



## The Status of Research, Treatment and Perception of Myalgic Encephalomyelitis (ME) in UK

### Introduction

The issues surrounding the treatment of people with Myalgic Encephalomyelitis (ME, sometimes referred to as ME/CFS, CFS/ME or even CFS) in the UK are a national scandal that must not be overlooked or ignored for any longer.

So much injustice has been done to people with ME and so much negligence and corrupt influences have existed around those responsible for ME that nothing short of a public inquiry is required to bring accountability for those who have failed patients for many years.

- Myalgic Encephalomyelitis is multi-system disease classified by the World Health Organisation in the chapter on Diseases of the Nervous System at WHO ICD-10 G.93.3, along with post-viral fatigue syndrome, and benign myalgic encephalomyelitis since 1969 [1]. CFS is a term that was created in the 1980s and is listed in the WHO alphabetical index with a reference back to G.93.3. The recently published ICD-11 lists ME under 8E49 Postviral fatigue syndrome as a disorder of the nervous system.
- Despite ME being listed as a neurological disease, and officially being recognised by the UK government and Department of Health as a neurological disease, very few patients get to see a neurologist.
- A survey of members of the Association of British Neurologists published in 2011 asked if they viewed chronic fatigue syndrome (CFS) as a neurological condition - 84% of respondents did not [2], demonstrating the ignorance and bias that exists even in medical circles.
- In 2012 the Countess of Mar stated in the House of Lords "... there is no provision to examine the neurological aspects of this illness. Patients are simply allocated to either the CFS/ME group, where they are offered psychological therapies, or to various ad hoc diagnostic categories containing patients with neurological symptoms of unknown aetiology. In practice, these can be considered dustbins where no further investigations are considered necessary." [3].
- Provision of any kind of services for ME patients, let alone neurological ones, is sparse and inadequate and does not come anywhere near to meeting the requirement of the patients.
- Patients who are "lucky" enough to get a diagnosis of ME or CFS are mostly left to manage their condition on their own. Those patients who get a referral to any of the

remaining CFS Clinical Network Coordinating Centres across England often have to wait months for an appointment – and most of these centres offer nothing of any value - usually only CBT or GET, which have been proven not to be useful for ME patients and can actually make people far worse.

- The NHS is currently wasting a huge amount of funds in giving failed therapies to ME patients. More importantly, patients reject these therapies. At a time where the NHS needs all the funding it can get, it is a senseless waste of resources.
- Severely affected patients have no recourse to expert help and are often left in a desperate limbo with no services attempted and with their condition often worsening.
- In the UK there are estimated to be up to 250 000 patients diagnosed with ME or CFS (though nobody can really be certain, as figures are not kept). An estimated 25% of those affected may go on to develop severe ME which is an extremely debilitating condition, often rendering the sufferer completely housebound, wheelchair & bedbound and dependent upon carers for their everyday needs.
- ME has been estimated to be the greatest cause of long-term sickness absence from school in both pupils and staff.
- In 2015 the USA Institutes of Medicine produced a report that stated that ME “is a serious, chronic, complex, systemic disease that often can profoundly affect the lives of patients”

It is clear that the policies and influences of UK organisations and individuals who have been responsible for ME over the last decades have been flawed and negligent and have failed people with ME and their families.

We fear that these same influences still pervade the decisions and policy-making around ME.

If any public debate is to be carried out, whether it is part of a pre-determined result or not, an opportunity will be presented to discuss removal of the evil that has existed around ME for the last decades and perhaps give hope to patients that they will receive correct attention in the future.

We believe that a new beginning must be made.

In order to do that, and avoid the same manipulation of patients’ lives from continuing, Invest in ME Research calls for a comprehensive review of the way that ME is researched, funded and treated by the establishment.

Below the [Summary](#) of Issues assesses the status of the recommendations laid out in the CMO Report of 2002 – 16 years ago.

The [Recommendations](#) from Invest in ME Research are there to provide a way of going forward that removes all of the obstacles to making real change possible so that no more UK lives are lost due to negligence.

The [References](#) contain a list references relevant to these discussions.

## 1 Summary of Issues

In demonstrating the failure to address the problems of ME in UK we decided simply to look at the recommendations from an office that MPs and the public and the health service would agree ought to be beyond reproach, unbiased and concerned for the welfare of patients.

The Chief Medical Officer of England (whose remit is here [4]).

If the CMO makes a recommendation for public health then people generally take notice.

If the CMO's recommendations are ignored or discarded then it must be a matter for further inquiry.

In 1998 a Working Group set out to consider how the NHS might best provide care for people of all ages who have this complex illness.

In 2002 a report was issued to the Chief Medical Officer of England from that Independent Working Group. [5]

### From CMO Report of 2002 [5]

CFS/ME is a relatively common clinical condition, which can cause profound, often prolonged, illness and disability, and can have a very substantial impact on the individual and the family. It affects all age groups, including children. The Working Group has encountered extensive evidence on the extent of distress and disability that this condition causes to patients, carers, and families. It has examined the evidence on the effectiveness of interventions used in the management of this condition.

The Working Group is concerned about several issues.

- Patients and carers often encounter a lack of understanding from healthcare professionals. This lack seems to be associated with inadequate awareness and understanding of the illness among many health professionals and in the wider public.
- Many patients complain of the difficulty of obtaining a diagnosis in a timely manner.
- There is evidence of underprovision of treatment and care, with patchy and inconsistent service delivery and planning across the country.
- Finally, there is a paucity of good research evidence and very little research investment for a serious clinical problem that in likelihood has a pervasive impact on the individual and the community.
- Insufficient attention has been paid to differential outcomes and treatment responses in children and young adults, the severely affected, cultural, ethnic and social class groupings.

The Working Group has identified measures that should be taken **with some urgency** to address the current situation.

The CMO report made a number of recommendations.

If one examines each of those recommendations from 2002, in turn, it is plainly evident that, were those recommendations enacted and fulfilled today, then it would go a long way to turning around the situation for people with ME and their families.

In 2007 Invest in ME Research issued a status review of these recommendations from the Chief Medical Officer's Report.

None of the recommendations had been implemented at that time.

In 2018 we revisited the CMO report and the recommendations from 2002 and it is clear that still none of the recommendations have been implemented.

### **None!**

What are the views of the establishment organisations responsible for the health of patients concerning these recommendations and their status?

- The current CMO seems to care little about them.
- They have not been used to guide the NHS.
- The Medical Research Council is ignorant of them.
- Successive Departments of Health ministers pay no attention to them.

There is little more that needs to be said.

### **Nothing has changed since 2002 for people with ME and their families.**

The issues relating to perception, treatment and research of ME are the same today as were laid out by the CMO Report of 2002.

From Section 6 of the report **Recommendations of the Working Group** (of 2002) these were the recommendations –

## 6.1 Recognition and definition of the illness

Status June 2018:

### CMO RECOMMENDATION from 2002:

- The NHS and healthcare professionals should recognise CFS/ME as a chronic illness that, despite uncertain aetiology, can affect people of all ages to varying degrees, and in many cases substantially.
- In view of current dissatisfaction among some groups over the nomenclature applied to this illness, we recommend that the terminology should be reviewed, in concert with other international work on this topic.

The NHS generally does not recognise or understand ME.

There is still no clinical speciality for ME. Patients are being shunted to different areas of medicine to be treated or offered quick fix therapies such as CBT and GET – both of which have been shown to be ineffective or harmful to people with ME.

The level of knowledge within the NHS has been entirely influenced by the Biopsychosocial (BPS) [6] dogma from a lobby of psychiatrists who have vested interests relating to their having done consultancy work for insurance companies and DWP. This influence has not been investigated fully and has been allowed to continue and to affect the lives of patients.

The lack of adequate funding for any biomedical research from the MRC or NIHR has led to an imbalance in research that further aggravates the situation for people with ME. [7]

People with ME suffer with a stigma associated with the disease due to ignorance in the NHS and an appalling indifference to this ignorance from the NHS leadership. The treatment is totally inadequate; the research strategy has been totally inadequate.

From the foreword of the CMO 2002 Report above -

'...there are concerns from patients and their representatives, and from a broad range of clinicians, over the way the illness is managed. These concerns on management apply to the NHS, to other government Departments and to the private sector. In particular, patients and health professionals involved in the care of CFS/ME find much disbelief about the nature of the illness and of its impact. Perhaps as a result, in many areas of the country there appears to be a lack of appropriate health care facilities.'

We have stories of severely affected patients entering hospital and being sectioned or being made even worse.

The NHS has been responsible for a constant use of misinformation about ME in their departments and on their websites and for a failure to keep up to date with current research on ME – as was amply demonstrated by the deplorable MUS Commissioning documents. [8]

The situation has not changed today.

In correspondence with the outgoing NHS National Medical Director, Professor Sir Bruce Keogh (correspondence that took three months to receive any reply) [9] Invest in ME Research received this response from Sir Bruce –

"The most recent NICE guidance advises that Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET) are the most effective forms of treatment for ME/CFS."

This ignorant and superficial response is typical of career civil servants who occupy these positions of power. Had he discussed with NICE director Professor Mark Baker he would have been aware that everyone considered NICE guidelines to be unfit for purpose and CBT and GET harmful to ME patients.

Sir Bruce's response illustrated to many a dysfunctional NHS management hierarchy that has no interest in tackling the issue of ME.

The nomenclature is in as much disarray as ever.

The most recent NICE Guidelines from 2007 [10] were a poor attempt to provide direction in this area and did nothing to help this issue – instead setting patients against doctors. There was also a conspicuous absence of comment from the CMO, the MRC and the Department of Health. The head of NICE guidelines development Professor Mark Baker has even admitted that the existing NICE guidelines for ME did not meet NICE's needs and neither did they meet patients' needs – essentially unfit for purpose.

- Myalgic encephalomyelitis (ME) is recognised by the World Health Organisation in classification ICD-10 G93.3 as well as the latest ICD-11.
- The Department of Health uses the term CFS/ME.
- NICE are now using the term ME/CFS
- Most patients use the acronym ME – for myalgic encephalomyelitis
- The MRC seem not to have any view

Nomenclature around ME is a mess.

The lack of clarity and consistency is, frankly, appalling and aids the confusion that has been created by certain parties who are not interested in progress.

It also has repercussions on research into the disease.

**CMO Recommendation Implementation Status: FAILURE**

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## 6.2 Treatment and care

### **CMO RECOMMENDATION from 2002:**

- Patients of all ages with CFS/ME must receive care and treatment commensurate with their health needs and the disability resulting from the illness.
- Healthcare professionals should have sufficient awareness, understanding, and knowledge of the illness to enable them to recognise, assess, manage, and support the patient with CFS/ME. Healthcare workers who feel they need extra skills should seek and receive help from those experienced in this area.
- General Practitioners should usually be able to manage most cases in the community setting, but must be able to refer patients for specialist opinion and advice where appropriate (e.g. because of complexity in diagnosis and treatment).
- CFS/ME of any severity in a child or young person – defined as of school age – is best co-ordinated by an appropriate specialist – usually a paediatrician or sometimes a child psychiatrist – in concert with the GP and a paediatric or CAMHS multidisciplinary team.
- Sufficient tertiary level specialists in CFS/ME should be available to advise and support colleagues in primary and secondary care.
- Management should be undertaken as a partnership with the patient, should be adapted to their needs and circumstances, and should be applied flexibly in the light of their clinical course.
- The support of the patient with CFS/ME and the management of the illness should usually extend to the patient's carers and family.
- Clinicians must give appropriate and clear advice, based on best national guidance, on the nature and impact of the illness to those involved in providing or assessing the patient's employment, education (primary, secondary, tertiary, and adult), social care, housing, benefits, insurance, and pensions.

### **Status June 2018:**

Patients of any age do not receive care and treatment commensurate with their health needs and the disability resulting from the illness.

The best healthcare professionals will do whatever they can for people with ME (as for any other disease), they will believe their illness, they will provide honest advice and remain up to date with current research.

Sadly, these professionals are by far the exception when it comes to ME.

Most healthcare professionals have little knowledge or understanding of ME.

Patients visiting their GP with symptoms of ME face a lottery – where diagnosis may be ignored or mistaken, referral may or may not be provided, but with no certainty of any outcome.

With no speciality for ME in the health service then no priority has been given to understanding the disease.

This inevitably means that healthcare staff who feel they need extra skills have nowhere to go to seek and receive help in this area.

General Practitioners would find it hard to manage moderate to severe cases of ME in the community setting without proper understanding and education about the disease.

With no leadership from the UK CMOs or Royal Colleges then this often fails.

Referrals to specialists, when they do occur, are to a variety of specialisms with little knowledge of the disease being applied to the choice of the specialism used.

The number of stories that the charity continues to receive from people with ME relating to disbelief over the physical nature of their condition indicates that much is still to be done in the healthcare area.

With NHS budgets being squeezed and healthcare staff being cut the future for provision of services for ME sufferers is not itself healthy.

The deplorable recommendations by NICE of CBT and GET, when evidence has been clearly available of how detrimental these treatments are for ME patients, is typical of the approach of governments, DoH, NICE and the apathetic CMO where soundbite healthcare is chosen in place of a real attempt to address the illness.

The national guidance mentioned in this recommendation will likely be those from NICE. The recent guidelines document on CFS/ME from NICE shows this area not to have progressed since the CMO Working Group made this recommendation.

In 2018 a review of NICE guidelines is being carried out, only after patient pressure to do so. Yet there are still two years to go until NICE have finished that review. The existing guidelines with harmful recommendations of CBT and GET is still left in place and correspondence that the charity has had with NICE guidelines director does not fill us with hope [12].

Whilst it is felt that progress is gradually taking place in the perception of ME by clinicians it is still too sporadic and is only being achieved due to the work of organisations such as UK charity Invest in ME Research.

A call from the CMO for all healthcare staff to adopt a standard diagnostic criteria, such as the Canadian Guidelines, might be a valid course of action to effect part of this recommendation – adopting Invest in ME Research’s view that such diagnostic criteria should evolve and improve as new research provides new information.

Healthcare professionals may be learning more about ME but they are still heavily influenced, and therefore biased, by the indoctrination from flawed NICE guidelines and lack of funding for good research.

Patients deserve honest advice and unbiased research leading to discovery of the aetiology of the disease and development of treatments.



Yet recognition, assessment, management and support of people with ME does not regularly, or even often, occur.

Where do healthcare workers who feel they lack the skills go to for more experience? Nothing has been done to support them.

The problem exists whereby patients may receive a diagnosis, and may even see a referral to some speciality decided by a GP. However, often patients are then left with no care as there are no treatments available and patients are then removed from the healthcare system.

The specialist options do not exist.

Stories abound of GPs not believing in the disease and therefore not treating patients correctly.

Children are very vulnerable to intervention from social services due to ignorance about the disease and by incorrect advice being directed from some paediatricians who also follow the BPS dogma.

This may impact families who are accused of Munchausen syndrome by proxy just because they are concerned for their child. Children are accused of modern-day superficial and ridiculous constructs such as Pervasive Refusal Syndrome.

This is an insidious situation that nobody has yet addressed.

If no support is in place at primary and secondary care then tertiary care is also absent. Testimony from patients shows that often patients are not believed. If they refuse to take CBT and GET then they are penalised by insurance companies, irrespective of whether that is legal or not. This has a knock-on effect in that patients become wary of engaging with a GP again – thus leaving the door open to the condition getting worse or other conditions being missed.

There is no evidence to suggest that management of the illness has been extended to cater for carers and family members and nothing to suggest this has even been considered. Carers are also left in a vacuum absent of attention.

Doctors refer to NICE guidelines for ME as they are afraid of being victimised if they try something different (13). Yet the guidelines programme director has himself stated that NICE guidelines for ME (the “best national guidance”) are unfit for purpose and will be “torn up”.

The welfare benefits system not only stigmatises people with ME but also penalises them if they make an effort to present themselves in front of the draconian PIP and ESA assessments.

Insurance companies refuse to pay any disability premiums if the patient declines to undergo CBT and GET or is unable to.

### **CMO Recommendation Implementation Status: FAILURE**

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## 6.3 Health service planning

### CMO RECOMMENDATION from 2002:

- Service networks should be established to support patients in the primary care and community setting, to access when necessary the skills, experience, and resources of secondary and tertiary centres, incorporating the principles of stepped care. Services should be configured so that individual professionals and aspects of the service can meet individual needs, particularly in the transition from childhood to adult life.
- Health service commissioning through primary care organisations, supported by health authorities or wider consortia, must ensure that local provision for these patients is explicitly planned and properly resourced, and that health professionals are aware of the structure and locale of provision. Health commissioners should be requested to take immediate steps to identify the current level of service provision for CFS/ME patients within their locality.
- Each Strategic Health Authority should make provision for secondary and tertiary care for people with CFS/ME, based on an estimated annual prevalence rate of approximately 4,000 cases per million population in the absence of more refined data.
- People who are so severely affected that their disability renders them housebound or bed-bound have particular constraints in regard to their access to care. These specific needs must be met through appropriate domiciliary services.
- The NHS should make use of the wide range of support and resources available through partnership arrangements with voluntary agencies, enabling suitable self-management by the patient.

### Status June 2018:

13 ME Clinics/Centres were established by the government in the UK. Opinion on these varies - a couple were given credit by their patients (example in Norfolk or St. Helier and Epsom in Surrey) - due mainly to the lead clinician believing in the organic nature of the illness.

However, the job adverts for some of these centres a while back showed the clear bias towards psychiatric therapies for ME which exists in the NHS.

These clinics have also lacked appropriate services, nullifying any of this CMO recommendation – one even stating in 2012 “As more is now known about chronic fatigue conditions...employing an immunologist directly is no longer necessary”.<sup>[14]</sup>

The level of service regarding the other recommendations is entirely inconsistent in the UK and does not appear to have been coordinated or funded properly.

Clinics have closed or are being led by occupational therapists only and ME patients are increasingly being referred to the newly established/trialled IAPT (increasing access to psychological therapies) services which seem to be just another form of the failed biopsychosocial paradigm offering CBT and GET.

Health service commissioning has not been performed.

A few sporadic attempts by some charities/organisations and patients to engage with NHS and CCGs does not amount to a policy that has been created and enforced.

Invest in ME Research spent four years sitting in meetings with NHS to address failures in healthcare provision for ME - wasted years that achieved nothing with no real intent by the NHS to change.

The approach has been shambolic at best and non-existent at worst.

None of this has been set up.

Strategic health authorities and primary care trusts were abolished on 31 March 2013 but the replacement for these has made no provision for additional services.

Severely affected patients receive no specialist or domiciliary services.

None of this has been set up.

The NHS does next to nothing in respect of enabling self-management by the patient – other than to allow them to be removed from the healthcare system due to neglect.

This is entirely due to DoH, NHS and NICE leadership ignoring the issues around ME – assisted by bias in MRC and NIHR funding policies.

**CMO Recommendation Implementation Status: FAILURE**

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## 6.4 Education and awareness

### CMO RECOMMENDATION from 2002:

- The education and training of doctors, nurses, and other healthcare professionals should include CFS/ME, as an example of the wider impact of chronic illness on the patient, on carers and family, and on many aspects of society.
- Healthcare professionals, especially in primary care and medical specialities, should receive postgraduate education and training so that they can contribute appropriately and effectively to the management of patients with CFS/ME of all ages.
- GPs and medical specialists should consider CFS/ME as a differential diagnosis in appropriate patients, and should at least be able to offer initial basic guidance after diagnosing this condition (Annexes 6 and 7).
- Awareness and understanding of the illness needs to be increased among the general public, and through schools, the media, employers, agencies, and government departments.

### Status June 2018:

The education and training of doctors, nurses, and other healthcare professionals does not include ME.

Medical school education regarding ME is often missing completely or limited to a page in a textbook that is completely out of date and even listed in the mental health category, despite the World Health Organisation and the UK government recognising the disease as a neurological illness under ICD-10 G93.3.

IiMER wrote to the GMC in 2010 believing them to be responsible for medical curriculum for students and asking why they do not act on this dangerous inconsistency [15] but little attention seems to be paid to this subject.

No up to date postgraduate education or training exists for ME. Invest in ME Research provide an annual cpd-accredited conference for professionals to hear of the latest research from around the world yet even the CMO declines every single invitation to attend that is sent to her and doctors remain under-educated about the disease.

We hear many stories of patients who are met with disbelief and even dismissal of their symptoms, and who consider ME to be non-existent. Much of this ignorance stems from NICE and DoH policies and the deleterious influences of BPS dogma. No courses exist for ME for doctors that has not been based on the BPS theories of ME.

Invest in ME Research has purposely funded the inclusion of medical students in the biomedical research being funded by the charity [16]. The response from medical

students has been encouraging but the charity has no support or comment from establishment organisations.

Awareness and understanding of the illness among the public, and through schools, the media, employers, agencies, and government departments is very difficult when the media only listen to press releases from the biased Science Media Centre (SMC) and when organisations such as the CFS/ME Research collaborative (cmrc) have for five years included both SMC and proponents of the BPS theories about ME in their group.

Awareness of the real story behind ME has been left to charities such as Invest in ME Research whilst others avoid rocking the boat.

GPs and medical specialists are dependent on NICE guidelines. IiMER has personal experience of the lack of willingness by healthcare professionals to do much more than note taking when examining children with ME.

The awareness of ME amongst the public and media has not increased due to any policies initiated by the CMO – there have been none.

Awareness has only been increased due to the work of the many unsung heroes in the ME community who perform their work without any reward or without any self-promotion.

We feel we cannot rate the education of healthcare staff or other sections of the community as having been performed well or even attempted to be performed.

The fact that a young woman can be sectioned in the twenty-first century in the UK, because she suffers from ME, means that education of healthcare professionals has not produced the desired result. [17]

As if to underline all of the above Invest in ME Research met with the CMO in 2017 to discuss these issues.

The CMO office showed little interest in medical education about ME, or prevalence of ME, or the consequences of ME and has done nothing to help people with ME. A disgrace! [18].

Ignorance and intransigence toward this disease stems right from the top.

### **CMO Recommendation Implementation Status: FAILURE**

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## 6.5 Research

### **CMO RECOMMENDATION from 2002:**

A programme of research on all aspects of CFS/ME is required. Government investment in research on CFS/ME should encompass health-services research, epidemiology, behavioural and social science, clinical research and trials, and basic science.

In particular, research is urgently needed to:

- Elucidate the aetiology and pathogenesis of CFS/ME;
- Clarify its epidemiology and natural history;
- Characterise its spectrum and/or subgroups (including age-related subgroups);
- Assess a wide range of potential therapeutic interventions including symptom control measures;
- Define appropriate outcome measures for clinical and research purposes; and
- Investigate the effectiveness and cost-effectiveness of different models of care.
- The research programme should include a mix of commissioned or directed research alongside sufficient resource allocation for investigator-generated studies on the condition.

### **Status June 2018:**

Government investment in research on CFS/ME has been next to non-existent other than to fund behavioural theories that either harm patients or are ineffective.

No research has been funded by MRC to look at aetiology and pathogenesis of ME. In the absence of this UK charity Invest in ME Research and its supporters have been funding research with the focus on this [19] – with patients and their families and charity supporters raising in excess of £800,000 for biomedical research to facilitate the development of a Centre of Excellence for ME [20].

The lack of any official epidemiological study is a failure. This should have been an obvious choice for funding but even the CMO has no idea of the prevalence of ME in the population and seemingly is apathetic to overtures made by Invest in ME Research to determine this.

Nothing has been done to look at subgroups at all – no strategy exists.

The lack of any strategy for finding treatments for ME has opened the door for quack therapies and businesses to be marketed – and even funded [21].

All of this allows vulnerable and sick patients to be exploited.

NICE completely failed patients in its 2007 guidelines review in producing a document that sold out patients in favour of the influence of the biopsychosocial lobby in recommending CBT and GET. [22]

No outcome measures have been defined for clinical and research purposes. This is still largely been left to individual researchers.

No models of care have been developed or implemented.

There has been no meaningful or sustained research programme.

The resources allocated also have failed to be either sufficient or well placed. Funding has been directed to completely the wrong areas.

The basic science and pathology behind this illness has been hijacked by lobbies of psychiatrists and others who have vested interests in retaining the status quo.

The various governments (via the Department of Health and ministers) and the Medical Research Council must bear the responsibility for this currently ineffective, unprofessional, unscientific, unjust and haphazard state of affairs.

Considering the disease burden on society, it should be stated that very little research (by comparison with other diseases) has looked at ME – and severely affected patients obviously suffer even further from this.

The tiny amount of funding that has been granted by funding bodies did not even go entirely to research into ME. [23]

There is already bias in using establishment organisations and individuals to maintain a status quo that deleteriously affects patients.

The irony is that the supporters of the biopsychosocial theories walked out of the 2002 CMO working group. Yet in the last 16 years their protagonists have received the lion's share of all funding for research and controlled and influenced all of the debate regarding ME - a staggering indictment of establishment organisations and the individuals tasked with ME.

Only the advent of social media has allowed patients to have a voice.

**CMO Recommendation Implementation Status: FAILURE**

## **2 Recommendations**

The CMO Report of 2002 made a number of recommendations to address the inequities regarding the treatment people with ME. Sixteen years later and nothing has changed.

What more needs to be said?

In 1988 a parliamentary motion was brought by Mr. Jimmy Hood, MP for Clydesdale [24].

The request from this bill from 30 years ago -

“The Bill is a simple measure which merely requires the Secretary of State to make an annual report to Parliament describing the progress that has been made in investigating the causes, effects, incidence and treatment of ME.”

An annual report into progress! Logical, simple, coordinated. Something that any health department or chief medical officer might well see as common sense for a disease that affects so many and costs so much.

The above CMO Report recommendations and the parliamentary motion from 1988 could have been brought before parliament today - and would be welcomed by people with ME, such is the lack of any progress made.

**None of the recommendations from the CMO Working Group report have been fulfilled** - a testament to the failure of governments, UK Chief Medical Officers, NHS and Department of Health – and the Medical Research Council and those from the MRC charged with changing things for the better.

In all of the ways that ME has been handled over the past decades one inexorable fact remains - people with ME have continued to suffer and have continued to be let down.

Little more needs to be stated in order for parliament to take action.

Since the CMO report on ME from 2002 people in positions of influence have had adequate opportunity to support biomedical research into ME.

Nothing has fundamentally changed regarding the policies towards research into ME, or the influences that seem to hold sway in the corridors of the establishment, and the scale of the failure of those chosen to deal with ME is apparent.

Instead, we witness dead-end MRC “expert” panels and collaboratives formed – coming and going every few years, ending in total failure and achieving nothing, before another dead end initiative is set up.

Excellent establishment time-wasters - and the lives of patients roll by.

Those who influence research policies for ME, and their supporters, seemingly oblivious to the waste of life, of opportunity, of any sense of really making a difference to families affected by this crippling disease.

This pattern of stalling tactics in UK is there to be seen and should fool no one.



It is not good enough and must end as it shames this nation.

It would be shortsighted merely to call for increased funding for biomedical research into ME, as this decision could also be manipulated to serve special interests or individual careers.

Accountability now needs to be accorded to avoid future policies being followed that cause harm to patients and denigrate their situation.

While funding needs to be made available for serious biomedical research it will not be possible to have faith in any approach unless accountability for the past failings has been enacted and a morally correct strategy of research is created for the future.

It is clear from merely examining the CMO Report of 2002 that many have abrogated their responsibilities toward people with ME.

No serious attempt has been made to address the real issues with regard to research into ME, development of treatments for ME, or the perception of ME.

Organisations and individuals who have so destructively interfered and influenced the lives of people with ME are either still in positions of influence, or actively working to support their own interests.

Yet it is not enough to call for more funding for biomedical research if it masks a false intent from some who have had enormous possibilities to change things for people with ME, but have done nothing.

In order to make real and fundamental change that cannot be manipulated then the following need to be performed.

### **1 A Public Inquiry into ME**

“The Gibson Report” Inquiry into the status of status of CFS / M.E. and research into causes and treatment November 2006 ; Group on Scientific Research into Myalgic into Myalgic Myalgic Encephalomyelitis Encephalomyelitis (M.E.) stated [25]

“There have been numerous cases where advisors to the DWP have also had consultancy roles in medical insurance companies. Particularly the Company UNUM Provident.

Given the vested interest private medical insurance companies have in ensuring CFS/ME remain classified as a psychosocial illness there is blatant conflict of interest here.

The Group find this to be an area for serious concern and recommends a full investigation of this possibility by the appropriate standards body. It may even be that assessment by a medical ‘expert’ in a field of high controversy requires a different methodology of benefit assessment.”

12 years later ME patients still have problems obtaining benefits unless they undergo Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET).

The guidelines director of NICE was seemingly (and incomprehensively) oblivious to this, as his recent correspondence with Invest in ME Research has shown [12].

The referenced letter by a former civil servant illustrates very well how MPs themselves could face the same problems as they have the same pension provider [26] [and here](#).

The largest ever trial into these therapies (CBT and GET), the so called PACE Trial [31], proved that these therapies do not work for even loosely defined fatigue patients yet NICE still has these therapies listed in its guidelines for CFS/ME unlike the US health agencies that have removed them from their recommendations [27].

The USA Centers for Disease Control (CDC) has updated their website about ME to use the 2015 Institute of Medicine report and has removed Graded Exercise Therapy (GET) and Cognitive Behavioural Therapy (CBT) from its recommendations [37].

The flagship trial for the BPS model in the UK (The PACE Trial) has been proven to be flawed [35], possibly fraudulent [34] and a complete waste of taxpayers' money

Reanalysis of PACE Trial results by Matthees et al (once some of the data was forced to be released from the authors following a FOI and legal challenge) states - "This re-analysis demonstrates that the previously reported recovery rates were inflated by an average of four-fold." [36]

The PACE Trial is now used as an example of how not to perform research – and it is widely seen as flawed and is ridiculed. Several articles by David Tuller academic coordinator of the concurrent masters degree program in public health and journalism at the University of California, Berkeley, have exposed these flaws and demonstrated that the PACE Trial cannot be considered valid [32]

After years of promotion by NICE and establishment-backed research groups and vested interests of deleterious treatments for people suffering from a chronic neurological disease, people with ME are now having to relive this negligent approach to their health as the same influences force ME into new biopsychosocial mistreatment.

Buzzword-groupings such as FND, MUS, IAPT, BDD and all of the other modern-day creations that retain the influence of this ugly side of the UK establishment are now being focused toward ME.

We cannot allow another decade of mistreatment of people with ME by the same forces.

**There needs to be a full and independent public inquiry into the handling of policies toward research and treatment of ME since the CMO report of 2002.**

We believe that a new beginning must be made.

In order to do that, and to avoid the same manipulation of patients' lives from continuing, we call for a comprehensive review of the way that ME has been researched, funded and treated by establishment organisations. These include the Department of Health, Chief Medical Officer, Medical Research Council, National Institute of Health,

Royal Colleges and other departments which seem to have influence over the lives of people with ME, such as the Department of Work and Pensions.

This public inquiry would examine the behaviour and policies of these institutes and officials and departments and ministers and other agencies and organisations dealing with ME since the CMO report of 2002.

It would provide accountability for past policies that have harmed people with ME.

It is difficult to trust any future policies of some of these agencies and offices if the same issues that have caused harm to people with ME are not addressed fully.

It would be folly to allow the same individuals who have manipulated this disease to have any involvement in future policy-making regarding research into and treatment of ME.

A public inquiry is justified.

## **2 Implement the CMO Report Recommendations**

The recommendations from the CMO Report of 2002 should be implemented.

This perhaps forces the CMOs of UK to be active in promoting awareness and research and treatment of this disease.

This would facilitate the implementation of solutions for most of the problem areas with ME.

The CMO must also be charged with establishing the correct prevalence of ME in UK in order that the correct burden on society of these patients can be established. This may then focus minds on funding research to find the cause and developing treatments, if only for the financial savings gained.

Nothing seems to work as well as saving money for governments and health departments (and insurance companies) – even though peoples' lives ought to carry equal weight, at least

## **3 Removal of Existing NICE Guidelines for ME**

Invest in ME Research have had extensive email discussions with Professor Mark Baker of NICE [12].

These discussions clearly demonstrate that Professor Baker accepts that CBT and GET, as recommendations from the existing NICE guidelines, have done harm to people with ME.

We therefore feel that the existing NICE guidelines for ME must be withdrawn in order that more harm is not done to people with ME.

To do otherwise would be negligent.

Negligence that has caused harm to people with ME must be met by accountability from those who ignore this harm and litigation may well be the consequence.

As a stop-gap measure NICE can remove CBT and GET as recommendations for ME immediately and issue an addendum to the existing guidelines warning all doctors that CBT and GET must not be recommended for ME.

NICE must also inform all healthcare providers around the world, who may be using the NICE guidelines for their own healthcare systems, that this addendum has been made.

**The NHS is currently wasting a huge amount of funds in peddling these failed therapies, CBT and GET, to ME patients which are either useless or deleterious to the health of ME patients. More importantly these therapies are rejected by patients and, at a time where the NHS needs all the funding it can get, there is no sense in wasting resources or funds like this.**

We need to do things differently.

### 4 Annual Report to Parliament

An annual update to parliament from the Secretary of State for Health to provide a simple measure that merely requires the Secretary of State to make an annual report to Parliament describing the progress that has been made in investigating the causes, effects, incidence and treatment of ME.

This proposal was good thirty years ago – it is good today.

### 5 Transparency of Meetings Concerning ME

Full transparency of any meetings between NIHR, MRC, DoH, NHS, CMO, Chief Scientific Officer and any charities or organisations purporting to represent people with ME or purporting to be interested in research into ME must be shown.

It concerns us that secret meetings have been going on between many of those departments and individuals with no minutes published and patients unaware of those involved.

It is difficult for anyone to have faith in these officials and departments when closed meetings are carried out with agendas that seek to promote one organisation or one institute, or a combination of self-interests.

### 6 Remove Those Responsible for Current Situation

All of those individuals who have been connected with MRC decisions on research into ME over the last decade, if still in positions of influence with regard to ME research, must be removed from having any influence on future decisions regarding ME.

The people whom the MRC has made responsible have failed.

Whether this has been on purpose or not remains to be seen.

In any case, they should play no further role in influencing any policies relating to ME.

We call on those who have conflicts of interest within the MRC, NIHR, DoH and who have any influence on ME research to declare those interests.

We call for the Principal Investigators of the PACE Trial to be barred from receiving any further public funding for future research into ME

### 7 Research

Invest in ME Research has been arguing consistently since 2005 for a funded strategy of biomedical research into ME.

Yet we hope that any debate is not a pretext to fund predetermined institutes favoured by the CMRC – an organisation that deserves no special treatment or favours and that has achieved nothing.

The MRC and NIHR policies must be open and transparent and not another period which favours an unrepresentative group that does not serve patients.

The fact that NIHR already is holding meetings with and favouring one group [23] does not augur well for honest and transparent policy-making.

Invest in ME Research advised the NIH to set aside \$50million for five years in our response to the P2P [29] and IOM [30] reports.

To realise real progress and develop effective treatments for ME then Invest in ME Research propose ring-fencing funding of at least **£20 million** a year for five years for biomedical research into ME.

This £100 million would likely end all of the years of suffering of people with ME and give hope for the future.

This is a relatively small amount.

Recently the government doubled its contribution to brain cancer research, on the spur of the moment, following the death of one MP by pledging an extra £20 million on top of its existing commitment.

It can surely do this to help over 200,000 citizens suffering from ME and the millions of carers and family members affected by the consequences of the disease.

This, along with our recommendations above, should level the playing field in favour of patients.

Naturally, we hope that our Centre of Excellence proposal will be adopted [20] and be part of this award.

However, we maintain that any funding must be awarded in fair and open competition.

We have also repeatedly called for the refereeing system for reviewing research applications for ME by the MRC to be overhauled and made transparent.

## **Read This**

Finally, we would ask MPs, or anyone in public office, to read this.

This is a recent letter sent to Invest in ME Research that clearly illustrates the failure of UK governments and health departments and the MRC in dealing with ME. It comes from a patient who was in the same union as most of MPs are in. This patient's experience could be any MP's experience if they find themselves with ME.

### **From a Patient: To Invest in ME Research**

I have been closely following your continuing correspondence in relation to the call for revision of the NICE guidelines.

In particular the removal of CBT/GET.

I have had M.E. for almost four years and am quite severely affected.

I am housebound most of the time and often bedbound.

I was previously a 'high flyer' (my neurologists' words) and a civil servant with a social work background.

Due to my illness I am no longer able to work, and have just been through the very painful process of applying for ill health retirement.

My pension provider (through the *(name provided)* pension scheme) has a two tier system for pension awards in the circumstance of ill health retirement.

I have undergone five medical assessments during the process and have been assessed as permanently incapacitated in terms of employment.

However, as I have not completed the treatment, as recommended in the NICE guidelines, I cannot obtain the higher rate pension.

The treatment namely being CBT and GET.

I have engaged with the specialist M.E. service in (location provided) but was unable to continue as attending sessions made me more unwell.

I tried CBT through my local mental health service, attending three out of six sessions, this made me more unwell and put me back into bed for weeks.

I am in receipt of the highest rate of both ESA and PIPS.

These were both awarded following the first medical assessment, which I understand is not the position for far too many M.E. sufferers.

I have taken my ill health retirement case to appeal within my pension service.

The position of the original decision not to award me the higher rate pension has been upheld on the grounds that I have not completed CBT and GET.

My pension provider will now escalate my appeal to stage two of the process.

However, the decision makes it clear that, in order to succeed, I need to prove that I have completed CBT and GET.

I am faced with a position that is unfair and takes away any right I have not to undergo treatment that exacerbates my illness.

I have had support from my union (name provided), however they aren't familiar with the fight that M.E. suffers like myself face.

I have previously had a life where i travelled up and down the country for my career, helping to make a difference in the lives of vulnerable children.

I had authority and was very much a professional.  
I have always worked within the public sector, both local and central government.  
I had a lively social life, always on the go with my partner and family.

Now my life revolves around my bedroom. I rely on pillows, blackout curtains and strong medication to try and control my pain. If I journey out, it is to visit my G.P. which takes around three hours to get me ready for, with lots and lots of assistance from my wife, who is also my carer and carer to our 18 year old disabled son.

I often find it difficult to construct challenges around my illness as I simply can't find the words due to my diminished cognitive functioning.

This is one of the hardest symptoms to deal with. The loss of intellect.

It's in there somewhere, I'm in there somewhere, but I just can't get the words to make sense.

It is imperative that someone listens to our voices and I am so thankful for your determination in challenging the medical profession around our treatment options.

It will probably be too late to make any difference to my case.

I hope that in the future no one will be penalised for not undergoing treatment that is harmful to their health as a result of your campaigning; that CBT and GET will be removed from the guidelines with immediate effect, rather than waiting for years while the guidelines are revised.

Please please continue the fight for those of us struggling to do it for ourselves

## **5 REFERENCES:**

### **About IIMER**

Invest in ME Research is a UK charity which seeks to educate about Myalgic Encephalomyelitis (ME or ME/CFS). Founded by ME patients and parents of children with ME/CFS the charity aims to campaign for research and funding to establish an understanding of the aetiology, pathogenesis and epidemiology of ME. Invest in ME Research are founder members, and current chair of the European ME Alliance, a group of 15 European national patient organisations campaigning for ME/CFS awareness and research in Europe.

The charity has so far organised thirteen annual international CPD-accredited ME conferences in London that have attracted delegates from 20 different countries. The charity has also organised eight international research colloquiums bringing researchers from around the world to London to build collaboration and sharing of knowledge.

The charity has campaigned consistently for a change in MRC strategy toward ME research to fund biomedical research into ME.

### **Centre of Excellence for ME**

What is required is a model which has been described by Invest in ME Research since 2010 which involves concentrating research into a hub with translational biomedical research and appropriate examinations of patients, correct diagnosis, biomedical research and development of efficacious treatments [20]



## Reference Links

- | <b>Ref</b> | <b>Reference Link</b>  |
|------------|--|
| 1          | <a href="#">WHO ICD Classifications</a>  |
| 2          | <a href="#">"Is chronic fatigue syndrome a neurological condition? A survey of UK neurologists"</a>  |
| 3          | <a href="#">Lords Hansard 20 Nov 2012</a>  |
| 4          | <a href="#">CMO remit</a>  |
| 5          | <a href="#">CMO Report 2002</a>  |
| 6          | <a href="#">Invest in ME Research - Flaws in BPS Theory for ME</a>   |
| 7          | <a href="#">Funding for BPS research</a>   |
| 8          | <a href="#">MUS Commissioning Document</a>   |
| 9          | <a href="#">Correspondence between IiMER and Bruce Keogh NHS</a>   |
| 10         | <a href="#">NICE Guidelines for ME</a>   |
| 12         | <a href="#">Correspondence between IiMER and Professor Mark Baker of NICE</a>  |
| 13         | <a href="#">The General Medical Council - Dr Nigel Speight</a>   |
| 14         | <a href="#">Leeds clinic</a>   |
| 15         | <a href="#">GMC education</a>  |
| 16         | <a href="#">Medical students in Research into ME</a>   |
| 17         | <a href="#">Sophia Mirza</a>   |
| 18         | <a href="#">Invest in ME Research Meeting with Chief Medical Officer</a>   |
| 19         | <a href="#">Projects Funded by Invest in ME Research</a>   |
| 20         | <a href="#">A Centre of Excellence for ME</a>  |
| 21         | <a href="#">The SMILE Trial</a>  |
| 22         | <a href="#">NICE - A Poverty of Reason</a>   |
| 23         | <a href="#">Chronic Fatigue Syndrome: Written question - 146298</a>  |
| 24         | <a href="#">Parliamentary 1988 a parliamentary motion</a>  |
| 25         | <a href="#">The Gibson Inquiry</a>   |
| 26         | <a href="#">Letter to IiMER Regarding NICE Guidelines</a>  |
| 27         | <a href="#">USA Agency for Healthcare Research and Quality (AHRQ)</a>  |
| 29         | <a href="#">Invest in ME Research Response to NIH Pathways to Prevention (P2P)Workshop Report</a>  |
| 30         | <a href="#">Invest in ME Research Response to IOM "Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness" Report</a>  |
| 31         | <a href="#">The PACE Trial Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): a randomised trial. Lancet 377: 823–836. doi: 10.1016/s0140-6736(11)60096-2</a> |
| 32         | <a href="#">David Tuller articles on PACE Trial</a>  |
| 34         | <a href="#">Kelvin Hopkins Questions in Parliament on the PACE Trial</a>   |
| 35         | <a href="#">A preliminary analysis of 'recovery' from chronic fatigue syndrome in the PACE trial using individual participant data</a>   |
| 36         | <a href="#">Reanalysis of PACE Trial results by Matthees et al</a>   |
| 37         | <a href="#">The CDC Updates their website about ME/CFS</a>   |

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