients and health professionals when making a diagnosis of Chronic Fatigue Syndrome IiME Comment: Are we now talking only of CFS? There is a complete lack of precision in this terminology	This has now been clarified.

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						!!! "A diagnosis of Chronic Fatigue Syndrome (CFS) is made on clinical grounds alone after the exclusion of conventional disease processes that could account for the wide-ranging symptoms that are usually experienced by patients with CFS. As there are no objective abnormalities to account for the illness experienced and the associated disability suffered in CFS, additional distress for patients, their families and the wider social network commonly occurs. Importantly, the lack of an objective definition of CFS as a discrete disease entity can jeopardise the therapeutic relationship between patient and healthcare professional with a consequent adverse impact	

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						on the healing process. The relationship between the individual with CFS, their families and health professional can be further stressed by disagreements about the origins of CFS. " IiME Comment: Are we now talking only of CFS? Complete lack of precision in this terminology !!! Appalling precision in these guidelines.	The terminology has been clarified.
SH	Invest in ME	138	FULL	134	*5 onwards*	"Entrenchment and polarisation of viewpoints about a physical or psychological origin of CFS undermines relationships that support recovery" IiME Comment: so much evidence exists to support the biological viewpoint that this should not be	The GDG accepts the Gibson Inquiry's conclusion that no current theory on the causes of CFS/ME is, as yet, supported by sufficient evidence, and that further biomedical research is necessary.

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						here at all. ME patients are concerned about treatment for ME patients – not CFS "Another consequence of the unclear definition and aetiology of CFS is the difficulty experienced by patients and healthcare professionals in distinguishing CFS from several overlapping conditions such as fibromyalgia and irritable bowel syndrome. " IiME Comment: This is ludicrous – ME has clearly distinct symptoms which proper medical examination will show. "Differing beliefs about definition and cause of CFS can extend from the patient and the doctor to family members and the wider community resulting in dissatisfied, disabled	The text has been revised. The GDG was conscious that some patients still experience delay in diagnosis. This section now includes statements intended to reduce this problem.

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						patients and frustrated doctors. " IiME Comment: It also results in bigoted and biased doctors "The patient journey can become an ordeal with unnecessary distress, added costs and waste for the health economy, the patient and their family. CFS has been described as part of a broader condition that includes a range of related disorders including fibromyalgia, irritable bowel syndrome, chronic pain, pelvic pain, temporomandibular joint dysfunction and atypical facial pain. " IiME Comment: Are we talking about CFS or ME? ME has also been described as a	See our comment above about acceptance of the Gibson Inquiry's conclusions.

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						multi-system order involving immunological, endocrinological, cardiovascular and gastroenterological…..	
SH	Invest in ME	139	FULL	134	*25 onwards*	"Terminology used by doctors such as 'functional syndrome' and 'medically unexplained symptoms' are part of common usage in clinical practice today. The terms have arisen to describe non-conventional diseases and are intended to validate CFS and overlapping conditions to help improve patient care and research into the disorder. Although the term 'functional' has been found to be more acceptable with patients than terms such as 'psychosomatic' or 'medically unexplained', some terminology has become derogatory with use. "	This section has been revised. We seek to acknowledge that different people hold different views on causation, and sometimes these views are strongly held. Since we do not know what the cause of CFS/ME is, the GDG cannot accept any of the current theories, but must instead encourage more basic research and encourage those who hold strong views to take a more tolerant, open-minded attitude to ensure that patients who may benefit from various interventions do have access to those interventions.

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						IiME Comment: Are we talking about CFS or ME? This shows the hypocrisy with current healthcare in the UK toward ME. The reason that some terms have become derogatory relates to the lack of guidelines to healthcare staff to see the biomedical evidence behind ME and to obfuscate the issue by insisting on treating ME with psychological therapies. "*The terms have arisen to describe non-conventional diseases and are intended to validate CFS and overlapping conditions to help improve patient care and research into the disorder*". The term ME has been in the WHO ICD category as a neurological	

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						illness for a long time. NICEcould have taken the initiative and used the WHO term. Instead it does nothing but perpetuate the myths here.	
SH	Invest in ME	140	FULL	135	*2 - 5*	"For some patients and health professionals, the functional concept and all associated terminology are deemed unacceptable. The 'mental or physical' condition debate predominates in the clinical encounter undermining the doctor patient relationship. " IiME Comment: These NICEguidelines are doing little to prevent this from continuing.	We hope the revised version of this section of the guideline will lead to improvements in this regard.
SH	Invest in ME	141	FULL	135	*6*	"Outcomes are likely to improve if the diagnosis of CFS is	It should have been CFS/ME, as

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					onwards	communicated more successFULLy through a collaborative approach between the patient and doctor leading to a therapeutic relationship. " IiME Comment: Are we talking about CFS or ME? "This requires doctors to take an active approach to provide accurate information and to discuss key issues with patients on an ongoing basis to achieve better outcomes. " IiME Comment: It also requires the doctor to be aware of current and past biomedical research. If an effective therapeutic relationship is to develop, doctors must acknowledge that, despite the current lack of understanding of	throughout the guideline. Noted and healthcare practitioners should be aware of the relevant research to their practice. We agree that the clinician should

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						underlying causes of CFS (IiME Comment: Are we talking about CFS or ME?), the symptoms are real and the suffering and associated disability is genuine. The ideas, concerns and expectations of the patient, carers, families and the doctor should be explored for differences and similarities. Appropriate and agreeable terminology and understanding is important when making a diagnosis and establishing a therapeutic relationship. The definition and concept of CFS (IiME Comment: Are we talking about CFS or ME?) through a biopsychosocial model acknowledges the role of both external and internal influences on the development of and recovery from CFS (IiME Comment: Are we	acknowledge that the suffering and disability are genuine and hope the revised text is helpful. Please see the Diagnosis chapter for a further discussion of these additional issues.

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						talking about CFS or ME?). The biopsychosocial model negates the duality of mind or body and a significant cause of conflict between the patient and healthcare professional. IiME Comment : The failure to explain the biopsychosocial theory on which NICErecommendations for treatment are based; This is caused by bodies such as NICEperpetuating these myths in the face of evidence and patients' experiences, supported by overwhelming biomedical evidence, proclaiming that Wessely-style theories are nonsense. What is the science behind biopsychosocial approach.	

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						As with any other chronic disorder the patients attitude to his or her illness experience and disability, the understanding of the nature of the condition and its likely course over time together with the relationship between patient and doctor are likely to have a significant impact on long term outcomes. IiME Comment: This document purports to discuss CFS/ME – but the number of times CFS alone is mentioned shows poor editing, analysis and devalues the contents. This chapter is named MAKING a DIAGNOSIS of CFS/ME – CFS is mentioned alone many times. CFS is not the same as ME!	
SH	Invest in ME	142	FULL	135	*25*	*References* IiME Comment: The references	There is no separate agenda. We hope the revised text is helpful.

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						below are related to psychiatric papers and should have no place in discussion about neurological ME. Unless there is a separate agenda with the NICEdocument?Why not list references from Spence, Hooper, Hyde, Carruthers, Jason, Cheney, Peterson, De Meirleir, Myhill, Kerr, Puri etc.	
SH	LocalME	79	FULL	105		Diagnostic Recommendations This is a curious paragraph in a number of respects: ME is a neurological illness (ref. to WHO classification) – so why would patients with neurological signs be excluded from diagnosis? Cardiovascular abnormalities have been found in patients with ME (ref. 'Human Tragedy and the Heart of the Matter', vascular research by	We have revised the recommendations on the other symptoms that are to be investigated urgently to be more specific.

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						ME Research UK). Surely anxiety and depression indicate anxiety and depression – rather than acting as markers for some 'serious underlying pathology'. Of course anxiety and depression should be treated in their own right if present. More Generally, the implication is that a diagnosis of ME/ICD CFS does not in itself indicate a likelihood of 'serious underlying pathology'. Even if 'serious' is intended to be read as 'life threatening', this does not always hold true: fatalities, although rare, do occur (ref. Carruthers et al, 2003, p34, and the documented deaths of [X, X, X]).	

National Institute for Health and Clinical Excellence
CFS/ME consultation draft
29 September – 24 November 2006
Comments on chapter 5

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SH	LocalME	80	FULL	126	1	Spatial disorientation CAN be an alarming symptom of CFS/ME.	Noted but is not characteristic.
SH	ME-letterforce National e-group	1	FULL	110	7-8	'The definition of CFS/ME is based upon its classification as a 'syndrome,' that is, a pathological condition characterized by its symptoms rather than its cause'. This statement constitutes a major falsity, and urgently requires correction. A definition (a well defined and clear description) cannot be 'based upon its classification', because a classification can only group like entities together after they have been defined. Like all classificatory (stereotyping) systems of convenience, very crucial detail can be lost through human attempts to	Noted and revised. In addition, the recommendations on diagnosis have been revised and clarified. We have also noted that healthcare professionals should acknowledge the reality and impact of the condition and symptoms.

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						make seemingly similar items fit. The definition of 'syndrome' is also misleading and requires correction. Quote line 7-8: "…a 'syndrome,' that is, a pathological condition characterized by its symptoms rather than its cause". The word 'syndrome' is a collective term for a group of typically co-occurring signs and/or symptoms characteristic of a specific disease state (pathological condition). The common cold (acute viral nasopharyngitis) is a syndrome, characteristic (typical) of a viral infection. It is therefore misleading and potentially hazardous, to suggest that a syndrome (CFS/ME) is characterised only by its	

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						symptoms. Many if not most syndromes are characterised by signs and symptoms and causes ('triggers') and proximate biological mechanisms and other characteristics, about which there are at least some 4000 peer reviewed published papers relating specifically to ME/CFS/Post Viral Fatigue Syndrome. It is stated at 3.3.2 in the 2002 UK Chief Medical Officer's Report on ME/CFS: 'Good-quality evidence indicates that certain infections are more common triggers for CFS/ME than others. Glandular fever, viral meningitis, and viral hepatitis are followed by CFS/ME in about 10% of cases of the primary infection. CFS/ME can follow infections with herpes viruses, entero viruses,	

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						hepatitis viruses, and some other viruses, and also non-viral infections such as Q fever. CFS/ME has been reported after salmonellosis, toxoplasmosis, and brucellosis. Influenza and 'flu-like infections can trigger CFS/ME, but common upper respiratory tract infections do not seem to.' Additionally and more recently, in 2006 (1), Kerr et al. have reported that '…the genes identified in CFS suggest a complex picture but most prominent within which is "immunity and defense". This supports previous findings on the role of the immune system in the maintenance of this disease', while Lloyd et al. reported in 2006 that (2) 'This post-infective fatigue syndrome phenotype was stereotyped and	

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						occurred at a similar incidence after each infection. The syndrome was predicted largely by the severity of the acute illness rather than by demographic, psychological, or microbiological factors. A relatively uniform post-infective fatigue syndrome persists in a significant minority of patients for six months or more after clinical infection with several different viral and non-viral micro-organisms. Post-infective fatigue syndrome is a valid illness model for investigating one pathophysiological pathway to chronic fatigue syndrome'. (Quote: The NICE GDG state: 'CFS/ME is based upon its classification…') The National Institute of Clinical	

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						Excellence Classification Scheme (3) is based upon the World Health Organization's International Classification of Diseases Tenth Revision, which is in line with the policy of the UK Department of Health. In ICD-10 Myalgic Encephalomyelitis/Post Viral Fatigue Syndrome/Chronic Fatigue Syndrome comes under the rubric of Diseases of the Nervous System (G00-G99)/ Other Disorders of the Nervous System (G90-G99), under the subcategory of 'Other Disorders of the Brain', at G93.3. The corresponding NICE classification to ICD-10 is 'Central Nervous System' (CNS). NICE state that their classification	

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						'separates some of the larger topic areas into smaller subsets (e.g. separating mental health and CNS disorders into, mental health, behaviour and CNS) In accordance with NICE and the UK Department of Health and the WHO IDC-10, a diagnosis of ME/CFS/PVFS (G93.3) precludes a diagnosis of neurasthenia/fatigue syndrome, which appears in ICD-10 under the rubric of Mental and Behavioural Disorders (F00-F99)/ Neurotic Stress-related and Somatoform Disorders (F40-48), under the subcategory of 'Other Neurotic Disorders', at F48.0. The corresponding NICE Classification is 'Mental Health/Behavioural'	

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						Therefore the statement: 'The definition of CFS/ME is based upon its classification as a 'syndrome,' that is, a pathological condition characterized by its symptoms rather than its cause', requires rejection and should instead be replaced to express the following: 'The definition of ME/CFS/PVFS as a syndrome is based upon the observation of regular identifiable symptom and/or sign patterns with good evidence of some viral causation (triggering) and immune system dysfunction, and is classified by the World Health Organisation as a disorder of the brain and nervous system (WHO ICD-10 G93.3)'. Adjusting this should be	

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						straightforward and would be in keeping with the facts of the matter and of the use and citation of WHO ICD-10 in other NICE Guidelines, amongst which this Guideline should not be an exception. Akagia et al. (4) make it clear that the criteria, which attempt to delineate and hence define the condition, originating from Oxford in 1991 is equivalent to 'neurasthenia' F48.8, and not M.E./CFS/PVFS G93.3. 'The Department of Psychological Medicine in Oxford, UK has been using the cognitive behavioral approach to the management of patients with CFS since 1991…Patients selected for follow-up were: all patients referred to the	

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						Department of Psychological Medicine (DPM) between 1991 and 1997, aged between 16 and 65 at presentation, satisfied diagnostic criteria for CFS (Oxford Criteria) /neurasthenia (F48.0) and offered CBT'. This would perhaps explain why Jason and Friedberg have commented that (5) 'A near-complete resolution of the illness, as reported in Sharpe et al. (1996)—suggests the presence in many patients of primary psychiatric illness with prominent fatigue symptoms, rather than CFS.' Bagnall and Chambers confirm this anomaly (i.e. that M.E./CFS ICD-10 G93.3 is not equivalent to Oxford 'CFS' 1991) by stating in NICE	

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						Appendix 1 p 73 (6): 'Main results of alternative medicine treatment trials (Table 4). Two RCTs assessed the effectiveness of homeopathy. One study reported 'greater improvement' with treatment, however no measurements were presented and so it is difficult to interpret the findings. The authors of the study state that participants were suffering from ME, however the Oxford criteria for CFS were used to make the diagnosis.' Authors of the Oxford '91 and CDC '94 definitions demonstrate their contradictory current use and understanding of these terminologies in the following manner (7): 'The term CFS subsumed a multitude of previous terms used to describe patients with	

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						similar symptoms. These include chronic Epstein—Barr virus infection, myalgic encephalomyelitis and post-viral fatigue syndrome, as well as neurasthenia (which remains a specific diagnosis in ICD-10)… Whilst the different definitions have been a source of confusion and dispute, it should be remembered that all have been constructed by committees to aid research. Clinical practice should therefore not necessarily be tightly bound by them. The ICD-10 criteria for neurasthenia are summarized in Table 5.2. TABLE 5.1 Diagnostic criteria for chronic fatigue syndrome (adapted from Fukuda et al.)…' (Michael C. Sharpe and Simon Wessely)	

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						Along with Professors PD White and T Chalder they also state that (8): 'Although the term "chronic fatigue syndrome" is a relatively new diagnostic label...in the late nineteenth century...this was known as "neurasthenia...alternative diagnoses... (to neurasthenia include)... chronic brucellosis, chronic Epstein-Barr virus and myalgic encephalomyelitis (ME), as well as the psychiatric diagnoses of depression and anxiety...' Historically, the term neurasthenia has been use as a cloak of ignorance to cover just about anything not properly understood, and presumably the authors would not find it acceptable today to use the nineteenth century moniker of 'hysterical paralysis' to describe and	

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						fail to identify and separate out Multiple Sclerosis, Poliomyelitis and other diseases once described through ignorance under that term. Authors and participants in the 1991 Oxford Criteria along with colleagues, including Dr D Eminson, a Guideline Group Expert Co-optee, and the original engineers and enthusiasts of Beck's 'CBT' for use in the UK, were involved in the 1992-3 expansion of the WHO ICD-10 F48 'narrower'* definition of 'neurasthenia', the obviously irresponsible insertion of the synonym 'Fatigue Syndrome', and the addition of a previously absent but now meaningful six month stipulation, within the new ICD-10 F48.0 'research' definition	

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						(9). (*'Fatigue syndrome: neurasthenia revived - psychiatric illnesses are worth considering' BMJ Vol 298 May 1989: 'The provisional draft of the 10th International Classification of Diseases has retained the concept of neurasthenia with a narrower definition than that of Beard. It describes fatigue, weakness, and exhaustion after minimal effort, with accompanying symptoms of reduced interest, irritability, insomnia and hypersomnia, poor concentration, and various physical symptoms. Appreciable depression and anxiety are absent [...] P White and A Clare, annual conference of the Royal Australia	

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						and New Zealand College of Psychiatrists, Sydney, 1988 […] World Health Organisation, Mental, behavioural and developmental disorders. In International Classification of Diseases, 10th revision, 1986. Geneva; WHO, 1987. (Draft chapter V (F).) However, it was only in 2002, following the 2nd Consensus Conference in Kuala Lumpar in February 2000, which included as attendees Professor Wessely of the Oxford 'CFS' definition, and Professor Ian Hickie of the Australian 1988 'CFS' definition, that Professor Edmond Chiu, Chairman of The World Psychiatric Association Group of Experts in Neurasthenia declared (10): 'The construct of neurasthenia has not	

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						been up to now the subject of vigorous phenomenological research backed by good-quality psychometric analysis. In recognition of this lack, the World Psychiatric Association (WPA) undertook the first step in the journey to clearly delineate the syndrome. A technical report, which was the outcome of a consensus meeting held under the auspices of the WPA, was approved by the WPA General Assembly at the World Congress of Psychiatry in 2002'. In spite of there still being no adequate or reliable scientific research base for 'neurasthenia', during 2001-2002, Professor Rachel Jenkins (who was also involved in the '92-'93 expansion of	

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						the WHO 'neurasthenia' F48 definition), and others at the Institute of Psychiatry WHO Collaborating Centre, attempted unilaterally to reclassify ME/CFS (G93.3) as 'neurasthenia' (F48.0), for the purposes of their own publication, which included propagating their beliefs about ME as being equivalent to neurasthenia ("fatigue syndromes both chronic and not, both with and without an established physical precursor, may be classified under 'neurasthenia' F48.0"*), throughout the NHS. They were eventually forbidden by the WHO in Geneva from proceeding and were forced into retracting this misinformation. However, in response they proceeded defiantly, by renaming their Guide the 'WHO	

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						Guide to Mental and Neurological Health in Primary Care' presumably in a bid to include and retain influence and control of G93.3 'neurological' issues, and hence continue as suppliers of their alleged, yet not 'remotely curative' (Wessely JAMA 2001), 'treatments' of CBT and GET. (*The WHO Guide to Mental Health in Primary Care 2001) In their NICE National Clinical Practice Guideline Number 31 'Core interventions in the treatment of obsessive compulsive disorder and body dysmorphic disorder', NICE state that: 'Although there has been a keen debate between proponents of psychological and biological approaches to understanding OCD	

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						and its treatment, as yet there is no unified theory that can readily accommodate the key elements of both approaches of OCD' (11). This is a reasonable approach alerting health professionals to what is termed a 'keen debate', such that users of the OCD Guidelines can think and act appropriately on behalf of patients. In view of the foregoing issues, the NICE Guideline Development Group should therefore be obliged to include an alert for users of these Guidelines for CFS/ME, stating, and making it abundantly clear, that there is not just a 'keen debate' involved in ME/CFS, but a veritable and verifiable 'turf war' between professionals in the field, with some	

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						psychiatrists and psychologists using often very disabled, defencless members of the public affected by ME/CFS, many of whom may be unable to follow and discriminate as to precisely what constitutes the genuine and objective science in ME/CFS, as pawns in their seemingly ideological 'CBT' war against science and the public affected by M.E. One psychiatrist reduced to ad hominem argument wrote in 2005 (12): 'Cancer patients do not lobby for psychologists because they believe that psychological factors are why they developed cancer in the first place (which is certainly progress given that in previous times there	

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						have been scientists who have made those erroneous claims). They do so because they feel that it is safe and permissible to engage with psychological therapies precisely because their doctors do not hold with psychosomatic theories of cancer. Once the physical basis of disease is established, then one can explore the psychological in safety, but not before. Compare and contrast this with the well known reluctance of sufferers from chronic fatigue syndrome (CFS) to do the same. Here is a group who are not demanding better access to psychotherapy. Instead, the principal focus of some activists is the reverse—to reduce and even eliminate all traces	

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						of the psychological from the CFS clinic, and even the planet itself if some ultras had their way, The difference between these CFS sufferers and those with cancer is the former are not confident that the somatic basis of their problems has been established beyond doubt, even if they are convinced that it will in time. Worse, they suspect, and with good reason, that their doctors are not confident either, and if pushed might well endorse a psychosomatic contribution to ill health. In these circumstances it would be foolhardy to lobby for better psychiatry, since that would only increase their sense of stigma and rejection'. It is not only members of the public who rightly object to this variety of	

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						psychologising, a priori conjecture and manipulative behaviour (of other professionals), there are many senior scientists and clinicians including psychiatrists and psychologists who object just as strongly, and one recent response from such a group stated in 2006 (13): 'The members of this group were also concerned at the trivialisation of CFS and the labelling of patients as sufferers of psychiatric, psychological or somatoform disease. To address the problem, a pilot study was performed to see if there was any evidence that the white blood cells of CFS patients exhibited a specific gene signature, as has been shown for several other immune mediated diseases.	

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						This pilot study provided clear support for the hypothesis that abnormalities of gene regulation occur in CFS...the genes identified in CFS suggest a complex picture but most prominent within which is "immunity and defense". This supports previous findings on the role of the immune system in the maintenance of this disease… We have performed a pilot study (protein biomarker) of this approach at Imperial College London which has identified statistically significant protein biomarkers in the blood of CFS patients' (Ref: Current research priorities in Chronic Fatigue Syndrome / Myalgic Encephalomyelitis (CFS/ME): disease mechanisms, a diagnostic test and specific	

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						treatments' J. Clin. Pathol. 25 Aug 2006, JR Kerr,1 P Christian,2 A Hodgetts,2 PR Langford,2 LD Devanur,1 R Petty,1 B Burke,1 LI Sinclair,3 SCM Richards,4 J Montgomery,4 C McDermott,4 TJ Harrison,5 P Kellam,6 DJ Nutt,3 ST Holgate,7 and the Collaborative Clinical Study Group.* 1Dept of Cellular & Molecular Medicine, St George's University of London; 2Dept of Paediatric Infectious Diseases, Imperial College London; 3Psychopharmacology Unit, University of Bristol; 4Dorset CFS Service, Poole Hospital, Dorset; Depts of 5Medicine and 6Infection, University College London; 7MRC Dept of Immunopharmacology, University of Southampton. *Collaborative Clinical Study Group	

National Institute for Health and Clinical Excellence
CFS/ME consultation draft
29 September – 24 November 2006
Comments on chapter 5

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						D Honeybourne (Birmingham Heartlands Hospital), AP Smith (Cardiff University), M Thomas (Cardiff University), JG Ayres (University of Aberdeen), J Main (Imperial College London), T Daymond (University of Sunderland), A Bansal (St Helier Hospital, Surrey), BK Puri (Hammersmith Hospital), R Morgan (Imperial College London), RC Peveler (University of Southampton), JS Axford (St George's University of London), W Weir (Harley Street, London), D Enlander (New York CFS Association, Fifth Avenue, New York, NY), JK Chia (ID Med, Torrance, CA) However, with respect to: 'the definition of CFS/ME...' upon which	

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						its classification and treatment depends, a recent empirically derived (from 20000 patients) definition states (14): 'A patient with ME/CFS will meet the criteria for fatigue, post-exertional malaise and/or fatigue, sleep dysfunction, and pain; have two or more neurological/cognitive manifestations and one or more symptoms from two of the categories of autonomic, neuroendocrine and immune manifestations; and adhere to item 7. 1. Fatigue: The patient must have a significant degree of new onset, unexplained, persistent, or recurrent physical and mental fatigue that substantially reduces activity level.	

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						2. Post-Exertional Malaise and/or Fatigue: There is an inappropriate loss of physical and mental stamina, rapid muscular and cognitive fatigability, post exertional malaise and/or fatigue and/or pain and a tendency for other associated symptoms within the patient's cluster of symptoms to worsen. There is a pathologically slow recovery period–usually 24 hours or longer. 3. Sleep Dysfunction:* There is unrefreshed sleep or sleep quantity or rhythm disturbances such as reversed or chaotic diurnal sleep rhythms. 4. Pain:* There is a significant degree of myalgia. Pain can be experienced in the muscles and/or	

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						joints, and is often widespread and migratory in nature. Often there are significant headaches of new type, pattern or severity. 5. Neurological/Cognitive Manifestations: Two or more of the following difficulties should be present: confusion, impairment of concentration and short-term memory consolidation, disorientation, difficulty with information processing, categorizing and word retrieval, and perceptual and sensory disturbances–e.g., spatial instability and disorientation and inability to focus vision. Ataxia, muscle weakness and fasciculations are common. There may be overload 1 phenomena: cognitive, sensory–e.g., photophobia and hypersensitivity to	

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						noise–and/or emotional overload, which may lead to "crash" periods and/or anxiety. 6. At Least One Symptom from Two of the Following Categories: a. Autonomic Manifestations: orthostatic intolerance–neurally mediated hypotenstion (NMH), postural orthostatic tachycardia syndrome (POTS), delayed postural hypotension; light-headedness; extreme pallor; nausea and irritable bowel syndrome; urinary frequency and bladder dysfunction; palpitations with or without cardiac arrhythmias; exertional dyspnea. b. Neuroendocrine Manifestations: loss of thermostatic stability–subnormal body temperature and marked diurnal fluctuation, sweating	

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						episodes, recurrent feelings of feverishness and cold extremities; intolerance of extremes of heat and cold; marked weight change– anorexia or abnormal appetite; loss of adaptability and worsening of symptoms with stress. c. Immune Manifestations: tender lymph nodes, recurrent sore throat, recurrent flu-like symptoms, General malaise, new sensitivities to food, medications and/or chemicals. 7. The illness persists for at least six months. It usually has a distinct onset,** although it may be gradual. Preliminary diagnosis may be possible earlier. Three months is appropriate for children. To be included, the symptoms must	

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						have begun or have been significantly altered after the onset of this illness. It is unlikely that a patient will suffer from all symptoms in criteria 5 and 6. The disturbances tend to form symptom clusters that may fluctuate and change over time. Children often have numerous prominent symptoms but their order of severity tends to vary from day to day. *There is a small number of patients who have no pain or sleep dysfunction, but no other diagnosis fits except ME/CFS. A diagnosis of ME/CFS can be entertained when this group has an infectious illness type onset. **Some patients have been unhealthy for other reasons prior to the onset of ME/CFS and lack detectable triggers at onset	

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						and/or have more gradual or insidious onset'. This definition is much closer than others to the various careful definitions stretching from 1938 to the present (Gilliam, Wallis, Richardson, Ramsey, Acheson, Shelekov, Parish, Pellow, Sigurdsson, and even Holmes in 1988, among others). Particularly at odds with these are the Sharpe White et al. Oxford/Neurasthenia 1991 definition, and to a lesser extent but similarly flawed, the Fukuda Sharpe et al. CDC 1994 definition, both of which appear as distinct aberrations within the larger scientific and historical context. However the GDG should understand and investigate why they were constructed, and	

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						acknowledge that as NICE points out: 'Health is a political topic' (NICE Communication Strategy 17TH July 2002 page 3). (15) To be consistent, and to at least attempt to uphold the tenets of scientific methodology, the GDG should remove all of the studies cited and used as evidence within these Guidelines that relied upon definitions of CFS/ neurasthenia (Oxford 1991 Criteria), or combined 'neurasthenia/cfs' Oxford 1991 with other definitions within individual studies, in order to protect science and not least, the public affected by ME/CFS/PVFS. In addition, as the GDG reject all case definitions, mainly because: 'measurement of these outcomes	

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						(fatigue, impaired sleep, cognition, concentration, quality of life and social functioning) is essentially subjective and therefore potentially biased', the GDG should uphold these standards consistently, and with the public interest obviously uppermost, reject all studies used in evidence harnessing outcome measurements that are also essentially subjective, and hence equally potentially biased (FULL Draft Document p112 lines 18-20). 1) Current research priorities in Chronic Fatigue Syndrome / Myalgic Encephalomyelitis (CFS/ME): disease mechanisms, a diagnostic test and specific treatments' J. Clin. Pathol. 25 Aug 2006, JR Kerr	

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						et al. 2) Post-infective and chronic fatigue syndromes precipitated by viral and non-viral pathogens: prospective cohort studylan Hickie 1, Tracey Davenport 1, Denis Wakefield 2, UteVollmer-Conna 3, Barbara Cameron 2, Suzanne D Vernon 4,William C Reeves 4, Andrew Lloyd 2*, for the Dubbo Infection Outcomes Study Group 3) Institute Classification Scheme, Communications Progress Report 18th September 2002, Item 12, Annex 1: NICE disease category classification: comparison with ICD10 and	

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						previous NICE compilation categories 4) 'Cognitive behavioral therapy for chronic fatigue syndrome in a General hospital—feasible and effective' by Akagia, Klimes, and Bass (General Hospital Psychiatry 23, 2001, 254–260), 5) Jason and Friedberg 2002, 'Understanding Chronic Fatigue Syndrome', the American Psychological Association 6) Work to support the NICE Guidelines' - from the Centre for Reviews and Dissemination at the University of York October 2005 (CFS/ME: FULL guideline Appendix 1 DRAFT page 73 September 2006),	

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						7)) Somatoform Disorders Volume 9, Editors Mario Maj et al. 2005 , Chronic Fatigue and Neurasthenia: A Review, Michael C Sharpe and Simon Wessely 8) NHS Plus Publication Date October 2006 28-09-2006 Occupational Aspects of the Management of Chronic Fatigue Syndrome: a National Guideline Wessely S White P Chalder T et al. 9) http://www.who.int/entity/classifications/icd/en/GRNBOOK.pdf http://www.who.int/classifications/icd/en/bluebook.pdf 10)) Does Neurasthenia Really Exist in this Century? Edmond Chiu WPA	

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						www.wpanet.org/publications/docs/ftoc.pdf 11) www.cambsmh.nhs.uk/documents/NICE/OCD.pdf?preventCache=23%2F06%2F2006+12%3A05 12) White P (ed), "Biopsychosocial Medicine: An integrated approach to understanding illness", (Oxford 2005) Foreword by Simon Wessely. 13) Current research priorities in Chronic Fatigue Syndrome / Myalgic Encephalomyelitis (CFS/ME): disease mechanisms, a diagnostic test and specific treatments' J. Clin. Pathol. 25 Aug 2006, JR Kerr et al 14) Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome: Clinical	

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						Working Case Definition, Diagnostic and Treatment Protocols Bruce M. Carruthers, MD, CM, FRCP(C) Anil Kumar Jain, BSc, MD Kenny L. De Meirleir, MD, PhD Daniel L. Peterson, MD Nancy G. Klimas, MD A. Martin Lerner, MD, PC, MACP Alison C. Bested, MD, FRCP(C) Pierre Flor-Henry, MB, ChB, MD, Acad DPM, FRC, CSPQ Pradip Joshi, BM, MD, FRCP(C) A. C. Peter Powles, MRACP, FRACP, FRCP(C), ABSM Jeffrey A. Sherkey, MD, CCFP(C) Marjorie I. van de Sande, BEd, Grad Dip Ed., Journal of Chronic Fatigue Syndrome, Vol. 11(1) 2003) 15) NICE Communication Strategy 17TH July 2002 page www.NICE.org.uk/download.aspx?o	

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						=34648	
SH	ME-letterforce National e-group	2	FULL FULL FULL FULL FULL FULL FULL	133 133 133 133 134 134 134	20 22 24 27 3 6 9	'A conceptual framework for patients and health professionals when making a diagnosis of Chronic Fatigue Syndrome ' It is usually a doctor who makes a medical diagnosis and not the patient. Making a diagnosis cannot have a 'conceptual framework' because it is not an abstract matter, but a real life action performed by a doctor. This statement should be removed. 'A diagnosis of Chronic Fatigue Syndrome (CFS) is made on clinical grounds alone after the exclusion of conventional disease processes that could account for the wide-ranging symptoms that are usually	In the framework we have sought to provide a basis for improved partnership of patients and professionals in order to improve care, services and health. The framework has been revised with this objective in mind. The term 'conventional' has been

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			FULL FULL FULL FULL FULL FULL FULL	 134 134 134 134 135 135 135	 14 20 25 29 2 6 10	experienced by patients with CFS.' There cannot be 'conventional' disease processes because disease processes do not act according to conventions. The term 'conventional' should be removed and replaced with 'other' because the personification involved and the manner in which it is written might lead some to think in terms of the actual disease 'CFS' as being somehow a matter of convention, or rather it's opposite. This is particularly important in a disease which has been so systematically trivialised and exploited following the opportunistic BMJ example of Beard and McEvedy (1970). 'As there are no objective abnormalities to account for the	removed. In considering the explanation for CFS/ME, we have followed the report of the Gibson Inquiry, which accepts that there is insufficient evidence to fully substantiate any of the current theories of causation, and that more high quality biomedical research is needed. The framework has been revised to make this clear.

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			FULL FULL FULL	136 135	16 21	illness experienced and the associated disability suffered in CFS, additional distress for patients, their families and the wider social network commonly occurs. ' Abnormalities will not be found without looking for them, and it is disingenuous to suggest that a lack of 'objective abnormalities' causes 'additional distress' to the patient, let alone 'the wider social network.' There is no diagnostic test available at present and this fact is rather obviously exploited by the less than scrupulous, to trivialize and promulgate inadequate (usually psychological) theories of M.E., while others who fuel this useful trend, use it as an excuse to deny the public affected provision of the	

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						financial and other badly needed assistance they are rightly entitled to. This causes distress and hardship to an extent which is clearly outwith the direct experience of this GDG. Some physiological and biochemical abnormalities from replicated studies found in "CFS" cohorts include: Biochemical Oxidative stress (e.g., Richards et al., 2000; Manuel et al., 2001; Pall & Scatterle, 2001; Kennedy et al., 2003; Vecchiet et al., 2003) Anti-viral dysregulation (Suhadolnik et al., 1994; De Meirleir et al., 2000; Shetzline SE et al., 2002; Tiev et al., 2003) Vascular Endothelial dysregulation (Spence et al., 2000; Khan et al., 2003; Khan et al., 2004) Brain perfusion (Schwartz et al,	

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						1994; Costa et al, 1995) Orthostatic Hypotension (Streeten et al., 2000; Stewart, 2003) Brain Metabolic abnormalities (Tomoda et al., 2000; Puri et al., 2002; Chaudhuri et al., 2003) Muscle Metabolism (e.g., FULLe et al., 2000; Vecchiet et al., 2003) Abnormal recovery after exercise (e.g., Paul et al., 1999; McCully & Natelson, 1999) Enteroviral sequences in muscle (Lane et al., 2003) These account for at least some of 'the illness experienced and the associated disability'; therefore the authors above falsehood should be removed. 'Importantly, the lack of an objective definition of CFS as a discrete disease entity can jeopardise the	The discussion of the definitions has been expanded.

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						therapeutic relationship between patient and healthcare professional with a consequent adverse impact on the healing process.' Definitions are by definition 'objective', whilst a subjective definition constitutes a contradiction if terms; therefore the term (objective) is redundant and should be removed. It appears to be being used as a semantic device to mislead. Precise definitions which identify 'CFS' as a discrete disease entity have existed since the 1930's (see Carruthers et al. and various careful others mentioned above), therefore this comment should be removed. The term 'therapeutic relationship'	We disagree that the term therapeutic relationship implies one of manipulation.

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						originates from psychotherapy and suggests a highly asymmetrical relationship, which is rarely made explicit, wherein one individual believes, commonly without any basis, that her manipulations of her subject to obtain conformity with her thinking is somehow 'therapeutic'. That is not an appropriate relationship between 'healthcare professionals' and patients, and the term 'therapeutic relationship' and it's equally misleading euphemism 'collaborative' (used oxymoronically and revealingly as'collaborative therapeutic relationship' on p185) running through this document should be removed. Otherwise it should be made absolutely clear and distinct that the word 'therapeutic' (from the Greek	The GDG is not saying that the lack of a definition directly prevents people getting better. This is not the case. We hope the

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						'one who treats') is not being used in any authentic medical sense. As it stands however, the GDG are making a series of remarkable claims which in essence say that the alleged lack of a definition of ME/CFS actually directly prevents people affected by ME/CFS from recovering. The impression given is that GDG are attempting to shift responsibility from incompetent professionals responsible for the current confusion and alleged lack of a definition (over 20 years and 4000 papers after the CDC went to Lake Tahoe), by deflecting attention from this and various ensuing infractions, onto the public affected by ME/CFS. This sentence should therefore be	revised framework helps to address this impression.

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						removed. 'The relationship between the individual with CFS, their families and health professional can be further stressed by disagreements about the origins of CFS. Entrenchment and polarisation of viewpoints about a physical or psychological origin of CFS undermines relationships that support recovery.' It has recently been suggested by Lloyd et al. that a viral hit-and-run injury to the brain may be involved in CFS. A similar phenomenon and mechanism has been described in Acquired Immune Deficiency Syndrome related dementia. Clearly anyone ascribing a psychological causation to ME/CFS, is not	The GDG is not saying that CFS/ME has a psychological causation. We follow the Gibson Inquiry, as stated above.

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						listening to those affected by ME/CFS, is not familiar with the science involved in ME/CFS/PVFS, and is ignorant of other areas of uniquely relevant research. The GDG's suggestion that a 'relationship' with a health professional can be responsible for recovery is presumptuous. A good relationship with one's doctor would be based on honesty and respect for both the patient and science. Obviously unhelpful and stressful encounters with doctors who psychologise patients makes matters worse. This should be removed. 'Another consequence of the unclear definition and aetiology of CFS is the difficulty experienced by	We hope that the revised framework

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						patients and healthcare professionals in distinguishing CFS from several overlapping conditions such as fibromyalgia and irritable bowel syndrome.' 'Healthcare professionals' are paid to diagnose, and the public consult those professionals competent enough to do this. 'Healthcare professionals' unable to diagnose accurately (misdiagnose) should be sued and struck off the GMC Medical Register. The GDG make the remarkable suggestion that <u>both</u> patients and 'healthcare professionals' should make diagnoses, but cannot however make accurate diagnoses of other conditions, including IBS (which may now be treatable with an targeted antibiotic) because of an	clarifies the point the GDG is making.

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						alleged 'unclear definition and aetiology of CFS'. This does not make sense, and should be removed. 'Differing beliefs about definition and cause of CFS can extend from the patient and the doctor to family members and the wider community resulting in dissatisfied, disabled patients and frustrated doctors. The patient journey can become an ordeal with unnecessary distress, added costs and waste for the health economy, the patient and their family.' The GDG suggest that 'beliefs' result in 'disabled patients' and that the patient spreads these beliefs into 'the wider community' thereby causing frustration, and whilst going	The GDG does not suggest this.

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						on a 'journey', the patient causes yet more distress and even wastes tax payers money, wastes their own money, and that of their family. The individual writing this appears to be experiencing a very severe problem with reality (cognitive distortion). It is so far fetched that the only sane and reasonable explanation possible would be that the author and like minded colleagues have become so practised at habitually blaming others in order to avoid 'detection' and responsibility, they have no choice in the matter, and therefore this has no place in NICE Clinical Guidelines and should be removed. 'CFS has been described as part of a broader condition that includes a	

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						range of related disorders including fibromyalgia, irritable bowel syndrome, chronic pain, pelvic pain, temporomandibular joint dysfunction and atypical facial pain.' The subdivision of this broader condition into several different entities is thought to be due to the specialisation of secondary-care medicine and the predominating symptom at time of presentation e.g. fibromyalgia in rheumatology and irritable bowel syndrome in gastroenterology.' This is dangerous speculation when one considers for instance that fibromyalgia can be a symptom of Hepatitis C virus infection, and that IBS can be a bacterial infection, and so forth. Psychiatry and some of the	The GDG is not saying that this is its view of CFS/ME, merely that this is a view some people have expressed. We hope the revisions to the framework help clarify this point.

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						thinking behind much of that specialisation, has a very poor track record, some might say an appalling and abysmal history, of jumping to conclusions out of sheer ad hoc expediency in areas of medicine obviously beyond most of its capabilities. This rank conjecture should be removed from the Guidelines. 'However, the predominating symptom can change over time causing uncertainty for the patient and diagnostician leading to further tensions and distress. The original clinical diagnosis of CFS becomes irritable bowel syndrome because bowel symptoms predominate over fatigue despite the same illness and disability experience.'	It is entirely natural that health professionals should worry about missing important diagnoses.

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						It is unclear how or why a change in a symptom causes 'further tensions and distress' in <u>both</u> the 'diagnostician', (who presumably is a paid professional trained and able to maintain herself emotionally and withstand and not become involved or be affected by transitory uncertainty), and the patient simultaneously. Nor is it clear how CFS can gradually convert to IBS and remain the same illness, when by definition ('the same illness') that is impossible. This extemporization has no place in Clinical Guidelines and should be deleted. 'Terminology used by doctors such as 'functional syndrome' and 'medically unexplained symptoms'	The GDG does not make this suggestion; it merely recognises that there are different views about the causes of CFS/ME. The GDG accepts the Gibson Inquiry's conclusion that no current theory on the causes of CFS/ME is, as yet, supported by sufficient evidence, and that further biomedical research is necessary.

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						are part of common usage in clinical practice today. The terms have arisen to describe non-conventional diseases and are intended to validate CFS and overlapping conditions to help improve patient care and research into the disorder.' It is unacceptable and potentially dangerous for the GDG to suggest that there are no organic causes ('functional') to CFS/ME when all of the evidence suggests the complete opposite. Furthermore, it is highly disingenuous of the GDG to suggest that this politically expedient, non-medical manufactured terminology is 'intended to validate CFS', when it is precisely this fabricated terminology and the calculated implications and effects behind it,	See the responses above. The GDG is nor promoting these terms; on the contrary, the framework is attempting to move attitudes on from polarised opposites to respecting debate.

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						that are being used against the public affected by ME/CFS, to deny them proper and meaningful assistance both financially and medically. There is no place for such arrant speculation in these Guidelines and it should be removed. 'Although the term 'functional' has been found to be more acceptable with patients than terms such as 'psychosomatic' or 'medically unexplained', some terminology has become derogatory with use.' Changing offensive deceitful and potentially dangerous self-serving terminology without changing the equally dangerous offence behind that terminology (to 'Sorry, we don't know/understand yet'), by	This assumption is incorrect. The assertions that follow rest on this incorrect premise. We hope that the revisions to the framework help clarify matters.

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						misleading people into believing that the offence has been removed while they don't yet FULLy understand the implications behind the contrived use of the next euphemism, is repugnant, and these devious suggestions should be excised from these Guidelines. 'For some patients and health professionals, the functional concept and all associated terminology are deemed unacceptable. The 'mental or physical' condition debate predominates in the clinical encounter undermining the doctor patient relationship.' Although it is not being made explicit, it is not unreasonable to assume from the unfolding of this	

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						argument thus far, that the author herself is the one being confronted ('undermining') by patients legitimately offended by the authors psychologisation of them, their illness, their families, and the 'wider community'. It is illegitimate to Generalize that this 'debate' predominates or undermines doctor- patients' relationships. This appears to be part of a systematic and habitual ruse of deflecting attention away from professional incompetence, onto almost defenceless others (the public with ME), and the invitation to other 'professionals' to ramp up the blame game, is deeply unethical. This should be removed. 'Outcomes are likely to improve if the diagnosis of CFS is	Respectful communication by the health professional focused on the patient's health (i.e. a therapeutic relationship) should help patient and professional talk openly together and reach agreement on the best clinical management for the individual. Information and discussion do not bring about recovery, but they are the means by which patient and professional decide what action to take to bring about recovery.

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						communicated more successFULLy through a collaborative approach between the patient and doctor leading to a therapeutic relationship. This requires doctors to take an active approach to provide accurate information and to discuss key issues with patients on an ongoing basis to achieve better outcomes.' The GDG make the claim that people's health can be recovered only if the diagnosis of CFS/ME is somehow communicated through an 'approach' leading to a 'relationship'. Normally a diagnosis is communicated verbally and received through the auditory system of the recipient, and it is unclear what advantage this novel approach to communication has, or	The assumptions here about the beliefs of the GDG are incorrect and rejected. The framework is not seeking to establish one set of views about the causes of CFS/ME; quite the reverse. It is seeking to foster acceptance of

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						how it in fact works. It is further suggested that 'information' and 'discussion' will bring about recovery, although again it is not clear how that happens and by what mechanisms. This should be removed. 'If an effective therapeutic relationship is to develop, doctors must acknowledge that, despite the current lack of understanding of underlying causes of CFS, the symptoms are real and the suffering and associated disability is genuine. The ideas, concerns and expectations of the patient, carers, families and the doctor should be explored for differences and similarities. Appropriate and agreeable terminology and understanding is important when	people's views, encourage more basic research, and enable patients to gain access to interventions that can alleviate some of the symptoms.

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						making a diagnosis and establishing a therapeutic relationship.' The GDG advise undermining (and underestimating) other people's integrity by suggesting that they (the GDG) believe the symptoms and suffering to be real, whilst concealing the fact that they do not believe there is any organic lesion, that CFS/ME is psychosomatic ('functional'), and that somehow an 'effective' (but uncalled for) and highly inappropriate relationship will 'develop' as a result. This is particularly unethical because individuals who are already in weakened states, often after years of abuse and neglect resulting from the psychologisation of ME/CFS originating with the authors of this	

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						piece, are uniquely vulnerable to anyone who offers any attention, but especially from one who hints at cure (recovery). Although it is not made explicit, it is nevertheless obvious from the context of this section that pressure to conform to their beliefs about CFS/ME as neurasthenia (psychosomatic), is to be exerted through the manipulation and agency of carers, families and doctors (exploring 'differences' and 'similarities') and that it will be perfectly acceptable for professionals to deceive the public affected by ME ('agreeable terminology'), in order to reinforce that deception within a highly manipulative ('collaborative' being the euphemism for 'therapeutic') relationship. This sinister comment	The text has been amended.

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						should obviously be removed. 'The definition and concept of CFS through a biopsychosocial model acknowledges the role of both external and internal influences on the development of and recovery from CFS. The biopsychosocial model negates the duality of mind or body and a significant cause of conflict between the patient and healthcare professional.' CFS is not a concept, but a serious physical disease ruining people's lives, careers and much else. The definition of CFS cannot be found 'through' a model, because a model is a vastly simplified description of a system. The definition of CFS/ME is found through careFULLy aggregating its sign and symptoms	

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						and causes and effects, from the reality of the disease in human subjects, although various animals can suffer from a form of ME (see Walter Tarello). An effective biopsychosocial model would presumably involve modelling the 'wider community' of the entire planet backwards in time to include bio-evolutionary processes as well, otherwise its basis would be too incomplete and unreliable for any kind of a serious and useful model, and given the absurdity of that prospect, the lack of any remotely conceivable mechanisms, the fact that such a coherent system in reality could not have evolved, it can therefore only amount to a manufactured (made up) technical sounding idea (not unlike the	

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						equally spurious "CBT 'model' of CFS") mimicking science by providing the illusion of 'expertly' fitting notions conveniently to a theory (model), which on closer inspection turns out to be an endlessly pliable theory of anything and everything, which sounds impressive, but in reality of course cannot explain or predict (as genuine models do) anything. How that 'negates' the alleged 'duality' of 'mind' OR 'duality' of 'body', whatever a 'dual mind' OR a 'dual body' might mean, and how that causes 'significant' conflict between the 'patient and healthcare professional', is simply unfathomable. Furthermore, how and why a model, which cannot exist, 'acknowledges' the	CFS/ME is like other chronic conditions in some ways, and differs in others. The similarities can be helpful in thinking about practical support and management. The GDG recommends further biomedical research. There are some highly dedicated health professionals trying to establish services for people with CFS/ME. The GDG rejects the view that it is projecting its failures or the failures of professionals onto patients. Specifically, it is not expressing any criticism

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						'development' and alleged 'recovery' from CFS, borders on the insane. This is highly inappropriate for a serious health Guideline aimed at serious health professionals looking for sound safe advice in dealing with their patients. It is amateurish (in the poor sense) speculation, and should be removed. 'As with any other chronic disorder the patients attitude to his or her illness experience and disability, the understanding of the nature of the condition and its likely course over time together with the relationship between patient and doctor are likely to have a significant impact on long term outcomes.' The GDG will be very well aware	whatsoever of patients with CFS/ME. The framework points out to professionals that the beliefs of some professionals may prevent some patients gaining access to appropriate services, and seeks to promote better understanding and acceptance.

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						that CFS/ME/PVFS is not like 'any other chronic disorder'. There are no rational and effective treatments readily available, although there are some suggestive remedies including high dose Eicosapentaenoic Acid. There is no Government funding or even a will to find money for the purposes of appropriate biomedical research into the disease. The level of disability can be profoundly shocking, but most importantly, it is the attitudes of 'healthcare professionals', who psychologise, trivialise, and continue misanthropically to do so, that is the problem, not the patient or his attitude. This is well illustrated throughout this imperious and	Surely it is a more desirable goal to eliminate tyranny altogether?

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						deviously penned section of your Guidelines, in which the authors repeatedly project their failures very publicly onto those affected by ME, without compunction. It is their malign influence through a willing Government making it extremely difficult for people with ME to survive materially, and so, to state that it is the 'patients attitude' that determines 'long term outcomes', whatever that might mean, says everything about the authors and their collaborators in this diatribe, and nothing whatsoever about the attitude of those affected by ME/CFS/Post Viral Syndrome. As Professor William Epstein has pointed out (2006*):	

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						'Psychotherapeutic practice is benign during benign times and predatory when culture turns a more solemn face to social and personal need.' This entire section should be removed and replaced with the following warning: "Of all tyrannies a tyranny sincerely exercised for the good of its victims may be the most oppressive. It may be better to live under robber-barons than under omnipotent moral busybodies. The robber-baron's cruelty may at some point be satiated; but those who torment us for our own good will torment us without end, for they do so with the approval of their own conscience." C.S. Lewis	

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						* 'Psychotherapy as Religion- The Civil Divine in America' William M. Epstein University of Nevada Press A Reno & Las Vegas 2006	
SH	NHS Direct		FULL	126	1	Spatial disorientation CAN be an alarming symptom of CFS/ME.	Noted but is not characteristic.
SH	Royal College of General Practitioners Wales	4	FULL	135	14	After FULL-stop add: This process includes being genuinely willing to discuss in an informed way the explanatory models of the illness that are being adopted by the patient or carer. See page 36-7 for most likely variations. This process may raise the possibility of a FULL review of the primary diagnosis.	This section has been heavily revised. We hope this point is now made.
SH	Royal College of Nursing	32	FULL	104	1	Diagnosis to be considered if fatigue plus one additional symptom – It does not clarify the symptom	We have given guidance on broad criteria to alert the clinician to the possibility of CFS/ME, not for use as

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						presentation later when making the diagnosis	diagnostic criteria specifically. This has been clarified in the guideline.
SH	Royal College of Nursing	33	FULL	133	15	Not sure that this conceptual framework is helpful nor does it help clarify what CFS/ME is	We have revised the framework, and drawn on the report of the Gibson Inquiry in thinking about what CFS/ME is/are. We hope that the revised version will help patients and professionals work together to manage the condition.
SH	Royal College of Paediatrics and Child Health	39	FULL	110		5.3.1.5 We wonder why this statement is added here. It does not seem to answer the key clinical questions and is based (as far as we can tell) on a paper (ref 42, Smith 2003) that has been considered of poor validity and lower evidence level. We are concerned that doctors reading this guideline might interpret this guideline as that anxiety and depression are primary causes of	This comment refers to an evidence statement which is a statement that synthesises the evidence findings. The GDG discussed the evidence and agreed this statement. However, as noted, the study had been graded as 2-, so the issues around quality are implicit, and therefore no recommendations have been made based on this statement.

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						CFS/ME for which, as far as we are aware, there is no evidence of.	
SH	Royal College of Paediatrics and Child Health	40	FULL	122	1	Diagnosis in children. This is given a definite time frame of 3 months. Why? The RCPCH document chose not to give a definite time frame, rather using the definition of 'severe persistent fatigue not explained by other disorders'. We recognise that it probably takes about 3 months to work through the system but do not agree with a restrictive time frame.	The 3-month time frame was recommended in the CMO report and is used in many of the papers. The GDG supported this time-frame.
SH	Royal College of Paediatrics and Child Health	41	FULL	132		Why do all children with mild CFS/ME need to be offered referral to specialist care after 4-6 months. As I read it from the table, it is appropriate to refer those who wish for a referral or who are not doing so well, but in the recommendations of the guideline it comes out as a	The recommendation has been changed and an alteration has been made to the flow chart.

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						'should'. Many General paediatricians are competent to oversee the management of these children, leaving specialist care for those who really need this scarce resource.	
SH	Sheffield South West Primary Care Trust	3	FULL	105		Recommendations (5.2.8) Regarding red flags. Need to clarify that anxiety and depression can be secondary to having a long term medical condition such as CFS/ME and may not always need to be considered as a red flag. In fact it may be an indication for referral to a specialist CFS/ME service.	We have clarified the details of these recommendations, and other related ones to address this.
SH	St Bartholomew's Hospital Chronic Fatigue Services	43	FULL	88	9	If neither pain nor fatigue are prominent, this calls into question the diagnosis of CFS/ME. Alternative diagnoses, such as sleep and mood disorders, are	Noted and this sentence has been revised.

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						more likely explanations of prominent sleep and cognitive complaints.	
SH	St Bartholomew's Hospital Chronic Fatigue Services	44	FULL	104	5.2.8	"Recurrent flu-like symptoms" No symptom can be described by an analogy. Muscle and joint pains are separate symptoms already mentioned, so these "symptoms" are both ill-defined and redundant. They should be omitted. • "dizziness, nausea and palpitations." These symptoms are not part of any research criteria or replicated empirical studies of CFS/ME. Their inclusion will dissuade doctors from properly investigating these symptoms, which is both poor and potentially dangerous clinical care.	The section on symptoms has been revised.

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						These symptoms should be omitted.	
SH	St Bartholomew's Hospital Chronic Fatigue Services	45	FULL	111	4	The Oxford criteria were not developed by two psychiatrists, not even those as eminent as mentioned in the guideline. They were developed using the Delphic technique by some 27 CFS/ME doctors and scientists, only 7 of whom were psychiatrists (Sharpe MC, Archard LC, Banatvala JE, Borysiewicz LK, Clare AW, David A, Edwards RHT, Hawton KEH, Lambert HP, Lane RJM, McDonald EM, Mowbray JF, Pearson DJ, Peto TEA, Preedy VR, Smith AP, Smith DG, Taylor DJ, Tyrrell DAJ, Wessely S, White PD. A report - chronic fatigue syndrome: guidelines for research. Journal of the Royal Society of Medicine	Noted and revised.

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						1991:84;118-21.)	
SH	St Bartholomew's Hospital Chronic Fatigue Services	46	FULL	132	5.4.5.1 and 5.4.5.2	Point made above: Severity of disability is more important than severity of symptoms; yet you do not mention this. We suggest substituting "disability" for "symptoms"	We have revised the language used in the recommendations. We have used CFS/ME alone, so as to include both symptoms and disability.
SH	St Bartholomew's Hospital Chronic Fatigue Services	47	FULL	133	15 +	Conceptual framework: We warmly welcome this very helpful explanation of models of understanding, which we think important to include.	Thank you for this comment. We have attempted to improve the framework further to take account of other comments received.
SH	The British Psychological Society	37	FULL	88	9	If fatigue is not always a prominent feature, why diagnose CFS? This is inconsistent with all other criteria. If fatigue and pain are not prominent features, what are?	Noted and this sentence has been revised.
SH	The British	38	FULL	88	General	This does identify those with ME	The evidence reviewed in this guideline

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	Psychological Society					who experience muscle fatiguability following minimal exertion plus a delay in the recovery of muscle power after exertion ends. The guidelines are very broad. It's like not differentiating between tension headaches, migraines and cluster headaches. There is now enough evidence to at least separate ME/post viral fatigue and stress-related CFS (TATT). Lumping everyone together is contrary to the way that doctors approach other conditions.	does not allow us to distinguish between these groups when making recommendations. However, we have stressed the need to consider both preferences and needs of the individual throughout the recommendations.
SH	The British Psychological Society	39	FULL	91	19	Here the draft recognises the post-viral group and the lack of association between psychological predictors and chronicity. It underlines the need to include alternatives to CBT/GET or GA. Counselling may be more	We have removed the recommendation on post-viral management. Throughout we have noted the need to tailor management options to the needs and preferences of the individual. No evidence on counselling was

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						appropriate for patients who have realistic attributions but require additional support to help them deal with the burden of illness.	identified.
SH	The British Psychological Society	40	FULL	132	1 (box)	We agree with point 5.4.5.1 that referrals to specialised care should be based on a consideration of the person's needs and symptoms, illness duration and severity, and in partnership. It may therefore not be necessary, and it may even be counter-productive, to give time-scales for referral (5.4.5.2). Instead, each case should be considered on its merits, and account should be taken of the likely outcome of referral. The guidelines should be wary of creating an expectation in patients for referral to specialised care where no suitable services	We agree that each case should be considered on its merits, but the view of the GDG was that some time scales would be helpful. A definition of specialist services is given. These may vary in different localities.

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						exist.	
SH	The British Psychological Society	41	FULL	134	14	There have been studies evaluating the concept of functional somatic syndromes, e.g. Moss-Morris and Spence (2006). Doctors should be able to tell the difference between CFS, IBS and facial pain and there's no rationale for treating them all the same. Doctors do not treat all cases of IBS in the same way. Some patients respond to dietary changes, some to anti-spasmodics, some to hypnosis etc (OHCM 2004, 249). In relation to facial pains, the history is important and some patients will be offered drugs, others may be sent for dental treatment to correct malocclusion etc. Differences matter. It's a moot point whether this concept contributes to our understanding of	This section has been revised. We seek to acknowledge that different people hold different views on causation, and sometimes these views are strongly held. Since we do not know what the cause of CFS/ME is, the GDG cannot accept any of the current theories, but must instead encourage more basic research and encourage those who hold strong views to take a more tolerant, open-minded attitude to ensure that patients who may benefit from various interventions do have access to those interventions.

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						CFS and unless arguments against it are included for balance, it should be removed. Patients may well regard the link with facial pain and IBS as evidence of the trivialisation of their condition. See Komaroff et al (1996). This section gives the impression that the authors assume CFS to be a single entity, barely distinguishable from other disorders. It takes no account of the findings of ongoing disease in subgroups.	
SH	The British Psychological Society	42	FULL	135	19	The biopsychosocial model is one of several ways of studying CFS but there are problems. In the literature, the model as it relates to CFS does not recognise the possibility that ongoing symptoms may be due to a	We do not debate the cause of CFS/ME in depth; our aim is to show that there are widely divergent, sometimes strongly held opinions on causation, but that these views must not be allowed to prevent patients gaining access to the

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						persistent disease process (viruses, an abnormal immune response etc). Even somatic symptoms are explained in terms of stress and inactivity (clearly shown in Burgess 2006). Chronicity is attributed to inactivity, stress, abnormal perception of symptoms and maladaptive beliefs. It comes across as highly reductionistic (Song and Jason 2005). In the case of CFS, this model is essentially a psychosomatic model. "The biopsychosocial model negates the duality of mind or body and a significant cause of conflict between the patient and healthcare professional." Given the descriptions in the literature, this is not the case in	support, care and interventions that can help them.

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						relation to CFS at the moment.	
SH	University of Manchester	4	FULL	132	1 (box)	We agree with point 5.4.5.1 that referrals to specialised care should be based on a consideration of the person's needs and symptoms, illness duration and severity, and in partnership. We would therefore suggest that it is not necessary, and may be counter-productive, to give time-scales for referral (5.4.5.2). Instead, each case should be considered on its merits, and account should be taken of the likely outcome of referral. The guidelines should be wary of creating an expectation in patients for referral to specialised care where no suitable services exist.	We agree that each case should be considered on its merits, but the view of the GDG was that some time scales would be helpful. A definition of specialist services is given. These may vary in different localities.
SH	Welsh Association of	62	FULL	89	6	This seems confusing	Thank you for pointing this out. This has been revised.

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	ME & CFS Support						
SH	Welsh Association of ME & CFS Support	63	FULL	90		The evidence base, low grade or otherwise, for the statements in section 5.2.4.2. are poor and of limited value. They are also offensive.	This is an evidence statement which is a statement tha tsynthesises the evidence findings. However, because of the lack of utility of this evidence statement, this has been deleted.
SH	Welsh Association of ME & CFS Support	64	FULL	92	18	The changing of terminology between CFS/ME and CFS is confusing and makes one wonder if we are dealing with two different conditions.	Noted with thanks, this has been changed.
SH	Welsh Association of ME & CFS Support	65	FULL	93	4 - 5	Decisions made in partnership - surely the final decision is the patient's and the partnership refers to the exchange of information between practitioner and patient.	In accordance with the methodology for clinical scenarios, the assumptions that form the basis for answering the questions must be explicit. So that respondents have a common understanding of the factors which influence the appropriateness of

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							treatment. . These statements were agreed as assumptions for the questionnaire. They are not guideline recommendations. A fuller explanation is in the methodology chapter.
SH	Welsh Association of ME & CFS Support	66	FULL	94		Some of the blood tests etc for both adults and children are needed to exclude some conditions which can be treated. E.g Lyme disease,	This table documents the questions and responses to the questionnaire for transparency. They cannot be changed now.
SH	Welsh Association of ME & CFS Support	67	FULL	104		5.2.8. Confusing list of symptoms which need a great deal of improvement to enable doctors to recognise a symptom pattern of CFS/ME if they are not given a comprehensive listing of those symptoms with guidance on how common such symptoms are?	We have given guidance on broad criteria to alert the clinician to the possibility of CFS/ME, not for use as diagnostic criteria specifically. This has been clarified in the guideline.
SH	Welsh Association of	68	FULL	105		After 'pathology' A list of possible alternative diagnoses should be	The GDG discussed this but it would be impossible to be inclusive without

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Status	SH organisation	Order no.	Document	Page No.	Line no.	Comments	Response
	ME & CFS Support					included here.	rewriting a medical textbook..
SH	Welsh Association of ME & CFS Support	69	FULL	105		Assuming recovery in children. Some children will not recover and this should not be seen as an opportunity for blame to be attached to either the child or their parents/carers.	This is not referring to recovery from CFS/ME.
SH	Welsh Association of ME & CFS Support	70	FULL	105		Is it normal for an assessment of mental health to be carried out before diagnosing with other chronic neurological conditions?	We have recommended that a mental health assessment be targeted to symptoms, so is not an obligatory assessment, but is targeted as appropriate.
SH	Welsh Association of ME & CFS Support	71	FULL	106		Where is the evidence for this statement on muscle function? What you are suggesting could be detrimental to the patient and their recovery.	These tests are excluding other diagnoses.

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SH	Welsh Association of ME & CFS Support	72	FULL	106		The addition of a test for allergies to foods should be included here with a careful clinical history taken of possible markers for lactose intolerance	We have noted the need for expert dietician input as appropriate, and where such allergies are suspected, tests should be undertaken. As noted in the guideline, we have concentrated on the management of CFS/ME, with appropriate symptom management.
SH	Welsh Association of ME & CFS Support	73	FULL	107		We would suggest all patients are routinely tested for Lyme disease.	The statistics on borreliosis from the National Reference Laboratory (England & Wales) in Southampton are that about 600 cases of borreliosis are diagnosed annually, of which only two to three have brain involvement. The lab has tested several hundred CFS patients using a validated and sensitive serological test and has found only one positive. This patient had evidence of prior infection - but the patient had had a tick bite and a feverish illness i.e. 'an indicative history'. Therefore, routine

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							testing is not warranted.
SH	Welsh Association of ME & CFS Support	74	FULL	107		We would suggest testing for virus activity could lead to appropriate treatment for patients.	This is addressed as testing is recommended where there is an indicative history.
SH	Welsh Association of ME & CFS Support	75	FULL	112	5 - 9	Too wide a definition	This is a quote from the RCPCH guidelines.
SH	Welsh Association of ME & CFS Support	76	FULL	112	28	We would suggest that it is post exertional fatigue which is a cardinal feature and not just fatigue.	We refer here to fatigue as a general symptom, with specific descriptions of fatigue in the recommendations.
SH	Welsh Association of ME & CFS Support	77	FULL	116	4 – 5	Decisions made in partnership - surely the final decision is the patient's and the partnership refers to the exchange of information between practitioner and patient.	This is reporting the agreed assumptions for the questionnaire and cannot be changed now.

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SH	Welsh Association of ME & CFS Support	78	FULL	124		5.3.5.3. This could be at the cost of social and other situations	We are not sure how this relates to the recommendation?
SH	Welsh Association of ME & CFS Support	79	FULL	125	20 - 22	Needs clarifying as badly worded.	Noted and revised.
SH	Welsh Association of ME & CFS Support	80	FULL	126	7 - 11	What happens when there are no competent doctors?	NICE guidelines set the standards. It is the responsibility of local implementation teams to ensure that the care outlined is available.
SH	Welsh Association of ME & CFS Support	81	FULL	127	11 - 12	When there are no competent healthcare professionals - what happens to the person with CFS/ME?	NICE guidelines set the standards. It is the responsibility of local implementation teams to ensure that the care outlined is available.
SH	Welsh Association of ME & CFS	82	FULL	133	1 – 2	Needs to have the Welsh specific information too.	This is a reference to a document.

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	Support						
SH	Welsh Association of ME & CFS Support	83	FULL	133	12 - 13	Needs to have the Welsh specific information too.	This advice would apply to Wales.
SH	Welsh Association of ME & CFS Support	84	FULL	133	20 – 21	Consistency of terminology. Or is another condition being discussed here?	This has been clarified.
SH	Welsh Association of ME & CFS Support	85	FULL	134	3	Terminology	We hope the corrections have addressed this problem.
SH	Welsh Association of ME & CFS Support	86	FULL	135	18	Insulting. Implies all in the head.	This is not the view of the GDG, as the revised wording should make clear.
SH	West Midlands	74	FULL	126	1	Disagree. Spatial disorientation can	Noted but is not characteristic.

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	Consortium					be an alarming symptom of CFS/ME.	