National Institute for Health and Clinical Excellence
CFS/ME consultation draft
29 September – 24 November 2006
Comments on Chapter 2

Status	Organisation	Order no.	Document	Page No.	Line no.	Comments	Responses
SH	25% ME Group	111	FULL	41	28	NICEclaims that "*The Guideline is based on the best available evidence from the research literature*". In relation to ME/CFS, this seems to be a misleading statement. Instead of focusing on the needs of the ME community and on the research literature that supports a biomedical model of the disorder, the GDG have created their own "key questions" to fit the NICEscope (the scope being the document that sets out what the Guideline will cover). These seem to preclude anything other than a biopsychosocial model; indeed, the Draft Guideline states: "*The key questions* ***set the basis for subsequent***	The key clinical questions are based on the Scope. Also please see details of the guideline development for how he Scope and key clinical questions are developed. The aim of the Scope and the questions are to identify and understand the evidence needed to make clinical practice recommendations to health care professionals in the NHS. The scope was subject to wide consultation. Question 1 issue: the text has been revised. Question 3: we reviewed all interventions, and the MRC has made CFS/ME a strategic priority for research.

						evidence reviews *and facilitated the development of the recommendations by the GDG*” (page 41, line 25). This seems to support the notion that the key questions were designed specifically to achieve a pre-determined agenda, especially as the York Review team was instrumental in the formulation of those five questions (page 41, line 28). For example, out of the five key questions, Question 1 is: “*what are the existing case definitions for chronic fatigue syndrome in adults and children?*”. The Draft Guideline states (page 36, line 11) that the Oxford criteria are “*frequently used definitions*”, which is misleading, since the Oxford criteria have never been adopted internationally, being used only in	

						the UK by Wessely School adherents. The Oxford criteria have been shown to have no predictive validity and have been rejected by world experts in ME/CFS. Question 3 is: “*does the evidence show that any particular intervention is effective in treatment, management or rehabilitation of adults and children with a diagnosis of CFS/ME*?”. Since only the psychiatric lobby has been able to obtain serious funding, it follows that the literature is replete with their psychiatric studies which purport to show that the intervention of CBT/GET is effective, so on a numerical evaluation of published studies, the answer to this question is inevitable and simply feeds the self-perpetuating psychiatric	

						paradigm.	
SH	25% ME Group	112	FULL	43	3	The Draft Guideline states (page 43, line 3): "*The aim of the literature search was to identify the most relevant published evidence* ***in relation to the key clinical questions*** *in order to produce an evidence review*". This seems to be yet another example of the self-perpetuating psychiatric paradigm that, by virtue of the acknowledged lack of studies other than psychiatric that address management, inevitably assures that the literature search will produce only studies that support a psychiatric intervention.	The guideline is based on published evidence, with the recognition that there may be interventions not yet researched and published – however, that is the case in all evidence-based guidelines.
SH	25% ME Group	113	FULL	43	21–22	*"The GDG recognised that the surveys from self selected respondents are subject to bias"* The surveys are subject to no more bias than the cohorts selected by Wessely School	Methodological flaws of all reviewed evidence have been discussed and documented (please see Appendix 1).

						psychiatrists for inclusion in their own studies.	
SH	25% ME Group	114	FULL	44	10	Patient groups have been asking for more funds to be directed into varied research for many years. These searches follow the bias of research into psychological treatments without mentioning the concerns of patients. It should be noted that many charities and researchers question the validity of the RCTs that have been done to date and the weakness of quality and quantity of such studies	Noted, and the Guideline Development Group have also made research recommendations. Details of the validity of the trials can be found in Appendix 1 – these were discussed fully by the Guideline Development Group.
SH	Action for M.E.	14	FULL	44	20–21	Identifying the evidence: we were unable to obtain the technical manual on-line and were informed in a follow-up phone call that hard copies would not be mailed. Some reference to its contents would have been helpful in your guide to explaining how the guidelines are	The Guidelines manual can be obtained from the NICE website at the following link www.nice.org.uk/guidelinesmanual

						drafted.	
SH	Action for M.E.	15	FULL	45		Formal consensus methods are welcomed in the development of this guideline. However, it was noted with some concern that there were areas where the disagreement of the wider group appeared to be ignored. This is particularly evident in relation to the use of GET for moderately affected (see P150 FULL guidelines).	As will all questions, the GDG considered and discussed the results of each question on the wider questionnaire and used it to inform their decision making. It is however the GDG ultimately take responsibility for the guideline.
SH	Action for M.E.	16	FULL	45	8–12	The phrase “there is little good research evidence for most aspects of CFS/M.E.” contradicts the claim made in both the FULL and NICEguidelines that there is 'clear evidence' for the effectiveness of CBT and GET. A transparent representation of the research context is needed.	Revised.
SH	Action for M.E.	17	FULL	50	19–21	The small sample size was noted by constituents and unfavourably compared with voluntary	Noted, and we are aware of the potential for bias in such surveys.

						organisations' membership surveys. The construction and distribution of the survey was also problematic for people with M.E., particularly for those who were severely affected.	
SH	Association for Psychoanalytic Psychotherapy in the NHS (APP)	8	FULL	41	5–18	why were there no counsellors or psychotherapists included on the GDG?	It is not possible to include all relevant healthcare professionals on the Guideline Development Group as the maximum number is around 10 to 12. The membership was considered to be appropriate and representative, and the Guideline Development Group were able to call on co-opted experts if appropriate.
SH	Association for Psychoanalytic Psychotherapy in the NHS (APP)	10	FULL	50–51	table	why were there no counsellors or psychotherapists included in your sample of respondents?	Volunteers from all professional stakeholder groups were invited to participate.
SH	BRAME Blue Ribbon for the Awareness of ME	55	FULL	41	21–22	We would argue that this guideline is not based on available evidence. Most available evidence both research based and patient based, was not included in the research review and is not evident anywhere within this document. If all the available	We have recognised that CFS/ME is a physical illness; however, aetiology is currently not known.

						evidence was looked at and listened to, then this guideline would discuss the true neurological, bio-medical illness ME/CFS is – not the ‘condition’ described in this document, which bears no resemblance to reality.	
SH	BRAME Blue Ribbon for the Awareness of ME	56	FULL	43	3–23	2.6.1.1.1 Literature Search and Evidence Reviews: We strongly question the review search for evidence on ME/CFS, as we do not feel that all relevant evidence was picked up in this search. For example GET research papers showing positive results were selected, but those which examined the negative bio-medical effects of exercise were not. We FULLy support the extremely thorough Margaret Williams report on these guidelines and her view on the NICEcomings of the literature	All reported adverse events were extracted and discussed by the Guideline Development Group – please see Appendix 1 for adverse events reported in the trials.

						search and evidence reviews, and hope that NICEwill give these the credit they deserve. Given that she has put these concerns so well, we will not go into detail further ourselves.	
SH	BRAME Blue Ribbon for the Awareness of ME	57	FULL	43	13–15 + 19–23	There has been a total disregard, yet again, for a balanced view of surveys produced by patient groups, and of patient evidence as a whole. This is especially relevant for the severely affected and children/young people, for whom there are very little or no research evidence, apart from that found from within patient community itself. Many of our respondents feel that given that information from the patients/patient groups is treated with such contempt, and that the Guideline authors believe it is 'subject to bias', how can we have	We have included and considered patient evidence – please see also the brief section added on potential sources of bias from patient surveys.

						confidence our comments on this draft will be treated with respect and accorded credibility?. As it is obvious that the patients' experience/voice has not been observed or listened to in the compilation of this draft. Given that research papers, particularly those written by psychiatrists on behavioural management programmes, are done with the pre-conceived bias that it is a somatic disorder, from which patients can exercise/think themselves better, and to produce the desired results they have used the flawed Oxford criteria, why have these not been charged with being 'subject to bias'? Why only prejudice against the patient population?	
SH	BRAME Blue Ribbon for the Awareness of ME	58	FULL	43–44	2.6.1.1.2	Health Economics: Given that there is no research on the cost-effectiveness of GET, and that	Patient evidence has been considered. A reference to a source of general terms (not specific to

						CBT was shown to be expensive – why disregard the patient evidence as to what they find to be helpful and effective, rather than throwing money at ineffective and deeply unwelcome management techniques, which will, in the long run, cost you more money, because they cause a worsening of health. There really needs to be an explanation of a QALY within the glossary as many of our respondents did not understand the health economics meaning of this term.	CFS/ME) has been added to the Glossary.
SH	BRAME Blue Ribbon for the Awareness of ME	59	FULL	45	8–12	2.9 Background – Consensus: The consensus process is only as good/effective as the membership of the group involved, if there is a predominant bias towards certain opinions, and if there is not an equal number of	Noted, and experts were consulted on the use of these techniques.

						people on the opposing viewpoint, the opposing viewpoint is therefore overwhelmed. For example if patient reps, who are fewer in number, have one view then this easily becomes swamped by the other opposing view. We would suggest, given that ME/CFS provokes such a dichotomy of views, that ME/CFS was not the right illness on which to trial the consensus method.	
SH	BRAME Blue Ribbon for the Awareness of ME	60	FULL	46	3–4	2.11.1.1 Consensus Overview: Lack of clarity in wording – should this not read, that if some members of the GDG did not like it/did not fit their viewpoint, then this was changed, to suit some members of the group.	Wording was changed if there was a lack of clarity.
SH	BRAME Blue Ribbon for the Awareness of ME	61	FULL	46	18	2.11.1.2 Ratings and measure of agreement: There is no clear definition of the	Details of all consensus ratings can be seen in the appropriate chapters.

						areas where there was extreme disagreement, and these have been ignored.	
SH	BRAME Blue Ribbon for the Awareness of ME	62	FULL	49	10	Questionnaire to Wider Group: It is obvious that the wider questionnaire was just NICE's lip-service effort to fulfil its obligation to the Government's Patient–led NHS. The results of the wider questionnaire were obviously ignored, if it differed with the views of the majority of the GDG eg the recommendation of GET for the moderately affected, despite the wider group disagreeing with the use of GET.	As will all questions, the GDG considered and discussed the results of each question on the wider questionnaire and used it to inform their decision making. It is however the GDG ultimately take responsibility for the guideline.
SH	BRAME Blue Ribbon for the Awareness of ME	63	FULL	50	19–21	Since there were many stakeholders and each could nominate from 5 to 50 people it is surprising that only 399 questionnaires were sent out, especially as BRAME and other groups put 50 people forward. We know that	Questionnaires were sent by post or electronically to all participants who agreed to take part. Your comments are noted.

						many on receiving the questionnaire did find it a daunting task to fill it all in, in one go, and respond to NICEin the time scale. Many others however, were very disappointed and angry at what they saw, feeling very let down, as it was just addressing the same approach to their illness of CBT/GET that they had been fighting against for years, and felt too disillusioned with what they read, and felt their efforts in responding would not be heard. Most of our respondents complained about the change of language, between ‘appropriate’ and ‘inappropriate’ half way through the questionnaire, on the sections dealing with management, leading to a large number of incorrectly placed answers due to the	

						confusion.	
SH	BRAME Blue Ribbon for the Awareness of ME	64	FULL	53	24 -26	'*as with other surveys, that the results (from the wider survey) were subject to bias'*. You ask patients, carers, and medical professionals who work with ME patients, to fill in a questionnaire, and then infer that the results are biased. So are we to assume that NICE, and the majority of the GDG, did not agree with incorporating the results into the Guideline? If bias is reflecting the facts and reality of the illness, and the impact it has on patients' lives, then why do you always accept without question the bias towards CBT and GET by the psychiatric/psychological school of thought. Our feedback is that the patient voice and experience has once again been ignored.	We would not have undertaken this work without support and agreement from NICE and the Guideline Development Group. Also we have taken the results into consideration – please see the chapters for details.
SH	Cambridgeshire Neurological Alliance	30	FULL	43	All 5,	"One search was carried out to cover all five review	All five questions were answered, but only one search was undertaken to search for

						questionnaire" It is unclear, as to why only one question was taken?	all relevant literature for the five questions.
SH	College of Occupational Therapists	26	FULL	41	2	What does 'modelling' mean in this context?	The details of the health economic modelling can be found in the relevant chapter.
SH	College of Occupational Therapists	27	FULL	43	5	Only RCTs have been included, which excludes other relevant research on management and interventions, and will favour those interventions, which have had the interest of researchers, such as CBT. Although non RCT information has been included for Health Economics.	The review included RCTs and non-randomised controlled clinical trials.
SH	College of Occupational Therapists	28	FULL	48	12	These definitions were originally defined by Cox and Findley and no reference is made. The correct reference is: Cox DL, Findley L (1998) Management of chronic fatigue syndrome in an inpatient setting: presentation of an approach and perceived outcome *British Journal of Occupational Therapy 61:* 405-	Noted and revised.

						409 as cited in the 2002 report to the CMO pg. 27.	
SH	College of Occupational Therapists	29	FULL	53	25	Spelling error – recognising.	This has been amended.
SH	Department of Health, Peninsula Medical School	17	FULL	43–44	24- .. - 9	Section 1.1.2. There should be specific mention as to whether or not (I think not) the economic analysis used complex models, specifically to assess the potential impact of services delivered in this way on other parts of the health economy (reduction in inappropriate referrals/consultations in other specialities or in primary care; reduced duration of illness/need for services because of better diagnosis/care/self-management), and other parts of the economy (benefits; employment). Even if analyses were not done, it is relevant to make a statement on these aspects, so that readers are aware that any costs deriving from these recommendations	Details of the health economic modelling can be found in the text for each clinical question.

						should be seen in the context of beneficial impact on these other areas.	
SH	Department of Health, Peninsula Medical School	18	FULL	48	13	These definitions were published by Cox and Findley, who should be credited as the authors, as shown in the Report to CMO.	Noted and revised.
SH	Invest in ME	69	FULL	40	22–27	IiME Comment: This review has been criticized by Professor Malcolm Hooper (Appendix 6 – 17). ‘As a summary of evidence-based medicine for the treatment of Chronic Fatigue Syndrome, section 3 of this systematic review from Bagnall et al. is a failure.’	We have added a paragraph responding to this and other criticisms.
SH	Invest in ME	70	FULL	41	5–7	The Guideline Development Group IiME Comment: By being broad enough the membership of this guideline development group perpetuates the current situation where a wide range of conditions are mis-represented as	Please see further discussion of this in the Introduction and Diagnosis sections in the full guideline.

						ME.	
SH	Invest in ME	71	FULL	41	24–2.4	*Developing key questions* The following questions were addressed: IiME Comment: Here we reiterate the criticism of the precision of the NICEguidelines with respect to terminology. The first question refers to chronic fatigue syndrome. The second and third questions refer to CFS/ME.	Noted and revised.
SH	Invest in ME	72	FULL	43	3–2.6	*Identifying the evidence* IiME Comment: who decides what is relevant? What process is in place to decide what is relevant? How is it that much biomedical research is not referenced in these guidelines? The York review is not adequate to use for this purpose (Appendix 6 -17).	Please see Appendix 1 for the inclusion and exclusion criteria applied.
SH	Invest in ME	73	FULL	43	21	“subject to bias and not necessarily representative of the wider population of people with CFS/ME”. IiME Comment:	Noted.

						The same applies to published research using different research criteria. To ignore the history of this illness (ME) and the way it has been shamelessly portrayed by psychiatrists as a somatoform illness is to ignore a vital part of why the state of treatment and research into ME in the UK is in such a mess.	
SH	Invest in ME	74	FULL	40 and Page 44		IiME Comment: "*best available evidence*" and "*Information for National Collaborating Centres and Guideline Development Groups*" There is some question about the "best available evidence" as input from biomedical researchers has been ignored in preference to the psychosocial input and the National Collaborating Centres have been subject to criticism in their approach to people with ME, especially with the	Please see the NICE guidelines manual (www.nice.org.uk/guidelinesmanual) for the hierarchy of evidence. We also used formal consensus methods, patient evidence and clinical expertise as described throughout the full guideline.

						Severity level of “severe”.	
SH	Invest in ME	75	FULL	44– 45		- *Review of the clinical evidence* IiME Comment: “Consensus development methods were also used”, however, all biomedical research and proposals of physical illness were downgraded or removed in preference to supporting the psychosocial model. Therefore, in ignoring the inputs available from {XX], et al, this Guideline cannot be considered to have included “consensus”.	Consensus was used, and a recommendation that CFS/ME should be recognised as a physical illness has been made.
SH	Invest in ME	76	FULL	49	20–27	IiME Comment: Is this already skewing the results as these are not all CFS/ME patients and are bound to include others who do not have neurological ME. Look at the stakeholders – even a cursory glance shows mental health institutes, pharmaceutical companies,	Noted, but the questionnaire was to a wider population than just patients – including carers and healthcare professionals involved in care.

						psychotherapy , Royal College of Psychiatrists. If we are blending these illnesses then the results of these guidelines are bound to be inaccurate and unusable.	
SH	Invest in ME	77	FULL	50	3 +	IiME Comment: This then amounts to a group of people selected to participate without knowledge of their diagnosis, selected by people on a committee who are not necessarily representative of ME patients, and provision of results from a study which is not accepted by the ME community!!!	As is stated in the methods, the questionnaire was not intended as a representative sample of people with CFS/ME. It surveyed the views of stakeholders. It was used by the GDG to inform their decisions, recognising this bias.
SH	Invest in ME	78	FULL	52	*7*	“4. “I truly believe that a lot of people without the condition would have a problem getting to grips with the information and questionnaire!!! I, for one will not be able to help you by returning the questionnaire, When I agreed to be sent the questionnaire I assumed it would be a simple task of	Noted.

						answering questions, that would go some way to helping the medical profession reach a worthwhile conclusion. I did not think for one minute it would need over 450 pages of accompanying notes!!!" 5. "How I, or anyone else with ME or even recovered could possibly read, digest and understand the NICEdocument enough to be able to answer the Questionnaire, is beyond my comprehension. I surely cannot be the only person who has had this problem, or am I the only honest one around? I would like this letter to go on record as I feel it is very important for Non-Sufferers to know how difficult a task this was for an ME Patient. Just writing this letter has been hard enough!" " IiME Comment:	A lay version of the guideline recommendations 'Understanding NICE Guidance' will be produced to facilitate understanding for patients/carers.

						This is surely typical for most people with ME? Most will have the same problems getting to grips with these guidelines.	
SH	Invest in ME	79	FULL	54	14	IiME Comment: Which recommendations are these if they are not substantiated even by the participants in the questionnaire?	The recommendations were rated by the Guideline Development Group throughout the process.
SH	Invest in ME	80	FULL	54	21	IiME Comment: Who was sitting on this ‘independent’ panel? These guidelines need to state this. Is this ‘independent’ panel broadly based or is it composed of career psychiatrists?	Details of the Guideline Review Panel can be found on the NICE website at www.nice.org.uk/guidelinesmanual and in the NICE version of the guidelines. The panels provide external validation for guidelines, mainly by ensuring stakeholders’ comments on the drafts of the scope and guideline are addressed and the final recommendations can be implemented. Please refer to the *Guideline development process - an overview for stakeholders, the public and the NHS (second edition)* available on the NICE website, for further information.
SH	LocalME	77	FULL	45	10	NICEacknowledges that there is at present little good research evidence	As will all questions, the GDG considered and discussed the results of each question on the wider questionnaire and used

						for most aspects of ME/CFS and acknowledges the need for consensus methods. However, NICElargely pays lip service to the principle of consensus with patient evidence being viewed as biased and virtually ignored.	it to inform their decision making. It is however the GDG ultimately take responsibility for the guideline.
SH	LocalME	78	FULL	51	7	This confirms (as mentioned previously) that an enormous reading burden was placed upon ill volunteers, many with severe cognitive difficulties which undoubtedly put many of them off before they ever got to the actual questions. Many of them may have been able to contribute significantly otherwise. The volume of required reading would tax most fully healthy people. As many key questions did not progress to the wider group, we wonder to what extent the stakeholder principle is being	Noted, and we provided as much support as we were able. . We made efforts to shorten it by not sending out all of the questions to respondents. While we recognise that it was long, we wanted stakeholders views on man issues. Please see details of the process explaining why not all questions went to the wider group.

						upheld.	
SH	National Coordinating Centre for Health Technology Assessment		FULL	45	10	NICE acknowledges that there is at present little good research evidence for most aspects of ME/CFS and acknowledges the need for consensus methods. However, NICE largely pays lip service to the principle of consensus with patient evidence being viewed as biased and virtually ignored.	There was a survey of patiient views and we used the patient evidence throughout to inform the GDG. It is however the GDG ultimately take responsibility for the guideline.
SH	Newcastle PCT		FULL	51	7	This confirms (as mentioned previously) that an enormous reading burden was placed upon ill volunteers, many with severe cognitive difficulties which undoubtedly put many of them off before they ever got to the actual questions. Many of them may have been able to contribute significantly otherwise. The volume of required reading would tax most fully healthy people. As many key questions did not progress to the	Noted, and we provided as much support as we were able. We made efforts to shorten it by not sending out all of the questions to respondents. While we recognise that it was long, we wanted stakeholders views on man issues. Please see details of the process explaining why not all questions went to the wider group.

						wider group, we wonder to what extent the stakeholder principle is being upheld.	
SH	North Staffordshire Combined Healthcare NHS Trust	15	FULL	41		It is surprising that the development group contained only one psychiatrist and one clinical psychologist despite the fact that most of the research comes from within the mental health arena. This is in marked contrast to the NHS Plus document which is led by acknowledged experts and thus has a great level of credibility.	The Guideline Development Group is a multidisciplinary group comprising technical experts, clinicians, professionals and patients. The membership reflects the range of stakeholders and groups whose professional activities or care will be covered by the guideline, and contains members with experience of patient and carer issues. Professional members do not need to be experts but have an interest and experience in CFS/ME and treat patients on a day-to-day basis in the NHS. Individuals were also co-opted to the group for specific discussions.
SH	PRIME Project (Partnership for Research in ME/CFS)	2	FULL	49	10	Whilst we appreciate that gathering patient views about treatments and interventions is challenging and can be problematic – the use of questionnaires with large appendices will have posed a real challenge for many, severely affected patients, who are already often excluded	We note the concerns on the wider survey, and therefore the importance of the validation phase where the comments of stakeholders are considered and responded to.

						from this sort of activity. As the severely affected make up a significant proportion of this patient group, other methods could have been explored such as video diaries, audiotapes or interviews. Our work has showed that for the more severely affected there is a real need to engage with them in their own environment, using the most non invasive technique possible, in order to get a FULL picture of their condition and its impact. Whilst we recognise that the systematic approach of using the clinical scenarios, the systematic review and the questionnaire is ‘scientific’ and robust, it is also complex and very dense in volume. This may have	

						deterred groups with limited recourses or limited exposure to this sort of material from contributing. Therefore, it is possible that these methods are severely limited in terms of the extent of patient experiences that can be represented. The methods will be possibly subject to several biases: • Recall bias, as participants may not report their views completely or accurately at the time of survey • Selection bias, in that: • some participants, especially the severely affected, will be physically unable to contribute • the views of recovered patients are likely to be missed	

						No statement is made of how NICE intends to remedy this potential bias. The PRIME Patient Experience Database, which went online in March 2006, provides access to primary data, which may fill some of these gaps.	
SH	PRIME Project (Partnership for Research in ME/CFS)	3	FULL	52	14	Because the PRIME Patient Experience Database was compiled using methods which best suited severely affected people (i.e. face-to-face interviews), we were able to circumvent these problems.	Thanks for this information.
SH	SWAME (South West Alliance for ME)	7	FULL FULL FULL	45 52 159 267	8–10 3–18 n/a 4–7	Consensus and Patient Involvement The guideline acknowledges that there is at present little good research evidence for most aspects of CFS/ME care and hence acknowledges the need for consensus methods, which is helpful and	There was a survey of patient views and we used the patient evidence throughout to inform the GDG. It is however the GDG ultimately take responsibility for the guideline. All stakeholder comments are responded to and can be seen on the NICE website at

						welcome, however it nevertheless seems that NICE subsequently pays lip service to the principle of consensus. Patient evidence is viewed as biased and virtually ignored. A wider group questionnaire was commissioned via stakeholders but many questionnaires were not returned. A massive reading burden was placed upon ill volunteers, which put many of them off before they ever got to the actual questions, which they may well have been able to otherwise answer usefully. Also many key questions did not progress to the wider group, and when they (randomly) did the disagreement of the wider group has been ignored (eg concerning GET for moderately affected p159). One wonders to what extent the	publication. The Canadian guidelines were also evidence considered by the Guideline Development Group.

						stakeholder principle is being upheld and even whether comments such as these now being submitted will reflect at all in what happens next. It seems that the whole basis upon which NICE guidelines are constructed, with it’s emphasis on quality of “evidence”(research evidence), is not applicable to CFS/ME (because of the lack of good research evidence mentioned in the FULL) and it was too early for NICE to attempt such a guideline. Unless the protocol is broken and more attention paid to wide-ranging clinician and patient experience and consensus, the guideline will have little practical value. In contrast, Canada has produced clinical guidelines on the basis of true consensus of practical experience of numerous experts	

						in the field, drawn internationally. The Canadian guidance has been widely welcomed by patient groups and clinicians across the globe and has already been used by eg Southern Australia as a basis for their own GP guidance. The Canadian guidance has also been endorsed by CFS/ME clinical champions and other CFS/ME scientists here in UK, and adopted by a majority of patient groups. It is disappointing to see so little reference by NICE to this very useful document. It seems the NICE guidance will have far less practical value than the Canadian consensus document. NICE have acknowledged the lack of good research and the need for a consensus approach, but nevertheless have stuck rigidly to a	

						strictly single-line-of-evidence-based approach and rigid thinking based on psychosocial inclusive diagnostic criteria, which in the past have skewed research results. The resulting document therefore will lag well behind what is available elsewhere in the world.	
SH	The Chartered Society of Physiotherapy	4	FULL	51	21	Physiotherapists responded. Not mentioned	This has been amended.