Response to the MRC Research Advisory Group (RAG) Draft Document for Public Consultation on "CFS/ME" Research Strategy dated 17th December 2002

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Preface: **On 14th January 2003 there is to be a meeting at The Royal Society of Medicine entitled "Chronic fatigue syndrome and factitious illness: interface between child psychiatric and paediatric services".**

[According to the Concise English Dictionary (Bloomsbury 2001), "FACTITIOUS" means "contrived or insincere rather than genuine; not real or natural but artificial or invented"].

Speakers include Professor Elena Garralda (a psychiatrist and one of the authors of the 1996 Joint Royal Colleges' report CR54 on "CFS" which in its Summary directed that *"No investigations should be performed to confirm the diagnosis (as) revealed changes are rarely substantial"* and which dismissed ME, claiming at para 13.3 *"Previous studies have counted people with ME, but these studies reflect those who seek treatment rather than those who suffer the symptoms"*); Dr Harvey Marcovitch (editor- in -chief of The Archives of Disease in Childhood: in 1999 after transmission of the BBC "Panorama" programme on ME which exposed the harrowing stories of several families whose very sick children had been removed from their home and locked away in "secure" psychiatric units, Marcovitch wrote that the BBC had performed a hatchet job on one of the psychiatrists involved for his use of 'active rehabilitation' as a treatment for chronic fatigue syndrome and stated "it's about time the (medical) profession hit back at those who are vilifying our colleagues" -- *Diagnose and be damned: BMJ 1999:319:1376*); Dr Peter White (who led the walk-out of psychiatrists from the CMO's Working Group on "CFS/ME" because he felt there was insufficient emphasis on psychiatric aspects in the final version of the CMO's report) and Professor Sir Roy Meadow, Emeritus Professor of Paediatrics and Child Health (known for his view that children with "ME" have parents who suffer from Munchausen's Syndrome by proxy). For the record, Munchausen's Syndrome is now known as "FII", which stands for "Fabricated and Induced Illness".

Response to the MRC draft document

We welcome the acknowledgement by the MRC "CFS/ME" Research Advisory Group (RAG) of the heterogeneity of the condition and the need for future research. We support the urgent need for a clinically accurate case definition, the need for carefully designed epidemiological studies and the need for the severely affected to be included in appropriate future research. We note the welcome inclusion of lay participation and hope this will include liaison with independent local ME groups and not only with the two prominent ME charities. However, it seems premature to agree with the uncritical acceptance of the MRC's draft document as manifest by the charity Action for ME: **on 17th December 2002 *The Scotsman* carried an item by Phil Hazelwood which quoted Brian Dow (Press and Campaigns Manager for Action for ME) as stating "As far as we're concerned, the MRC has fulfilled its side of the bargain".** Others, including ourselves, are of the view that there must surely be concerns about the following paragraphs in the draft document,

which exemplify a stance that is distinctly disadvantageous (and even actively harmful) to those with myalgic encephalomyelitis (ME).

paragraph 3: (Summary) **"The MRC CFS/ME Research Advisory Group fully endorses the conclusion of the Report of the CMO's Independent Working Group…"**

The CMO's Working Group on "CFS/ME" was not in any way "independent": it was financially supported by the Linbury Trust of the Sainsbury (supermarket) family (indeed, the MRC itself is often now funded by partnership schemes with industry). Since 1991, the Linbury Trust has provided over £4 million, mostly to adherents of the "Wessely School". to fund almost exclusively psychiatric research into chronic fatigue (which is then referred to as the chronic fatigue syndrome). The Linbury Trust states that it has "*funded the great bulk of CFS research conducted in the UK*"; that "*we can state confidently that CFS is not an inflammation of brain or a muscle disease*" and that "*numerous psychological disturbances have been identified*". Concerning "treatment", the Linbury Trust approach states that it "*deals only with graded exercise, cognitive behaviour therapy and antidepressants"*. (1)

The views of members of The Linbury Trust about "CFS" are well-known, particularly their claim that *"Before the Linbury Trust initiative, much of the knowledge base in this area was erroneous"*(2), thereby summarily dismissing 60 years of documented medical history of myalgic encephalomyelitis (ME) and its recorded signs and symptoms.

The Linbury Trust established a Scientific Advisory Panel on "CFS", one member being Professor Alan McGregor of Kings College Hospital, London, who has co-authored papers on "CFS" with Simon Wessely (3), (4) and who is now one of the members of the MRC "CFS/ME" Research Advisory Group. Another member of the MRC Group is Professor Philip Cowen (psychopharmacologist), who has co-authored on "CFS" with psychiatrist Michael Sharpe (5) and who contributed a chapter on "CFS" in one of the Linbury Trust publications entitled "Abnormalities of Mood". (2)

There has been considerable concern expressed by the ME community that the Office of Science and Technology and the MRC may be only too eager to accept advice from these "fresh to the field of CFS/ME" and "independent" members of the MRC "CFS/ME" Research Advisory Group (including those who have been funded by the Linbury Trust) that "CFS/ME" is, after all, nothing more than a chronic "fatigue syndrome" and that the MRC will recommend the direction of future studies accordingly. If they are not to lose credibility, how could Linbury Trust members and beneficiaries advise otherwise?

It may be salutary to reflect that since 1996, David Sainsbury has donated £7 million to the Labour Party; in 1998 he resigned as Chairman of his family's supermarket chain to become Labour Minister for Science and is now Lord Sainsbury of Turville (not to be confused with his brother John, now Lord Sainsbury of Preston Candover). This made David Sainsbury the Parliamentary Under-Secretary of State for Science and Innovation, giving him responsibility for the Office of Science and Technology, together with the chemical and biotechnology industries as well as all the Research Councils, including the MRC (where psychiatrist Simon Wessely is a member of various boards, including, perhaps significantly, the Health Services and Public Health Research Board -- *see comments on paragraph 13 below* --; Neurosciences and Mental Health Group and the Monitoring and Evaluating Group (MESG). Of possible relevance in the overall context, it may be noted that Wessely's wife Dr Claire Garrada is Senior Policy Adviser to the Department of Health).

The Office of Science and Technology monitors all Government funding of research and controls policy on the direction of that research. It has already been officially confirmed that it is "**policy**" which determines the research which is funded: *"The Department funds research **to support policy**"*. (6) This seems not to accord with the MRC's often-repeated assertion that funding depends entirely on the satisfactory calibre of the submitted research proposals.

paragraph 6: "A strategy is proposed **which reflects the current state of knowledge of CFS/ME and which aims to provide a rational framework for advancing the understanding of the illness and its management**"

For the reasons set out re paragraphs 35 and 36 below, this claim is meaningless without knowledge of which of the two interpretations of the term "CFS" is being used.

paragraph 10: **"the MRC CFS/ME Research Advisory group considers that the research community should be encouraged to develop high quality research proposals…that are amenable for study at the present time"**

What is meant by "amenable for study at the present time"? This raises concerns, given that one prominent "CFS/ME" investigator holds the view that people should not be too distracted by investigations and ideas which are on the borders of our present knowledge: (7) surely advances in medical science are achieved by intellectual rigour and commitment and by resolutely pushing ***beyond*** the borders of current knowledge. As the Countess of Mar has pointed out: *"Why should the doctor and the patient accept the limitations of scientific knowledge? I ask whether we would have been able to eradicate smallpox, prevent the infectious diseases of childhood or establish the link between asbestos and lung disease if the medical practitioners of the time had accepted the limitations of scientific knowledge"* (8)

paragraph 11: **"studies investigating…causal pathways and mechanisms…would not have…immediate impact on increasing understanding of CFS/ME"**

paragraph 12: **"the MRC CFS/ME Research Advisory Group considers it is appropriate to explore potential interventions for CFS/ME in the absence of knowledge of causation or pathogenesis"**

These two paragraphs seem to echo the Linbury Trust view (written by Simon Wessely) that *"It is usual to try to discover the cause of an illness before thinking about treatment (but) some illnesses are treated without knowledge of the cause…examples include chronic fatigue syndrome"* (2).

(See also paragraph 82 below)

paragraph 13**: "Given the present difficulties in identifying priorities for health services research in CFS/ME, it is not clear whether it is appropriate to make (such research) a priority at this time"**

Have the MRC "CFS/ME" Research Advisory Group members any intention or plans to visit any of the severely affected in their homes in order to focus their collective mind about what **ought** to be a health services research priority? As noted above, Simon Wessely is a member of the Health Services Research board at the MRC and in 15 years of his extensive

publications he has never included those severely affected by ME/ ICD-CFS in his studies of his own definition of "CFS". With such a precedent, is it likely to be the case that, despite lip-service to the plight of the severely affected in this draft document, the severely affected will turn out not to be a priority, and their suffering will yet again be deemed "inappropriate" and therefore ignored?

paragraph 14: **"It is essential that the researcher-funder-lay partnership is nutured…(we) consider that there is a key role for the patient organisations to help attract participants to research"**

We agree that there is a key role for lay participation, but not simply as a means of producing participants for research purposes.

What is needed is participation of the patient **as expert**: this should be fully recognised in the way now promoted by the Department of Health in its booklet "The Expert Patient: A New Approach to Chronic Disease Management for the 21st Century" (*Department of Health, September 2001*).

It is important that lay participation should be at a more inclusive level than was the case with the Chief Medical Officer's Report of January 2002 and that participation should involve individual patients and local groups of affected patients who are not necessarily associated with the ME Association or with Action for ME but whose voice needs to be heard. It is vital that the best interests and concerns of such people are addressed regarding important areas for research, as expressed in the Appendix to the Summary Report on MRC Consultation Questionnaire *(see below).*

paragraph 24: **"the MRC agreed to convene a CFS/ME Research Advisory Group made up of individuals who were not active in the CFS/ME field"**

See comments re paragraph 3 above.

The original Briefing given at the All-Party Parliamentary Group on ME by Dr Diana Dunstan, Director of the MRC Research Management Group, stated that the "CFS/ME" Group "comprised leading experts from various fields who did not previously specialise in CFS/ME, because since this was 'such a broad area, it was felt important to get a wide range of specialities' and to have an independent and fresh look at the issue" (9)

In response to written representations to Professor Sir George Radda (Chief Executive of the MRC) arising as a result of the MRC's claim that the panel of experts appointed to the "CFS/ME" Research Advisory Group were all "independent" and "fresh" to the subject of "CFS/ME", Radda was compelled to concede that this was not in fact the case: his reply was somewhat curious: *" We are aware of Prof McGregor's involvement with the Linbury Trust. You cite papers from some years ago in which he is a co-author…..The inclusion of Profs McGregor and Cowen is consistent with MRC's intention to select the working group from experts in various fields who do not specialise in CFS/ME"* (10)

paragraph 27: **"…the MRC CFS/ME Research Advisory Group did not consider the issue of service provision as this area was not within its role"**

Research into service provision for those with ME/ICD-CFS is important and necessary. Whilst there is an obvious distinction between medical research and provision of care for those whose disorder is being researched, this admission in paragraph 27 seems to be a worrying echo of the remit of the CMO's Working Group on "CFS/ME", which was expediently limited to looking only at "management" of ME and CFS. Seemingly the remit of the MRC Research Advisory Group excludes consideration relating to the care (including respite care) or any other NHS service provision for a UK population of at least 0.2% - 0.4%, which is 120,000 to 240,000 sick people (prevalence statistics taken from the CMO's Report on "CFS/ME" of January 2002), of whom at least 25% (ie. 30,000 – 60,000) are severely affected and are bed- or housebound.

By comparison, the Multiple Sclerosis Society states that there are 85,000 sufferers of MS in the UK.

paragraph 35: **"the MRC CFS/ME Research Advisory Group did not revisit this topic (of terminology)"**

Why not? Terminology lies at the very heart of this issue and requires to be addressed with diligence, otherwise there will be no real progress resulting from the MRC Research Advisory Group. Currently, due to the ambiguity of the chosen terminology, only the authors of both the CMO's Report on "CFS/ME" and the current draft document from the MRC have any idea of the patient population they are talking about.

The essence of this on-going confusion concerns the use of the combined term "CFS/ME", **given that "CFS" means different things to different people**. To the international research community, CFS is one of the names by which ME has come to be known and as such is the term used when referring to the disorder, but to the psychiatrists and adherents of the Wessely School, "CFS" means a somatoform (psychiatric) disorder in which personality style, suggestibility, depressed mood, avoidance of exercise, aberrant illness beliefs and dysfunctional behaviour are central, constituting a functional somatic syndrome which is amenable to behavioural modification regimes. This dichotomy has been summarised by Fred Friedberg, Clinical Professor in the Department of Psychiatry at the State University of New York: *"Descriptive studies of CFS patients in England, the US and Australia suggest that the CFS population studied in England shows substantial similarities to depression, somatization and phobic patients, while the US and Australian research samples more closely resemble fatiguing neurological illnesses"*. (11) Thus, the term "CFS/ME" as used in the MRC document means whatever the reader interprets it to mean, and is therefore meaningless.

How can sound research strategies be produced by the MRC Group on the basis of the combined term "CFS/ME", when there are two differing interpretations of the term "CFS"? Is this obfuscation acceptable to the MRC?

We once again ask that care be taken to clarify the correct situation, which is that ME / ICD-CFS is a formally classified disorder of the nervous system (ICD10- G93.3, *WHO:1992*) but that syndromes of chronic fatigue are formally classified as "Mental and Behavioural" disorders (ICD10- F48.0 *WHO:1992*), a category from which ME / ICD-CFS is expressly excluded.

Without understanding, acceptance and exposition of this clear distinction, and by continuing to equate one specific syndrome with another syndrome which does not have the same features, the MRC "CFS/ME" Research Advisory Group perpetuates a grave disservice both to those who suffer from ME / ICD-CFS and to medical science itself.

It is scientifically unacceptable that one name should refer to two different case definitions, each of which having different symptom profiles.

paragraph 36: "**There are separate entries in the World Health Organisation's International Classification of Diseases (ICD-10) for "chronic fatigue syndrome" and "myalgic encephalomyelitis"**

See comments re paragraph 35 above. This statement in paragraph 36 is erroneous (and can readily be shown to be erroneous) but it echoes the same obfuscation made in the CMO's Report of January 2002: even though this same error was pointed out to the authors of that report many times before the final version was published, clarification was not addressed.

Given the number and nature of the documents known to have been sent to the MRC for the attention of the ME and CFS Research Advisory Group, it is not credible to assume that the error about ICD classification is a simple mistake or that the members of the Group are unaware of the correct ICD classification.

The ignoring of the evidence on this issue must thus be seen as deliberate.

It would certainly be in accordance with countless attempts to eradicate ME /ICD-CFS and to subsume this distinct disorder within the undifferentiated term "CFS". The most blatant unauthorised re-classification of ME from a neurological disorder to a psychiatric disorder is to be found in Wessely's contribution to the WHO Guide to Mental Health in Primary Care (*November 2000*), which states about his own version of "CFS" that "*It is often known as 'ME*' (and therefore, according to the Guide's title, by definition ME becomes a "mental" disorder). As members of the UK WHO Collaborating Centre, Wessely et al were perfectly entitled to use the WHO imprimatur, but they did so apparently without such a change of classification having been approved by the World Health Assembly or by the WHO; moreover, the WHO has confirmed that it has no plans to change the classification of ME / ICD-CFS and that there is a "clear distinction" between ME / ICD-CFS on the one hand and syndromes of chronic fatigue on the other.

Notwithstanding, the pervasive re-classification "policy" from neurological to psychiatric was again presented as a fait-accompli in January 2002 in a document from the Royal College of Paediatricians and Child Health entitled "The Next Ten Years: Educating Paediatricians for New Roles in the 21st Century". This is a joint training project with the Royal College of Psychiatrists: a project director (Dr Quentin Spender, Senior Lecturer and Consultant in Child and Adolescent Psychiatry at St George's and Chichester) was appointed, whose job is to liase with psychiatrists about the most common mental health disorders of childhood. On page 30, under a heading " Support for children with mental health problems" is to be found "chronic fatigue syndrome" (along with substance abuse).

Not to be overlooked in the game of re-classification is the publication by the Royal College of Psychiatrists *(2nd edition: October 2001)* of their Fact Sheets entitled "Mental Health and Growing Up: Fact Sheets for parents, teachers and young people" Fact sheet 32 covers

"medically unexplained physical symptoms" and includes chronic fatigue syndrome. Fact sheet 33 is called "Chronic Fatigue Syndrome – helping your child to get better" and it talks about "tiredness" and states that symptoms are made worse by "worries" and by "emotional problems". The fact sheets give the internationally discredited Joint Royal Colleges' Report on CFS (14) as a source of further information.

The determination by psychiatrists of the Wessely School to re-classify ME/ICD-CFS as psychiatric is formidable and unceasing: it is therefore most unlikely that there will be a change of direction on the part of the MRC.

Given the meeting which is to take place at the RSM on 14th January 2003 (referred to at the beginning of these comments), it seems clear that, in continued defiance of the biomedical evidence, "policy" will not change.

Of potential significance is the fact that American researchers have demonstrated that in ME/ICD-CFS, a particular pathway in the body which is affected by viruses is also affected by chemicals (12). Is the endless insistence that "CFS" is a psychiatric disorder in any way connected with the fact that the incidence of ME/ICD-CFS is known to be increasing alarmingly? It is certainly the case that some doctors who have been funded by sources with links to the same industry that manufactures the chemicals which may be contributing to the rise in incidence are those who most persistently argue against an organic pathoaetiology for ME / ICD-CFS. If influential doctors can succeed in portraying ME as non-existent and "CFS" as psychiatric in origin, then the chemical / pharmaceutical companies **and the governments who granted them product licences** would not be at risk of being accountable, should there turn out to be a provable link with the synergistic effects of so many chemicals, daily exposure to which is now unavoidable.

paragraph 47: **"An integrated approach to determining causal pathways is needed. It could combine…functional (and) behavioural approaches. There is undoubted benefit to employing a multidisciplinary approach to research on CFS/ME, where experience and expertise from appropriate disciplines can be brought together"**

Why is it necessary to emphasise "behavioural" approaches to research strategies for

ME / ICD-CFS (a neurological disorder which the current Chief Medical Officer himself said on 11th January 2002 on BBC News should be classed as a chronic condition with long term effects on health, alongside other illnesses such as multiple sclerosis and motor neurone disease)? The use of specific terms such as "integrated approach" in which "behavioural" aspects feature clearly conveys to experienced NHS personnel (who are trained to understand the implied meaning of such terms) the preferred direction of approach.

Equally, the use of the term "**multidisciplinary approach**" signifies to the medical establishment that a disorder has a psychiatric component, whilst "**expertise from appropriate disciplines**" unmistakably signifies that input and control by psychiatrists is necessary.

paragraph 48: **"Predisposing factors included gender, personality (and) previous mood disorder…thus reported abnormalities may not reflect a true causal association"**

The implications of this paragraph are unmistakable. With regard to ME / ICD-CFS, they are incorrect and need to be robustly challenged. Nowhere in the "true" ME literature is such a statement supported.

paragraph 49: **"Many reported findings in the area of pathophysiology are not published in the peer-reviewed literature, or are not well described…..the lack of methodological rigour and independent replication mean that many of these claims find little support from the wider medical community, but may have strong currency among some patients and practitioners"**

It appears that the MRC "CFS/ME" Research Advisory Group members are unacquainted with what has been published on ME/ICD-CFS in international journals, (including peer-reviewed and high-impact factor journals), for example The New England Journal of Medicine; JAMA (Journal of the American Medical Association); Annals of Internal Medicine, Reviews of Infectious Diseases; Biological Psychiatry; Clinical Infectious Diseases; Archives of Internal Medicine; CRC Critical Reviews in Neurobiology; Journal of The Royal Society of Medicine; European Neurology, Biologist; Postgraduate Medical Journal, Quarterly Journal of Medicine; Journal of the Royal College of General Practitioners; Journal of Neurology, Neurosurgery and Psychiatry; Journal of Infection; Infectious Diseases in Clinical Practice; Journal of Psychiatric Research; Annual Reviews in Medicine; American Journal of Medical Science; Journal of Investigative Medicine; Journal of Clinical Pathology; Journal of Psychosomatic Research; Journal of Clinical Endocrinology; Current Therapy in Endocrinology and Metabolism; Proceedings of the Royal College of Physicians of Edinburgh; Annals of the New York Academy of Sciences; Acta Neurol Scand: Psychoneuroendocrinology; Clinical Autonomic Research; Applied Neuropsychology; American Journal of Roentgenology; Psychiatric Annals; Journal of Virological Methods; Journal of General Virology; Journal of Medicine; Journal of Medical Virology; Immunopharmacology & Immunotoxicology; Journal of Clinical Virology; Journal of Immunology; International Archives of Allergy and Applied Immunology; Journal of Clinical Microbiology; Clinical Experimental immunology; Journal of Clinical Investigation; Clinical Immunology and Immunopathology; Clinical and Diagnostic Laboratory Immunology; Annals of Allergy; Journal of Allergy and Clinical Immunology; European Journal of Medical Research; Toxicology; Clinical Physiology; Nuclear Medicine Communications; Journal of the Neurological Sciences; International Journal of Neuroscience; Journal of Virological Methods; Archives of Neurology; Journal of Clinical and Experimental Neuropsychology; International Journal of Molecular Medicine; British Journal of Clinical Psychology; Arthritis and Rheumatism; Seminars in Arthritis and Rheumatism; Journal of Rheumatology; European Journal of Medical Research; Advances in Neuroimmunology; Angiology. *(This list is not comprehensive but merely illustrative).*

In addition, there is the Journal of Chronic Fatigue Syndrome which, although denigrated by some UK "CFS" investigators, carries impeccably referenced papers, for example "Review: Immunology of Chronic Fatigue Syndrome" by Professors Roberto Patarca-Montero, Mary-Ann Fletcher and Nancy Klimas, a major review which lists 212 references (*see below and reference 29*).

Further, there are the published abstracts of countless international research and clinical conferences on ME/ICD-CFS.

It is hardly surprising that some of these prestigious journals "**may have strong currency among some patients and practitioners".**

From the 1950s to the 1980s, both the Lancet and the BMJ used to carry articles of repute on ME but now seem to have an editorial policy of publishing only studies on "CFS" as part of a psychiatric "Functional Somatic Syndrome", along with globus hystericus and pre-menstrual tension, (Functional somatic syndromes; one or many? S Wessely, M Sharpe et al *Lancet 1999:354:936-939*) and even of ridiculing patients' suffering. Recently, the BMJ ran a poll (organised by Wessely) asking readers to submit a list of what they considered "non-diseases": ME/ chronic fatigue syndrome was nominated, along with bags under the eyes, freckles and being overweight. Following intense media publicity, the poll was headline news, with banner headlines proclaiming "Obesity and ME are not diseases, say doctors" *(Daily Telegraph, 11th April 2002).*

Following the BMJ poll, unsurprisingly, yet more ME sufferers were struck off their GP's list, being told that it was the practice's policy not to treat "non-diseases".

paragraph 55: "**The lack of validated biological markers for CFS/ME has further hampered diagnosis"**

Whilst there is as yet no single, definitive diagnostic test for ME/ICD-CFS, nevertheless throughout the extensive literature there are established, internationally accepted, reproducible biological markers for it (but not for "CFS" as defined by the Wessely School) which in combination with the clinical picture enable a diagnosis to be made; thus for the MRC "CFS/ME" Research and Advisory Group to attempt to equate the two disparate conditions is unscientific and will inevitably result in failure to provide a suitable research strategy for those with ME/ICD-CFS. Is this the underlying political objective?

paragraph 60: "**The MRC CFS/ME Research Advisory Group has noted that there is support among some sections of the community for the use of the description of ME from Ramsay (Ramsay 1998)….(but the MRC Advisory Group) believes that researchers who wish to pursue this approach will need to operationalise the Ramsay criteria and then demonstrate their validity through peer-reviewed publication"**

The reference supplied at paragraph 222 of the MRC draft document for **"(Ramsay 1998)"** is cited as "Myalgic encephalomyeltitis and post fatigue states – the saga of Royal Free disease. Gower Medical Publishing 1998" (*sic).* Dr Ramsay died in 1990. His monograph is entitled "Myalgic Encephalomyelitis and Postviral Fatigue States. The saga of Royal Free disease". It was published (as a second edition) in **1988**, not 1998.

As noted above, the intention of Simon Wessely (and those whose "policy" he follows or perhaps initiates) has long been to eradicate ME (13), (14): paragraph 60 seems to be yet another attempt to re-write medical history as far as ME is concerned and to air-brush it from both existence and memory. In so doing, he and his political masters are wiping out everything of value about ME and about patients' experiences of it in continuing defiance of the evidence.

It is surely extraordinary how "evidence-based" medicine can exclude evidence which does not accord with a personal belief system or "policy".

The disorder ME does not **need** to be "operationalised". Since 1969, ME has been defined as a discrete disorder with specific signs and symptoms, and its diagnostic triad was established by Dr Melvin Ramsay in 1981 in conjunction with the UK ME Association.

The term "ME" was first introduced in 1956 in a Leading Article in the Lancet written by ED Acheson, who went on to become Sir Donald Acheson, Chief Medical Officer for England and Wales. Acheson wrote a major review of ME in the American Journal of Medicine in 1959 in which he assiduously recorded the many features, signs and symptoms (15). In 1978, the Royal Society of Medicine held a symposium on ME at which the disorder was accepted as a nosological entity. ME has been accepted by the WHO since 1969, yet here we have the MRC "CFS/ME" Research Advisory Group dictating that it needs to be "**operationalised**" and validated "**through peer-reviewed publication**" (which they know would not now be possible in the UK due to the prevalent bias of editors of UK medical journals in favour of the Wessely School beliefs).

Such a suggestion raises the question as to whether the MRC Group of chosen experts is even minimally acquainted with the published literature on ME / ICD-CFS *(see comments on paragraphs 49 above and 82 below).* The very first port of call (indeed, the **priority**) for the MRC "CFS/ME" Research Advisory Group should surely have been to study the literature: had they done so, their ignorance (or their political agenda) might not have been so manifestly exposed in this draft consultation document.

paragraph 61: "**The MRC CFS/ME Research Advisory Group considers that case definition is a key area for research but believes….the use of broad inclusion criteria should allow subsequent re-appraisal of experimental results (the Group considers that) it would not be possible to identify potential subgroups unless inclusion criteria are broad enough to encompass the necessary heterogeneity"**

Why does the MRC Research Advisory Group recommend "broad inclusion criteria" for research strategies into an ICD-classified **neurological** disorder?

Is it the case that the MRC recommends "broad inclusion criteria" for research strategies into ***all*** medical disorders which have as yet no single, definitive diagnostic test (and there are many), or is this special pleading only for "CFS/ME"? Would the MRC identify other poorly-understood medical disorders for which they would recommend that research strategies must be based on "broad inclusion criteria".

By what means does the MRC "CFS/ME" Research Advisory Group propose to identify subgroups from "broad inclusion criteria"?

paragraph 67: "**There is a lack of basic epidemiological evidence to help develop….management options for CFS/ME. This may stem from…the historical failure to recognise CFS/ME as an illness"**

There has been no historical failure to recognise ME as an illness. It has been documented in the medical literature since 1938 (16). There has, however, been denigration by psychiatrists of those with ME starting with McEvedy and Beard in the 1970s, when they claimed (without ever seeing a single patient) that the outbreak of ME in 1955 at The Royal Free Hospital had been "mass hysteria". Subsequently, one of the authors apparently admitted that he had no interest in ME as such, but was merely seeking a topic for a PhD thesis.

Without definition of the newly-coined composite term "CFS/ME" (used in the CMO's report of January 2002), it is not possible to recognise it as an illness and therefore the composite term can have no history.

paragraph 82: **"The MRC CFS/ME Research Advisory Group has not undertaken a detailed review of the current level of scientific knowledge on the aetiology or pathogenesis of CFS/ME, as this was not its function. The Group notes that the recent report of a Working Group convened under the auspices of the Royal Australasian College of Physicians (2002) has assessed the strength of evidence for a number of factors in the pathophysiology of CFS *(sic)*….As a consequence of the lack of consistent evidence, the MRC CFS/ME Research Advisory Group has considered a number of broad thematic areas with regard to research on CFS/ME"**

As noted above, it ought to have been a primary task of the MRC Group to have made a detailed study of **all** the mainstream published literature on ME/ICD-CFS (as well as on "CFS" of the Oxford definition so that comparison and distinction could readily be made). This is a remarkable omission and is surely essential if the MRC Group wishes to produce a credible research strategy.

It seems singularly disingenuous (or perhaps politically expedient) for the MRC Group to claim reliance on the Royal Australasian College of Physicians (RACP) report, given the abundance of substantial flaws which that report has been shown to contain. The ME/CFS Association of Australia Ltd (an affiliation of all State Associations of ME/CFS) is firmly of the opinion that publication of the RACP report will result in "further cases of misdiagnosis, inappropriate and inadequate medical care and the promotion of widespread misconceptions about the illness, with potentially far-reaching and long-lasting adverse effects for the 40 – 140,000 Australians with (ME)CFS". (17)

In a broadcast interview, Simon Molesworth AM, QC (President of the ME/CFS Association of Australia) said he was concerned that the guidelines suggest that "CFS" was "largely of the mind. The overall impression is that it's an illness that's very much exacerbated or somehow caused by perceptions". He registered his dismay that the Australasian report presented the syndrome as primarily psychological; that it characterised patients as malingerers and that it under-emphasised emerging research pointing to biological causes, whilst stressing psychological interventions which could be dangerous for those who are very sick.

Australians have warned that the Royal Australasian College of Physicians (which developed the Guidelines) and the Medical Journal of Australia (which published them) could be held legally liable if patients are made more ill as a result of doctors following the report's recommendations for graded exercise and cognitive behavioural therapy.

The international ME / ICD-CFS community was further outraged to read on Co-cure that in response to extensive legitimate criticism, the Convenor of the RACP report (Dr Rob Loblay) stated "The Guidelines provide an accurate summation of the best available evidence or, where evidence is lacking, a reliable consensus of professional opinion in this field" and that Professor Andrew Lloyd was on record as stating "CFS cannot be classified as a disease because the underlying mechanism that causes the condition is not known or understood". The fallacy of such a pronouncement was quickly pointed out by Dr Derek Enlander, an ME/CFS specialist from New York, who said that on such a premise, cancer, MS and lupus

were not diseases either, because the mechanism for those conditions is not understood. *(Co-cure: 9th May 2002)*

For the MRC "CFS/ME" Research Advisory Group to rely upon the RACP report shows either a surprising lack of professionalism and of scientific rigour, or else a sinister international political agenda.

paragraph 83: **"…the research areas discussed below are not the only ones where there is potential for advancing our understanding of the pathogenesis of CFS/ME, but reflect the areas that currently show the most promise"**

Comments on the areas which the MRC Group considers "show the most promise" are addressed in individual paragraphs below.

paragraph 86: (Infections): **"….in the great majority of cases no infectious cause can be found by routine microbiological investigation. There is reasonably strong evidence that ….enteroviruses are not causally related to CFS/ME"**

Routine investigations are not sufficient for such a complex disorder. In July 2001 the American Medical Association issued a statement explaining that 90% of ME/ICD-CFS patients show normal results on basic investigations: Anthony Komaroff, Associate Professor of Medicine at Harvard, said *"Researchers are already using imaging technology to measure brain hormones and are examining the function of the immune system. There is considerable evidence already that the immune system is in a state of chronic activation in many patients"*. (18)

Whilst it may be true that enteroviruses may not be ***causally*** implicated in ME/ICD-CFS, nevertheless there is a substantial body of evidence which clearly demonstrates enteroviruses are ***involved*** in some patients with ME/ICD-CFS (19) (20) 21) (22) (23). These papers suggest that an on-going enteroviral infection may exist in some patients with (ME) CFS.

John Richardson's recent book (Enteroviral and Toxin Mediated Myalgic Encephalomyelitis / Chronic Fatigue Syndrome: *Haworth Medical Press, New York 2001*) is described by Professor James Mowbray as "a remarkable clinical discourse of disease associated with enteroviruses". However, if investigators are repeatedly directed by "official" policy not to look for enteroviruses (or any other viruses which may be involved with the disorder) and if no funding is made available, they are not going to find them.

In Professor Roberto Patarca-Montero's latest book (Chronic Fatigue Syndrome and the body's immune defence system: *Haworth Medical Press, New York, 2002)* the author stipulates that enteroviruses might be important in some patients with (ME)CFS,

Patarca is one of the foremost researchers in the field of immunology. This book is a synthesis of reports by several hundred medical research experts based on worldwide studies. **It provides information relating to the autoimmune consequences of ME/ICD-CFS in exceptional depth, together with a review of therapeutic interventions that are immune-based (including herbal medicine). It also explores the links between immune, endocrine and nervous system abnormalities and stresses the need for a combined, aggressive research approach by these respective disciplines. The book explains the**

connection between (ME) CFS, fibromyalgia, Gulf War syndrome and multiple chemical sensitivity.

We would urge each of the MRC "CFS/ME" Research Advisory Group of independent experts to familarise themselves with this book before finalising their research strategy proposals.

paragraph 95: (Neurology): **"As the RACP report indicated, there is good evidence that muscle strength, endurance and recovery are normal. It is likely that abnormalities may be detected in the neuromuscular system of patients who are…immobile"**

Both the RACP and the MRC "CFS/ME" Research Advisory Group appear to be sadly unaware of the laboratory evidence which convincingly demonstrates that patients with ME/ICD-CFS reach exhaustion more rapidly than normal controls and that there is a continued loss of post-exertional muscle power (giving an additional loss of power) with delayed recovery for at least 24 hours, whereas sedentary controls recovered full muscle power after 200 minutes (24). Such effects are not due to de-conditioning or to patients being immobile.

paragraph 96: (Neurology): **"Clinical experience would indicate that most patients with CFS/ME have neurological signs that lie within the normal range"**

This is an interesting statement from the MRC Group, because both the 1991 Oxford criteria and the 1994 CDC criteria expressly exclude patients who have any clinical signs;

indeed, the 1994 Fukuda criteria are unequivocal: ***"We dropped all physical signs"***. (25)

Are members of the MRC Group aware of the fact that nystagmus is a common finding in ME? Are they unaware of the papers documenting neurological involvement in ME/ICD-CFS? (26) (27). Professor Komaroff from Harvard states unambiguously that *"The evidence indicates pathology of the central nervous system and the immune system"*.(28). What disorder is the MRC "CFS/ME" Research Advisory Group talking about? It cannot be ME/ICD-CFS, which is formally classified by the WHO as a **neurological disorder**.

paragraph 97: (Neurology): **"magnetic resonance (MR), SPECT and PET are relatively new techniques to have been developed"**

MRI scans have been in common use in the UK for over 20 years, ie. from the early 1980s. Notably, there is no mention of magnetic resonance spectroscopy (MRS), even though this has been shown to be very valuable in identifying significant biochemical deficits in the basal ganglia and brain stem (whereas MRI scans show no abnormality).

paragraph 102 (Muscle Fatigue and Weakness): **"The general opinion is that there is no physiological basis to the weakness and/or fatigue. These are general assertions and at no point has the literature been systematically reviewed…"**

Is the MRC "CFS/ME" Research Advisory Group hoping to rely on input arising from the consultation process to point out what is in the literature? How can they draw up even a draft document about research strategy if they do not know the literature which so clearly demonstrates delayed muscle recovery in ME/ICD-CFS ? (24).

paragraph 105 (Immunology): **"There does not seem to be a consensus on the nature and extent of immunological disturbance in CFS/ME"**

It would be true to say that there is more published evidence of the disrupted immunology of ME/ICD-CFS than on any other aspect of the disorder: Professors Patarca-Montero, Fletcher and Klimas state in the opening sentence of their major review of the immunology of (ME) CFS that patients "*have two basic problems with immune function that have been documented by most research groups: immune activation and poor cellular function (with) frequent immunoglobulin deficiencies. These findings have a waxing and waning temporal pattern"* (29). In the US, the disorder is known as **Chronic Fatigue and Immune Dysfunction Syndrome** for this reason. In 1994, Professor Paul Levine from the Viral Epidemiology Branch, Epidemiology and Biostatistics Programme, National Cancer Institute, Bethesda, Maryland, stated **" the spectrum of illnesses associated with a dysregulated immune system now must include (ME)CFS"** (30)

paragraph 106: (Immunology): **"proinflammatory cytokines act in the brain to induce a syndrome known as "sickness behaviour syndrome" which includes reduced motivation…lethargy and loss of appetite"**

paragraph 108: (Immunology): "**Animal studies, particularly in "sickness behaviour syndrome", have potential implication for CFS/ME. It will be important to develop and study models of "sickness behaviour syndrome", to assess outcomes and influences relevant to CFS/ME"**

paragraph 109: (Immunology): **"Clinical neuroimmunological studies are much more difficult to undertake and measurements of inflammatory mediators (eg. cytokines) are likely to be of limited value…. The Royal Australasian College of Physicians Working Group suggested that heterogeneity of findings might be explained in terms of…inadequate consideration of potential confounding variables"**

(ie. psychiatric morbidity).

On what evidence does the MRC "CFS/ME" Research Advisory Group state that results of clinical neuroimmunological studies "**are *likely* to be of limited value"?** This is hardly a scientific approach worthy of the MRC.

These three paragraphs seem to indicate the intention of the MRC "CFS/ME" Research Advisory Group to recommend instead a research strategy (which the Group regards as "important") to study "sickness behaviour". It seems that such studies will meet with the approval of the MRC Health Services Research board, which will decide that studying "sickness behaviour" is a "priority" after all (*see comments re paragraph 13 above).*

Wessely et al have studied "behaviour" in their own definition of "CFS" since 1987 and despite their immense efforts, they themselves are forced to concede that after a relatively short time, there was no difference between those who underwent a behavioural reconditioning programme and those who did not, as Michael Sharpe confirmed at an international conference held in Boston on 10-11 October 1998.

We submit that the MRC should be looking at provocation of cytokine release, ie. the origin of the illness, rather than looking at effects of final symptoms as expressed in a "sickness behaviour syndrome"

paragraph 112: (Neuroendocrinology): **"The high degree of co-morbidity of CFS/ME and depression would mean that studies in this area are fraught with potential confounds"**

The only studies which find a high degree of depression are those carried out by psychiatrists of the Wessely School, which are looking at heterogeneous "CFS" populations (31) (14) and this might indicate nothing more substantive than bias in patient selection. Studies carried out by non-biased investigators using more strictly defined cohorts do not find such a high degree of depression. Further, rates of depression are well-known to be increased in those who are medically ill (32), so even if rates of depression are higher than in the general population, this is not a psychiatrically-defining characteristic of ME/ICD-CFS.

paragraph 117: (Central Nervous System Function): **"Key symptoms of CFS/ME include fatigue, cognitive dysfunction and sleep disturbance, which are associated with disordered functioning of the CNS"**

Whilst these are key features of "CFS", there are other key features of ME/ICD-CFS which the MRC document fails to mention, such as post-exertional muscle fatiguability, intense malaise, vertigo, photophobia, dysequilibrium, neuromuscular incoordination, myalgia, cardiac involvement, pancreatic involvement, liver dysfunction, shortness of breath, irritable bowel, frequency of micturition, thermodysregulation, rashes, allergies, hair loss, spontaneous bleeds, prostatitis etc. These significant features are not usually considered by those who look only at "CFS", but they have enormous impact on the patient's quality of life and ability to function independently (and hence on cost considerations).

paragraph 126: (Cognitive Performance): **"despite reproducible demonstration of some reduction in performance, the specific nature of such deficits has not been identified"**

The authors of the MRC draft document appear to be unaware of the published work on ME/ICD-CFS of Sheila Bastien, neuropsychologist from Berkeley, California, for example, Patterns of Neuropsychological Abnormalities and Cognitive Impairment in Adults and Children . (33) Is the MRC "CFS/ME" Research Advisory Group aware that in 1993, a paper published in Biological Psychiatry found that in ME / ICD-CFS, cognitive impairment included difficulty with memory sequencing, processing speed, word searching, dyslogia, spatial organisation, calculation and decision-making; in relation to degree of impairment, the researchers found that ***"the performance of the CFIDS patients was sevenfold times worse than either the control or the depressed group. These results indicated that the memory deficit in CFIDS was more severe than assumed by the CDC criteria. A pattern emerged…supporting neurological compromise in CFIDS"*** (34).

paragraph 128: (Cognitive Performance): **"The effects of suggestibility …have only recently begun to be investigated"**

To bring "suggestibility" into potential research strategies for ME / ICD-CFS is offensive but it exposes the underlying agenda of the MRC "CFS/ME" Research strategy.

It is also indicative of the contempt in which some clinicians and investigators hold those suffering from a disorder which the CMO himself has made clear is a serious one ranking with other neurological disorders such as MS and MND.

paragraph 136: (Psychological factors): **"Several studies have suggested that personality factors may differ between those with CFS *(sic)* and other disorders…**

A prospectively designed study could allow the differentiation of the interplay between biological and psychological factors which may influence…maintenance of the disorder"

Given the concern expressed in paragraph 13 about identifying "priorities" for health services research in "CFS/ME" and whether it is "appropriate" to make HSR "a priority at this time", might it not be more cost-efficient to focus on research strategies which would be likely to deliver biological markers? In other disorders (such as lupus), it has been the discovery of biological markers which has enabled greater diagnostic precision.

[At paragraph 170, the document makes clear that the Health Services Research "**is used to guide research into the cost-effectiveness of management strategies"**].

paragraph 137: (Psychological factors): **"Given that the co-morbidity of CFS/ME with depression may be as high as 50%…"**

see comments re paragraph 112 above.

paragraph 138 ff (INTERVENTIONS)

This section is a re-inforcement of the alleged benefits of CBT: the document states that the MRC "CFS/ME" Research Advisory Group has chosen to consider how the "evidence-base" for such interventions can be strengthened. The document states at paragraph 166: **"Further research should concentrate on the effects of these interventions across the spectrum of the disorder"** (ie. on both the least severe and on the most severe cases).

At paragraph 184 (Strengthening Research Capacity), there is a sentence which many patients may find chilling: **"There may be a need for specific measures to promote multidisciplinary collaboration….such collaboration offers established centres of excellence the kind of new scientific opportunities that are essential if they are to sustain their competitiveness internationally".**

Comments:

Currently, within the NHS, the only "centres of excellence" for "CFS" are psychiatric units, whilst clinics for ME patients have now been closed (for example, Preston).

The MRC Research Advisory Group seems unaware of the substantial and growing concern about the dangers of CBT and graded exercise upon the severely affected. (35)

The Medical Adviser to the UK ME Association (Dr Charles Shepherd) wrote in *Medical & Welfare Bulletin (published by the ME Association, Spring 2001)* that he continues to receive more adverse reports about graded exercise than any other form of intervention and that there

is clear confirmation that many people with ME/ICD-CFS are suffering relapses through such programmes. Shepherd reminds people that doctors have now been warned by their insurance companies that any form of exercise treatment needs to be prescribed with just as much care as drug treatments, otherwise doctors could be taken to court.

It is intolerably patronising to insist that CBT and graded exercise therapy should be the way forward in "CFS/ME" on the grounds that such interventions may help patients suffering from other "physical" disorders such as cancer to manage their situation better, whilst at the same time promoting and limiting research into "CFS/ME" to that designed to "strengthen" psychotherapy strategies rather than looking into underlying causes (as is the case in cancer).

The MRC "CFS/ME" Research Advisory Group seems not to agree that "Behavioural and rehabilitative strategies are fine as far as they go, but attention (and funding) must be focused on developing diagnostic tests and medical interventions to address the biological and physiological underpinnings of the illness" (36).

It is noted with particular regret that no-where in the MRC draft document is there any mention of the RiME petition (Research into ME): this petition carried over 16,000 signatures and it asked:

"That a panel of specialists in the fields of Neurology, Immunology, Endocrinology and other disciplines, but with the exception of Psychiatry, be established to commission research into the aetiology (underlying physical causes) of ME. That a research programme be up and running by the end of 2002".

This petition was handed in to the MRC on 2nd September 2002.

The very next day, it emerged that the MRC was minded to grant £2.6 million to psychiatrists of the Wessely School for further research into cognitive behavioural therapy in "CFS/ME".

The MRC Group might soon be judicially required to consider the effects of their preferred approach (ie. the prevailing somatisation orthodoxy) upon ME / ICD-CFS sufferers' physical and mental health because as Barbara Rubin states: "The patient who is prematurely judged to have a psychiatric disorder or to be "malingering" will face medical, social, legal and financial penalties that can destroy them and their families" (37). This is indeed the case and currently there is in existence documentary evidence (which the present authors have seen) of a major action already lodged in the UK Courts against the Department of Health, specifically naming certain people prominent in the field of "CFS".

paragraph 201: (Conclusions and Recommendation): "**A strategy is proposed which reflects the current state of knowledge in CFS/ME"**

It is disputed that the MRC "CFS/ME" Research Advisory Group is aware of the current state of knowledge in ME/ICD-CFS.

Without such knowledge, it is not possible for the MRC "CFS/ME" Research Advisory Group to deliver any credible research strategy.

One is left with the disturbing conclusion that the recommendation underpinning the 1996 Joint Royal Colleges' Report on CFS (14) remains current, namely, that the many

documented abnormalities found in ME/ICD-CFS ***"should not deflect the clinician from the (psychiatric) approach…and should not focus attention towards a search for an 'organic' cause"***.

Summary Report on MRC Questionnaire

Appended to the main body of the document is a Summary Report on MRC CFS/ME Consultation Questionnaire (*November 2002*); it is an analysis of the responses to the MRC questionnaire (which had to be returned by 28th August 2002).

The Report states that only 187 responses were received by the MRC. This may have been because there was almost no publicity about the questionnaire so most people were unaware of it: it seems that the ME Association did not make it known to all its members and that Action for ME submitted a response on behalf of its members. An electronic response was requested by the MRC, which immediately eliminated many people who might have wished to respond.

An Appendix to this Summary Report lists important areas for research submitted by respondents to the questionnaire; these include cell biology; genetics; environmental influences; virology; epidemiology; diagnosis (including triggers and the use of imaging techniques) and case definition. (To this list, many patients would like to add nutritional interventions).

Inevitably, there is no mention of the 16,000 signature RiME petition in this Summary Report.

It is important to note that this appendix is not an appendix to the main document but only to the Summary Report of respondent's views of areas which should be addressed; (these being areas which have already provided evidence of abnormalities and of potential treatment direction).

CONCLUSION

Most importantly, the authors of the MRC draft document have ignored all the justified criticism of the information on which they place so much reliance; this is momentous, because that criticism revealed the misrepresentations, the misinterpretations, the denial of available credible evidence, the deception, the selectivity in use of the available evidence, the methodological flaws and the many omissions which pervade so much of the Wessely School literature. Both the Joint Royal Colleges' Report and the Royal Australasian College of Physicians' Report were very heavily and cogently criticised. Significantly, claims made by these psychiatrists are **not established facts at all**, nor are they supported in the international literature.

Is there a credible explanation?

The MRC "CFS/ME" Research Advisory Group is doubtless aware of an interesting and relevant document which is now in the public domain: it is called **Trends in Health and Disability 2002** and is produced by UNUM Provident, one of the major insurance companies. The Report opens with an Introduction by the Chief Executive Officer of UNUM who sets the scene: ***"Mental health issues have been of particular importance to us recently"***.

Psychiatrist Michael Sharpe (long known to be associated with UNUM and for his recommendation that claimants with ME/CFS should be subjected to covert video surveillance) provides a timely exposition of the politics behind the ME/ICD-CFS situation in his contribution entitled "Functional Symptoms and Syndromes: Recent Developments" (in which he includes "post-viral fatigue syndrome / CFS), as revealed by the following extracts:

"It is becoming increasingly clear that the problem of patients who have illness that is not clearly explained by disease is a large one.

There is a great deal of confusion about what to call such illness. A wide range of general terms has been used including 'hysteria', 'abnormal illness behaviour', 'somatisation' and 'somatoform disorders'. Recently the terms 'medically unexplained symptoms (MUS) and 'functional' symptoms have become popular amongst researchers.

Classification is also confusing as there are parallel medical and psychiatric classifications. The psychiatric classifications provide alternative diagnoses for the same patients.

The majority will meet criteria for depressive or anxiety disorders and most of the remainder for somatisation disorders of which hypochondriasis and somatoform disorder have most clinical utility.

The psychiatric classification has important treatment implications. Because patients may not want a psychiatric diagnosis, this may be missed.

There is strong evidence that symptoms and disability are shaped by psychological factors. Especially important are the patients' beliefs and fears about their symptoms.

<u>Possible causal factors in chronic fatigue syndrome:</u>

PSYCHOLOGICAL: personality, disease attribution, avoidant coping style.

SOCIAL: information patients receive about the symptoms and how to cope with them; this information may stress the chronicity and promote

helplessness. Such unhelpful information is found in 'self-help' books.

Unfortunately doctors may be as bad.

<u>Obstacles to recovery:</u>

The current system of state benefits, insurance payment and litigation remain potentially major obstacles to effective rehabilitation.

Furthermore patient groups who champion the interest of individuals with functional complaints (particularly chronic fatigue syndrome) are increasingly influential; they are extremely effective in lobbying politicians. The ME lobby is the best example.

Functional symptoms are not going to go away. However, the form they take is likely to change. Possible new functional syndromes are likely to include those associated with pollution (chemical, biological and radiological).

As the authority of medicine to define what is a legitimate illness is diminished, increasingly consumer oriented and privatised doctors will collude with the patient's views that they have a disabling and permanent illness.

In other words, it may be difficult for those who wish to champion rehabilitation and return to work to 'hold the line' without seeming to be 'anti-patient'.

It will be imperative that health and social policy address this problem.

This will not be easy. However, there are glimmers of progress. An example is recent developments in the politics of CFS. One of the major charities (Action for ME) is aligning itself with an evidence-based approach. These are early days but if this convergence of rehabilitation oriented clinicians and a patient advocacy group is successful, there could be very positive implications for insurers.

Funding of rehabilitation by commercial bodies has begun in the UK (with organisations such as PRISMA) and is likely to continue.

..an increased availability of rehabilitative treatment facilities is highly desirable. The NHS is not likely to pay for these.

Both health services and insurers now need to take a more positive approach."

Also in Trends in Health and Disability 2002 is a contribution by Mansel Aylward, Medical Director for The Department of Work and Pensions, who sets out some of the Government "planned initiatives" in the areas of Health and Welfare:

"There is a common interest across several Government Departments in measures which would reduce the high costs of sickness absence and improve the quality and availability of …rehabilitation.

The Government shares an interest…in the public, private and voluntary sectors which have a stake in the development of more effective models of rehabilitation.

Growth in benefit recipients due to mental and behavioural disorders has been rapid during the last five years….Another interpretation might be a migration in the diagnostic label from other medical conditions to 'mental health problems' ".

In the light of such clarification (notably about PRISMA, a multi-national healthcare company working with insurance companies to arrange rehabilitation programmes for those with "medically unexplained symptoms", where Simon Wessely is a member of the Supervisory Board, which in order of seniority is higher than the Board of Management) and despite the carefully-drafted reassuring words and lip-service to the value of "lay participation" in the MRC draft document, it seems inevitable that as far as ME / ICD-CFS is concerned, bad science will continue unabated in the UK and it will even be promoted by Government agencies. It also seems inevitable that there will be a corresponding growth in PRISMA company profits.

Bad science, bad "policy" and vested commercial interests deserve to be exposed and criticised but, as ever, it seems to be left to sufferers to do so. Even when they have done so, it seems likely from the MRC "CFS/ME" Research Advisory Group draft document that a substantial number of very sick people with a complex neuro-endocrine-immuno-vascular disorder are not going to be allowed to stand in the way of those vested interests.

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