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

Status	SH organisation	Order no.	Document	Page No.	Line no.	Comments	Response
SH	Action for M.E.	3	FULL, Appendix 1	17		It is stated that, "No studies were able to establish the superiority of one existing case definition over another". Our constituents have queried the omission of the Canadian guidelines in the development of diagnostic criteria.	We will feed these comments to the team who completed the review. Please also see the discussion of diagnosis in Chapter 5.
SH	ME Research UK (formerly MERGE)	35	References Consulted			References (in alphabetical order) 25% ME Group. 2004. Severely affected ME (myalgic encephalomyelitis) analysis report on a questionnaire issued January 2004. 25% ME Group, Troon, Ayrshire, UK. http://www.25megroup.org/ Acheson ED. The clinical syndrome variously called benign myalgic encephalomyelitis, Icelandic disease and epidemic neuromyasthenia. American Journal of Medicine 1959; 569: 595. Andersen MM, Permin H, Albrecht F. Illness and disability in Danish Chronic Fatigue Syndrome patients at diagnosis and 5-year follow-up. J Psychosom Res 2004 ;56(2): 217-29. Bolsover N. Commentary: the evidence is weaker than claimed. British Medical Journal 2002; 384: 294. Baraniuk JN et al. A chronic fatigue syndrome – related proteome in human	Noted – thanks.

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						Chief Medical Officer. A Report of the CFS/ME Working Group. Report to the Chief Medical Officer of an Independent Working Group. February 2002. Crowhurst G. Supporting people with severe myalgic encephalomyelitis. Nurs Stand 2005; 19(21): 38-43. De Becker et al. A definition based analysis of symptoms in a large cohort of patients whith CFS. Journal of Internal Medicine 2001; 250: 334-40. De Meirleir K, Bisbal C, Campine I, De Becker P, Salehzada T, Demettre E, Lebleu B. A 37 kDa 2-5A binding protein as a potential biochemical marker for chronic fatigue syndrome. Am J Med 2000; 108(2): 99-105. Deale A, Husain K, Chalder T, Wessely S. Long-term outcome of cognitive behavior therapy versus relaxation therapy for chronic fatigue syndrome: a 5-year follow-up study. Am J Psychiatry 2001; 158(12): 2038-42. Devanur LD, Kerr JR. Chronic fatigue syndrome. J Clin Virol 2006; 37(3): 139-50. De Lange FP, Kalkman JS, Bleijenberg G, Hagoort P, van der Meer JW, Toni I. Gray matter volume reduction in the chronic fatigue syndrome. Neuroimage 2005; 26(3): 777-81. Dowsett EG et al. Myalgic encephalitis - a persistent enteroviral infection? Postgraduate Medical Journal 1990; 66: 526-30. Essame CS, et al. Pilot study of a	

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SH	The British Psychological Society	58	Appendix	16	Table	The London criteria. The details are based on incomplete information. There are exclusions e.g. all psychiatric disorders. These are listed on the complete photocopy, available from AFME.	We will feed these comments to the team who completed the review.
SH	The British Psychological Society	59	Appendix	17	Para 2	The London criteria were used in at least one study in the review (Perrin), the Dowsett criteria of 1990 were not. Did the authors confuse the Dowsett criteria 1990 with the London criteria (Dowsett et al 1994) as Jason et al 2003 did?	We will feed these comments to the team who completed the review.
SH	The British Psychological Society	60	Appendix	18	Para 2	It's not clear from the article by Jason et al if they used the Dowsett criteria 1990 or just one of the criteria common to both the Dowsett and London criteria (i.e. post-exertional fatigue). In one place, they refer to the 'Dowsett London criteria 1990'. This is clearly an error. One solution may be to refer to the criteria for ME.	We will feed these comments to the team who completed the review.
SH	The British Psychological Society	61	Appendix	50	Para 1	One would expect the Ridsdale et al study on counselling to be included here. It was included in the original review.	The Ridsdale study included people with chronic fatigue, not CFS.

SH	The British Psychological Society	62	Appendix	54	Table	Friedberg and Krupp. This study combined CBT with pacing. That is possible. Results indicated an improvement in the subgroup with higher depression scores. This is not clear from the summary.	We will feed these comments to the team who completed the review.
SH	The British Psychological Society	63	Appendix	General	Table	Ridsdale et al 2004 compared CBT and GET in a sample with fatigue and CFS. Like Prins et al. Prins et al was included in the CRD review, though not everyone met criteria for CFS. Why did the CRD not include Ridsdale et al 2004 when mixed samples are acceptable?	Prins 2001 included people who met the CFS 1994 criteria.
SH	The British Psychological Society	64	Appendix	81	Para 2	This broad-based programme included medical care, drugs, and pacing. To describe it as “information and advice” is misleading. Validity score should be 3, not 2 (factual error).	We will feed these comments to the team who completed the review.
SH	The British Psychological Society	65	Appendix	88	Para 2	Again, no mention that CBT is as effective as counselling. Also, the CBT trial which showed no effect (Lloyd et al) did not have a low validity score, but did use a strictly-defined, severely-affected sample. This is significant. Studies using strictly-defined samples do not show the same benefits as trials involving more broadly-defined patients (see also Friedberg and Krupp). This may explain the discrepancy between research findings and the reports from patients. The summaries clearly favour CBT and GET, and do not take account of some of the serious flaws, e.g. failure to measure activity levels objectively (e.g. with actometer), no assessment of somatic symptoms, inclusion of the less	We will feed these comments to the team who completed the review.

						affected (Sharpe et al) etc.	
SH	The British Psychological Society	66	Appendix	94	Table	Re combination, ref 211. Treatment was judged to have no overall effect, despite significant differences on five outcome measures (somatic symptoms, fatigue, self-efficacy, anxiety and depression), 23% completely or virtually recovered within 6 months and the fact that 82% felt better or 'much better'. Improvements were maintained at 12 months follow-up. The judgement of no overall effect seems very odd. This is one of the few studies assessing an alternative rehabilitation programme to CBT/GET. It deserves an objective and accurate evaluation. Information about this trial elsewhere in the document also reveals a number of errors. Although obviously a coincidence, it adds to the impression that the CRD favours the CBT and GET trials, and appears less interested in alternative rehabilitation programmes.	We will feed these comments to the team who completed the review. Please also see the response to comments in Chapter 2.
SH	The British Psychological Society	67	Appendix	112	Ref 13	Reference is incorrect. Dowsett EG, Gouldsmit E, MacIntyre A. Should read Dowsett, E, Goudsmit, E, Macintyre, A and Shepherd, C.	We will feed these comments to the team who completed the review.
SH	The British Psychological Society	68	Appendix	170	Table	Jason et al 2003. Did they use the Dowsett criteria 1990? This just isn't clear from their paper. They appear to have studied patients with post-exertional malaise.	We will feed these comments to the team who completed the review.

SH	The British Psychological Society	69	Appendix	420	Table	Perrin. This paper mentions using the London criteria as well as the CDC criteria (1998, p.2).	We will feed these comments to the team who completed the review.
SH	The British Psychological Society	70	Appendix	426	Table	Re Goudsmit. There is no Hamilton Anxiety and depression scale. Do they mean the Hospital Anxiety and Depression Scale. Re Self-efficacy, if there was a significant difference, p=.013, not .13? (Outcome 2) Significant difference in depression and anxiety scores (p=.04). Table states no significant differences. (This study comes from a member of the British Psychological Society, hence the detailed knowledge).	We will feed these comments to the team who completed the review.
SH	The British Psychological Society	71	FULL	442	Table B	Validity score Goudsmit is 3, not 2. It was 2 in the original review, since changed to 3 (2005).	We will feed these comments to the team who completed the review.