Invest in ME Research

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on NICE Draft Guidelines 2020

December 2020

UK Charity Invest in ME Research
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1 Introduction

The NICE Draft Guidelines for ME document was published on 10th November 2020 [1].

They are destined to replace the NICE Guidelines for ME CG53 that were published in 2007 [2].

Invest in ME Research is a stakeholder in NICE Guidelines for ME and has reviewed the draft guidelines after they were published.
The charity has returned comments to NICE using the required pro-forma [3].

This document describes the view of the charity regarding these guidelines.

The 2020 NICE Draft Guideline is primarily being treated as a stand-alone document.

However, sometimes we feel it necessary to look at this document’s heritage and recognise that many injustices towards ME patients have been maintained over the years, some of which we attribute to the existing 2007 NICE guidelines (CG53).

NICE took over twenty months to formulate the 2020 Draft Guidelines.
Invest in ME Research, along with those who had no advance sight of the draft guidelines, were limited to a month and a half to respond with comments.

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3 Summary of Analysis of NICE Draft Guidelines

When a national organisation that is responsible for clinical excellence and care announces that a new set of guidelines for a disease is to be created, following thirteen years having passed since the last version of such guidelines was published, then it might be considered to present a great opportunity. An opportunity to evaluate new research, to bring in new treatments and practices, and to introduce new recommendations and guidance.
After all, new research into the disease would inevitably have taken place during those thirteen years that would demand modification and more effective treatments may well have become available.

It is, therefore, a damning indictment of the state of affairs regarding myalgic encephalomyelitis (ME or ME/CFS) in the UK that the new NICE draft guidelines document for this disease that was published on 10th November 2020 can do no such thing.
Instead, the draft guidelines of 2020 are even sparser than those of the 2007 version.

The 2020 document stands as a testament to thirteen years of nothing much changing, evidence of the apathy, ignorance and mendacity from government and establishment healthcare and research organisations in treating this disease, evidence of failure.

That the NICE draft guidelines of 2020 are a shallow and sparse document reflects not just on the negligent approach to research into the disease that was maintained but also on the extent to which the 2007 NICE guidelines had failed patients and doctors.

There is little cause for rejoicing that one flawed recommendation from the 2007 guidelines is finally to be removed in 2021 when the full updated guidelines will be published.
Rather patients and carers should be aggrieved and angry that nothing has changed in thirteen years for those who have this disease.

People with ME expect that their illness will be taken seriously by the medical profession as the neurological disease that the WHO recognises and that research is properly funded to provide early diagnosis, effective treatment and hopefully a cure.
Thirteen years with little progress.

We commented on the NICE Draft Guidelines by examining the document and using the NICE form.

These comments may be seen here [3]

This is a summary of the major points from the guidelines –

- There is still inconsistencies around terminology and ME/CFS is now used in place of CFS/ME
- Graded Exercise Therapy (GET) is likely to be removed as an option for management
- Cognitive Behavioural Therapy (CBT) is still retained
- Specialist Teams were frequently mentioned

- Retraining was mentioned but not in any context of changing mentality of healthcare staff and correcting the damage of previous NICE guidelines
- NICE admitted that the evidence base for all treatments was poor.
- A series of recommendations (guidance) was made but they are less than clear and without any real teeth to implement.
- A disclaimer in the evidence reviews admits that these guidelines are not mandatory and are open to interpretation.
- The document format is clumsy and laborious to read.

4 Background

During the period that the charity has been formed there has been one set of NICE guidelines created (in 2007) and a review performed, leading up to this current draft version being created.

The previously created (i.e. current) NICE guidelines from 2007 (CG53) were reviewed by the charity in 2006 when they were published in draft form (our review of the 2006 Draft guidelines was made here [4]).

The review of the full CG53 NICE guidelines was made after their publication in 2007 [5].

The charity characterised the 2007 guidelines as a profound disappointment with NICE having chosen to continue to highlight Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET) as the most effective forms of management (aka treatment) for ME. Also -

- GET, already known to be potentially harmful to people with ME, was put forward as a therapy/treatment, along with CBT.
- The NICE group formulating those guidelines compared the use of CBT for ME with the use of CBT for cancer and diabetes and other illnesses – a falsehood as CBT was not offered as a first line treatment for those illnesses as NICE were recommending for ME.
- The 2007 NICE guideline put forward a psychosocial model for ME and promoted CBT and GET as the options for management despite ME patients and groups stating they were ineffective or harmful.
- The previous NICE guidelines were inconsistent in a number of areas - especially terminology – a major failing for an organisation such as NICE.
- The inclusion of as wide a possible base of chronic fatigue states in the draft guidelines was clearly evidenced and did a disservice to ME patients
- Biomedical research that distinctly showed the biological nature of ME seemed to be ignored
- The lack of proper discussion of the modern guidelines showed not only a bias in favour of outdated and flawed information but invalidated much of the data used to justify the proposals
- The objectives of the Nice Draft Guidelines were not met
- ME patients seemed to be on the receiving end of another counter-productive and biased analysis

The 2007 NICE document was lacking in impartial analysis of all areas of research into ME.

NICE failed to conform to the AGREE Instrument which requires that NICE is obliged to give equal weight to three main sources of data: “evidence-based” medicine, usually deemed to be random controlled trials (RCTs); the opinion and experience of physicians with expertise in the area, and the opinion and experience of the patient group for whom the Guideline is intended.

Invest in ME rejected the original NICE guidelines as unfit.
Many of our comments submitted to NICE in 2007 were left unanswered or unsatisfactorily answered, or ignored.
A judicial review was brought against NICE regarding these guidelines in 2009 – a judicial review brought by patients! [6]

NICE Guidelines Director Professor Peter Littlejohns made the following comment after ME patients had taken NICE to a judicial review of the guidelines -

> “*The 2007 guideline was welcomed by patient groups as an important opportunity to change the previous situation for the better, helping ensure that everyone with CFS/ME has access to care appropriate for the individual. Today's decision means that the NICE guideline is the gold standard for best practice in managing CFS/ME.*"

Those false comments have not aged well but they did illustrate the contempt and disdain in which NICE held ME patients at that time.

In 2010 there was a consultation review – and the charity submitted a response [7].

In 2013, the NICE board agreed that a new programme for reviewing clinical guidelines should be developed and created a list of candidates to put on a static list to ensure sustainability and efficiency.
Subsequently, NICE’s Senior Management Team (SMT) agreed the first list of candidate topics for stakeholder consultation and this included CFS/ME.
NICE then asked for comments on this process – which the charity supplied [8].

In 2017, a review of the guidelines was rejected by NICE. NICE produced a derisory response to requests from patients and this charity to perform a full review of the guidelines in 2017. Our comments on that decision were made here [9].

Invest in ME Research’s extensive correspondence with NICE Guidelines Director Professor Mark Baker unravelled many of the NICE arguments for retaining CBT and GET and further illustrated how necessary it was to develop a new set of guidelines [10].
We requested that Professor Baker and NICE remove recommendations for CBT and GET immediately when we wrote in 2018.
Failing that, we asked for an addendum to be added immediately to inform doctors to ignore recommendations for CBT and GET.
NICE refused then.

NICE finally agreed in 2018 to review the guidelines.
In 2018, the set-up of a working group for the current draft guidelines work was announced.
We witnessed NICE’s creation of this review committee that was determined to create a "balance" of viewpoints – something the charity considered entirely unnecessary and

shambolic [11]. The creation of that group lacked transparency and decisions were made away from the eye of the public and patients.

After the Draft guidelines were published on 10th November 2020 [12] the charity issued a press release in response to the NICE press release [13].

Invests in ME Research then contacted the current NICE Guidelines Director Dr Paul Chrisp to request again for an addendum to be added whilst these draft guidelines were being analysed and pending the introduction of new guidelines in April 2021 [14].
Though Dr Chrisp declined that [15] we subsequently discovered that NICE had relented – to some degree – and taken on board Invest in ME Research's request by adding an advisory for doctors to be aware of the new guidelines and the likely removal of GET as a recommended treatment [16].

All of the campaigning regarding NICE guidelines can be seen using this reference page [17].

The 2020 draft guidelines will take months before NICE produce the full guidelines in April 2021.

With these comments in mind it was interesting to determine how far NICE had come in fourteen years, if at all, in their guidance for myalgic encephalomyelitis.

5 Analysis

Invest in ME Research supplied comments on the guidelines using the official NICE comment form [3].

However, it is easier to group these comments here in a form that gives a better appraisal of the work performed for the guidelines.

Introductory Section Missing

While examining the draft guidelines it became obvious that if this document was to be of any value then it needed to have an introductory section that explains to GPs and healthcare staff what the disease is.
Some of this information is found at the end of the document in the “Context” section but this should be placed at the start in order to maximise healthcare education.

Busy GPs and healthcare staff are unlikely to read any Appendices to these draft guidelines so important information must be present in this introduction.
For example in the Appendix on Severely affected patients it states –

> Many participants perceive that the medical profession view ME/CFS as a predominantly psychological illness. Many suggest that there is too little focus on existing or new biomedical research on causes and pathogenesis of the illness.

The experiences of children also highlight issues with understanding the disease by healthcare staff and would be well to include briefly here.

This suspicion of the medical profession and the ignorance shown by some has resulted, in part, as consequences from the flawed NICE2007 Guidelines – despite NICE having been warned by patients that those guidelines were unfit.

This valid information needs to be imparted early on in these new guidelines and this section would allow that.

This section should contain the following –

- the definition of myalgic encephalomyelitis
- an explanation of the little research that has been funded over the last thirteen years which is why recommendations in these guidelines were quite vague and why the evidence base was so poor despite so much time having elapsed since the last guidelines for ME were published
- a statement that CBT and GET do not work and are not recommended for ME
- recognition and admittance that the previous NICE guidelines failed patients
- general information on ME/CFS such as number of people affected (and how this number has been derived)
- mention of the most common triggers for the disease etc.
- As the IOM report [18] is mentioned and as these guidelines are based on the IOM report then they should use the same description

> " ME/CFS is a serious, chronic, complex, and systemic disease that frequently and dramatically limits the activities of affected patients."

- It should also describe the terms being used and the reason for the update – and possibly admit to the flaws in the 2007 guidelines that were rejected by (most) charities and much later declared by a NICE director of guidelines to be unfit for purpose
- mention of the WHO ICD-10 classification G93.3 and as well as ICD-11 classification code of 8E49.
  WHO ICD-10 and ICD-11 both use post viral fatigue syndrome as the lead term and include myalgic encephalomyelitis in ICD-10 with chronic fatigue syndrome in the alphabetical index/indexed to G93.3.
  ICD-11 includes both myalgic encephalomyelitis and chronic fatigue syndrome under the lead term post viral fatigue syndrome.

It is important to have this section before any recommendations.

Separate Sections for Children and Severely Affected

It would be prudent to produce separate sections within the guidelines to cover children and the severely affected (maybe even splitting this category into severe and very severe sections).
At the moment these groups, and the particular differences in approach to the patient, get lost in the overall text and there may be valuable benefits to separating the detail for these groups. Busy GPs will not read the appendices so the specific information concerning children and severe, very severe ME patients should be clearly visible and not imbedded in the overall text.

This will aid healthcare staff in understanding and treating the disease better.

Terminology and Coding

The terminology may be crucial in dealing with ME/CFS, especially as GPs, paediatricians, other healthcare personnel and the media often use different terms.
The 2007 guidelines (CG53) used the term CFS/ME – so NICE need to explain why the old guidelines (the “***Gold Standard***” as described by NICE director Professor Littlejohn) used CFS/ME but are now being updated by these 2020 draft guidelines to use ME/CFS, for consistency according to NICE.
These guidelines need to describe ME, CFS and a better reason for the use of ME/CFS to avoid a free for all interpretation happening again.

We would prefer to use the term ME for the illness but recognise that ME/CFS is used in many places – and in the Canadian guidelines [19].
The true term for ME (or ME/CFS) is myalgic encephalomyelitis and IiMER has used the correct WHO IDC 10 G93.3 classification (now replaced by ICD-11 classification code of 8E49) of this neurological illness within this document in our comments in order to standardise.

We commented on terminology used by NICE fourteen years ago when we commented on the draft guidelines and the finalised guidelines CG53.
Yet NICE again use the term “encephalopathy”.
As we stated 13 years ago, the title is misleading and incorrect.

It is not in NICE's remit to discuss or amend the name myalgic encephalomyelitis.
Names of diseases are not always accurate and there is no value in cherry-picking symptoms in order to discuss or debate at this point in time – especially when NICE’s own review has found all evidence to be weak.
Chronic Fatigue Syndrome is not necessarily accurate either.

Research will eventually decide the name once credible evidence is found to satisfy everything.
Until then NICE should not dabble in name changing.

Even if SNOMED (code 52702003) does accept encephalopathy as a less used alternative then it would make far more sense, and be more responsible of NICE, to use the term that WHO uses as the preferred term in order to reduce the amount of confusion and possibly mistakes.

NICE advises no delay in making a provisional diagnosis of ME/CFS as soon as it is suspected, based on the criteria in recommendation
So it would be of value to specify in the guidelines how suspected ME/CFS would be coded in healthcare records? Advice to GPs here would be useful.

The correct coding and terminology is important for data collection on the incidence and prevalence and healthcare planning and NICE could have aided in this aspect by standardising on the WHO terminology.
It would help GPs, commissioners and other healthcare professionals to see the category of disease they are dealing with.

NICE unnecessarily introduce yet another term in **Post-exertional symptom exacerbation (PESE).** Is this really necessary when the term PEM is well established in the literature and used in research criteria?
PEM is currently the most commonly used term.
It may not exactly describe what patients experience but NICE consensus guidelines cannot just decide to use yet another term.
There should be some basis in the literature for changes like this to be used in NICE guidelines. Otherwise, we will end up using various terms as and when people choose to do so.

Prevalence

The continued use of the ubiquitous figure of 250,000 people in the UK who have ME is again made yet nobody really knows because no precise figure has been obtained.
We feel that this should be one of the research questions posed by NICE.
The national UK Biobank can be seen as a trusted resource if used and developed.

Invest in ME Research invited the UK Biobank Senior Epidemiologist Professor Naomi Allen to speak at our International Biomedical Research Colloquium in London in 2018 and they presented on what they had found in ME patients who were registered in the biobank.
If SNOMED is being used everywhere then we should find a correct number for those who have ME in UK.
We should be able to find which comorbidities people with ME have.
We should be able to determine familial clusters of patients with ME in UK.
All of this data could be there – why is it not used? Why is NICE not requesting it?
Why is NICE not asking this question in its recommendations?
We should get away from these long established guesswork and bring analysis of ME into this century.

Management Plan / Care Plan

There is frequent comment in the draft guidelines document of a “management plan” when really there ought to be used the term care plan instead.
There is also talk of the diagnosis and care (management) plan being taken care of by separate healthcare professionals. Yet it was not clear who is in charge/takes responsibility for the overall care. This is a serious omission.

GET/CBT

Invest in ME Research and many of our supporters have consistently campaigned for both CBT and GET to be removed from the NICE guidelines since they first were introduced in 2007.

Despite the likely removal of GET from the full guidelines, when they are eventually published, NICE continues to recommend CBT. One can only feel suspicious that it still leaves the door open for biopsychosocial protagonists to reinvent themselves and continue to apply flawed ideology to this disease.
It is quite obvious, after all of these years, that there is no credible evidence base for use of CBT with ME. NICE even admit this in their evidence document.

This is a relic from the past flawed guidelines and demonstrates that NICE is still partly wedded to vested interests who are peddling this therapy for reasons other than for the well-being of patients.
This alone will stain these guidelines for the future.

The NICE document describes the controversy over GET as resulting in confusion.
This is completely disingenuous of NICE.
The only confusion was purposely brought on by the flawed 2007 guidelines that perpetuated the myths and careers around this deleterious therapy. NICE were told that GET should not be recommended for people with ME when the 2007 guidelines recommended it.
NICE did not listen and to this day retain those flawed recommendations.
There has been no confusion from patients.

The section **Psychological support: cognitive behavioural therapy,** has chosen to highlight CBT only instead of a range of psychological therapies, simply because the current specialist services offer it.
That is not a good reason to justify this or to continue to promote this therapy especially as NICE already admit that the evidence base is poor. All of the history behind CBT and the funding awards for research using CBT and the practices of vested interests pushing this have been predicated on assuming ME patients have abnormal illness beliefs.
The guidelines do not offer any assurance that the CBT described here is any different from the current practice. It still refers to meaningful goals, priorities, sleep, activity and rest.

This whole section gives too much credence to a talking therapy that has been found to have a low or very low evidence base for ME/CFS.
This applies to the whole section on CBT that should not have been present.

There is certainly no evidence of efficacy of CBT for children with ME/CFS.
If children feel supported and listened to all the way through the investigations/diagnosis/follow-up then there is less likelihood of any problems occurring that need psychological intervention.

The NICE document states that healthcare professionals delivering CBT to a person with severe or very severe ME/CFS should adjust the process and pace of CBT to meet the person’s needs. It is incomprehensible as to why this is thought appropriate, as though CBT is somehow essential. Severely or very severely ill patients surely do not have excess capacity to engage in any therapy needing cognition. All their energies are taken by basic needs

If patients need counselling then NHS can provide that through appropriate paths available to all patients for all conditions.
Any psychological problems should be addressed by professionals trained to deal with such problems and not by healthcare professionals who have had a weekend course in CBT.
This again seems to show the bias (or is it policy) of NICE in retaining CBT despite the lack of evidence of efficacy.

The 2007 NICE Guidelines stated that patients were in control of what treatment they would use but this did not stop both of these harmful therapies (GET and CBT) being forced onto patients by organisations, insurance companies and some parts of the NHS.

CBT should not be offered in this guideline.
The Royal College of Psychiatrists say: -

> “When does CBT help?
> CBT has been shown to help with many different types of problems. These include: anxiety, depression, panic, phobias (including agoraphobia and social phobia), stress, bulimia, obsessive-compulsive disorder, post-traumatic stress disorder, bipolar disorder and psychosis. CBT may also help if you have difficulties with anger, a low opinion of yourself or physical health problems, like pain or fatigue.” [20]

Based on the above description this topic is already covered in the section “Managing coexisting conditions” with links to relevant NICE guidelines.

> "For recommendations on identifying and treating associated or comorbid anxiety, depression or mood disorders see the:
> - NICE guideline on depression in adults
> - NICE guideline on depression in adults with a chronic physical health problem
> - NICE guideline on depression in children and young people
> - NICE guideline on generalised anxiety disorder and panic disorder in adults
> - NICE guideline on common mental health problems."

Children

We do not believe that these draft guidelines emphasise enough that the most important aspect is that healthcare and social care professionals truly need to listen to the child and believe in them and learn from them to be able to support them.

It also needs to be more clearly stated who is in charge of the child's overall care if there are various professionals involved.
Why does NICE state that the paediatrician who diagnoses the child need to refer further to a paediatric ME/CFS specialist team?
As NICE probably ought to know there are paediatric "ME/CFS specialist teams" that have considered ME as a problem arising from childhood trauma.
How does NICE ensure that there are specialist paediatric teams available whose approach is in line with the new guidelines?

NICE talk about providing information for children and young people with ME. It would be best to learn from the child and provide the information they ask for.
Find out what is important to the child.
This is one of the most important aspects of this guideline.

If the right kind of information is given to all involved (patient, school, employers etc.) at the point of diagnosis then there is no need for all of the extra and unnecessary talk of tailored goal setting and other top down guidance that dominates this document.

Patients are just ill and have not lost their intelligence.

Specialist Teams

Even though there is much talk about specialist services and multidisciplinary teams throughout the document the reality is that there are very few specialists or multidisciplinary teams in the UK – yet there is no acknowledgement that this is the case.

It is therefore quite obvious to us that there would need to be substantially more resources provided for providing the care outlined in this document – something that we feel NICE underestimate. Additional resources are required to overcome discriminatory practices that have been built up from erroneous guidelines in the past.

Early diagnosis is going to demand more resources especially as the current ME/CFS services tend only to operate part-time.
Proper diagnostic criteria are also required to be standardised.

There is no description of a specialist paediatric team – despite this being used as a referral point. This is very precarious as we know from experience how badly wrong this can go where a paediatric team is headed by somebody who does not believe in ME.
This is where many lives begin to unravel.

What are the definitions of specialist teams - who decides this? The track record in the last thirteen years has not been one of success in this respect.

The make-up of the desired specialist team should be described to give commissioners some direction as, at the moment, there is no national standard.
What is the minimum staffing requirement for such teams?
Some direction and information on where these trained and experienced professionals can be found would be essential.
Is there a register of such professionals?
Do they have training in ME in reality?
Perhaps a separate section on specialist teams needs to be written in the guidelines.

No mention of the cost of retraining staff and, in the current economic climate, seemingly no chance of them being created.

Training

In the section **Training for health and social care professionals** it was suggested that training should provide relevant and evidence based content.
Yet anyone can create training that purports to fit these NICE guidelines but they will not necessarily be held to account if it is wrong and nothing here relates to setting standards and consistency for training.
Another example where these guidelines are open for interpretation, and therefore of minimal value.

It seems a common thread from this document that it does not and will not connect to GP education or to DWP practices.
If that becomes the case then what value is it for patients?

The need is for nationwide specialists with an agreed training program that is kept updated from up-to-date biomedical research (if and when it arrives).

There is a great deal of re-education that is needed to be arranged and performed in order to change the current thinking of healthcare professionals and social workers.
Most of the current specialist services need to be educated themselves first before they can be trusted to educate others.

For fourteen years, Invest in ME Research has provided education to counter the official misinformation and develop new possibilities through international collaboration.
Our cpd-accredited international ME conferences have provided education from around the world - how much has been used by "specialist services" that you assume exist?

Recommendations

The recommendations in these guidelines are quite general as to be valueless.
NICE do not expand on these recommendations either.
They could potentially be all things to all people.

NICE talk of rest periods as part of all management strategies for ME/CFS and how to introduce rest periods into a daily routine.
Yet in the NICE guidelines of 2007 NICE advised against sleep in the day.
In CG53 from 2007 it was stated –

> “1.4.2.3 Sleep management strategies should not include encouraging daytime sleeping and naps. People with CFS/ME should be advised that excessive sleep does not generally improve physical or mental functioning, and excessive periods of daytime sleep or frequent napping may further disrupt the sleep–wake cycle.”

Now the 2020 draft guidelines state –

> “• how to introduce rest periods into their daily routine, including how often and for how long, as appropriate for each person”

How strange that NICE took 13 years to agree with us that patient should do what they need to when they need to – despite there being no new research evidence.
Why has NICE changed this advice?
Only properly conducted sleep investigations can determine what is appropriate for each person.

The guidelines also leave much open to interpretation

How does primary care (NICE) diagnosis link to consultant/specialist care?
There has to be the same diagnostic criteria used by all second level consultants.
This should have been decided here as there needs to be some consistency in diagnosis.

Re-education of healthcare professionals should begin with the introduction section of the document.

Many of the specialist services that were set up following on from the 2007 guidelines were within mental health services headed by a spectrum of professionals with no one speciality adopting ME/CFS.

There should be a recommendation for a minimum set of appropriate blood tests as well as most common “red flags”/other conditions to keep in mind for exclusion especially as it is known that there is a high rate of misdiagnosis?

In the CG53 guidelines of 2007 NICE did include recommendations under chapter 1.2.2 History, examinations and investigations.
What has changed since 2007?

NICE state in the evidence review [21] –

> "The committee took the view that an exhaustive list of all possible conditions which might be considered was not possible, nor was it appropriate to provide advice on these conditions in this guideline, where there is relevant NICE guidance it is referenced in the recommendations."

There is no need for an exhaustive list but some of the most common examples of exclusions to keep in mind would be helpful as misdiagnosis is very common and GP appointments do not allow much time to be spent on each patient.
NICE should recommend standard tools to be used for the assessment.

All of the research recommendations seem too general and without any proper explanation or thought behind which makes it pointless to make any comment on them.

If the research recommendations were meant to be based on the content of the NICE guidelines then collecting information on patients using standardised and validated tools would be a good starting point.

Document

The style of this document is, we feel, challenging – certainly for people with ME (one of the - intended recipients of these guidelines).
We do not believe this document will be easy to use in its current form and therefore will be less useful for clinicians and perhaps even ignored.

It also feels as though somebody has put together a balance of opposing views and come up with something that satisfies most but without alienating anyone.

General Comments

In **Symptoms for suspecting ME/CFS** NICE use modified criteria from the IOM 2015 report. Perhaps NICE ought to mention that.

When NICE states that it should be recognised that people with ME/CFS may have experienced prejudice and disbelief and feel stigmatised by people who do not understand their illness then they should also admit that the previous 2007 NICE guideline and its recommendations contributed to this. The travel of research and clinical considerations that followed the 2020 guidelines contributed to the prejudice, stigma and build-up of distrust between patients and healthcare professionals.
Perhaps this should be mentioned in the introduction.

Advice for patients should begin by reducing their activities and listening to their body (common sense approach).
It is not fear that stops ME patients from doing anything. They know if they are well enough to leave the house or not.

In the Evidence review G regarding Flares and Relapse NICE state [22] –

> "The committee noted this was a common part of ME/CFS and had explained in the Information and support section of the guideline that ME/CFS involves periods of remission and relapse."

The talk of flares and relapses in the document might be better referred to as worsening symptoms. Otherwise, it makes it sound as if people are usually fairly well. Some patients are in a constant bad state of health. Remission implies that patients are well at times. Many ME/CFS patients never experience remission but adapt to living at a certain level and others have a steady decline no matter what they do.
Flares and relapse imply that there has been a period of improved health.
For many ME/CFS patients the reality involves maintaining their level of health and avoiding making things worse.

When NICE talk of providing up-to-date information about ME/CFS when ME is suspected it begs the question of what kind of sources would be considered reliable and up-to-date?
Who decides the credibility of sources of information?

The following statement would best be placed in an introduction at the beginning -

> "Be aware there is no current treatment or cure (non-pharmacological or pharmacological) for ME/CFS."

The section on Energy Management tries to please everyone and is open to anyone's interpretation. It resembles a dressed-downgraded exercise programme.
NICE makes it look as though patients cannot judge their limits themselves.
They can if they are informed of the disease in an honest manner and told that one cannot exercise one's way out of ME/CFS.
Advice on reducing activities and finding a level that is manageable should be considered as part of standard medical care.

If patients feel supported and are allowed/encouraged to find their own limits/ judge their own function and monitored at regular follow-ups by their GP or a relevant specialist then that is what is required.

As there is no evidence for any treatment, management or therapy in ME/CFS then standard medical care principles should be followed.
The patient must be in charge with knowledgeable healthcare professionals giving input if necessary/available/needed.
If the patient's condition worsens for years then the most important thing is to monitor the patient.
Advice in these situations should not be more complicated than necessary.
Simply, increase activity when possible, decrease when necessary.

There is too much talk of plans and goals etc.
It makes it all sound as if patients had lost the skill to live and need to be managed.
There seems little point in repeatedly mentioning an activity plan as though it is an objective regardless of the disease.
The objective is to get well not to achieve a textbook goal.

Activity need not be planned – it should surely be done only if/when the patient can.
By the nature of the disease that means it cannot be planned.
The continued emphasis on physical activity seems to be a remnant of the previous guidelines, despite GET now being removed.

We wonder if it is sensible to try to establish energy management plans for severe or very severe ME patients.
One would think that provision of practical help and aids in managing the demands of daily living is required.

NICE state -

> “The committee agreed that if energy management strategies are inappropriately applied in people with severe or very severe ME/CFS this will increase the potential for harm. To reflect this, they recommended specialist advice and additional care in this group.”

How confident is NICE that there are enough specialists that can safely provide this advice?

The section on physical maintenance could be considered as part of standard medical care for anyone with a long-term chronic condition and is welcomed.

The committee justifies this physical activity chapter with their statement –

> “Because of the harms reported in the qualitative evidence, as well as the committee’s experience of the effects when people exceed the limits of their energy envelope, the committee recommended that people with ME/CFS should not undertake a physical activity or exercise programme unless it is delivered or overseen by a physiotherapist or occupational therapist who has training and expertise in ME/CFS. The committee reinforced there is no therapy based on physical activity or exercise that is effective as a treatment or cure for ME/CFS.”

What is the purpose of this physical activity then if it is not a treatment or cure?
An evidence based guideline should stick to evidence and this chapter is very confusing as it tries to cover all bases and leaves it open to anyone’s interpretation.

It tries to shoehorn exercise into the guideline whilst saying there is no evidence to support it and leaves the door open for out-dated and discredited models to continue.

The chapters of energy management and physical maintenance should suffice.

As and when patients feel their energy envelope limits increase they start to do more intuitively. It does not need to be made up into another “management” plan.

We make the observation that this guideline seemingly tries to replace the 2007 guideline by addressing the same therapies in a more “patient friendly” way instead of starting from a blank page and just going by the evidence.

If there is no evidence of any treatment then we feel it would be best to follow standard medical care principles until more evidence is established.

In 2017 IiMER representatives met the deputy CMO of England and what was said then still applies we feel [23]:

> “In Practical terms: we need physician led services (very few of which currently exist) which provide help and continued surveillance.
> ME is an identifiable problem due to the characteristic of post exertional malaise (PEM).
> Surveillance is needed as other diseases such as lymphoma can be hidden in that cohort.”

In section 1.11.16 NICE instructed not to offer –

> “any therapy based on physical activity or exercise as a treatment or cure for ME/CFS generalised physical activity or exercise programmes – this includes programmes developed for healthy people or people with other illnesses”

Yet in section 1.11.18 NICE states

> “A physical activity programme, if offered, should ….”

This is conflicting and dangerous statements. As we have stated in this analysis it is open to interpretation.

In any case, most of the physiotherapists and OTs that have specialised in ME/CFS in the past 13 years need to be retrained.

In the section **Dietary management and strategies** does NICE presume that there are enough dieticians who specialise in ME/CFS to fulfil their recommendation?
What is NICE’s solution if not?

Are there enough paediatric dietitians who specialise in ME/CFS to cover the demand as suggested by NICE?

A regular review of the patient, just as with any other chronic illness, should be part of ME/CFS patient’s care.
Many other illnesses can hide in this patient group and misdiagnosis is common.

NICE state that common themes across the qualitative evidence showed a lack of belief about ME/CFS as a real condition by health and social care professionals, and a lack of understanding about what it is and the impact it has.

Yet NICE does not admit to their part in causing this. Thirteen years of denial and abrogation of responsibility are supposedly to be ignored.
Surely, it was partly due to poor NICE guidance in the past.
Perhaps that should be recognised.

In any case this needs to be stated in an introduction at the beginning of the guidelines
This does not just apply to ME - it would be the same for all diseases where a patient has had a bad experience.
The real issue is that these bad experiences are based on the fact that healthcare professionals have been fed misinformation and false beliefs about the disease - which has then, in turn, affected their perception and treatment of ME patients.

NICE state in **How the recommendations might affect practice** that the recommendations will improve consistency of best practice and do not need any additional resources to deliver.

We doubt this very much. Of course, it will require more resources as existing social services staff need to be re-educated and there is little knowledge of ME at present.

> *'The committee was aware that difficulties accessing care are intensified in people with severe or very severe ME/CFS, particularly when they need hospital care. The evidence showed that, as a result of this, some people with severe or very severe ME/CFS have little contact with and support from health and social care services'*

There needs to be some practical solution offered here.
We need to establish places around UK that have experience and knowledge about severe or very severe ME/CFS and can provide advice as necessary.

We do not feel that NICE appreciate that children are leaving education due to lack of support. The fact is that children can be excluded from school due to ignorance and lack of interest in helping. Children are excluded because of the illness with schools making little effort to assist in adjusting to the child's needs – both short and long term.

Again, NICE state that their recommendations regarding school support will improve consistency of best practice and do not need any additional resources to deliver.
This is doubtful. It will require adjustment from schoolteachers and possibly classes – possibly re-training.

> *"Allocating a single point of contact to the person with ME/CFS is not routine practice across the NHS. This could be implemented differently in different regions according to local service structures and may not necessarily need the addition of new staff. It could improve the efficiency of care for people with ME/CFS by reducing the burden of repeated appointments."*

This almost inevitably will lead to addition of new staff in the current climate where resources are already limited - if the intent is really to improve the care of people with ME. It will require re-training.

NICE stated that there was limited evidence for any intervention to manage ME/CFS and this was supported by the committee's experience yet you go on to assess some interventions in detail. This does not make sense. In practice, you can only recommend standard medical care.

> *"To avoid potential harms through energy management being wrongly applied to people with ME/CFS without adequate support and expertise, the committee recommended that in specific circumstances people with ME/CFS should be referred to a specialist ME/CFS physiotherapy or occupational therapy service"*

Yet these specific circumstances are not defined.

It is worth noting that there is no clinical trial evidence to justify recommendation of energy management. There is only patient experience and patients do this because it is common sense and guided by their instinct rather than some proven intervention.

> *"The committee reinforced there is no therapy based on physical activity or exercise that is effective as a treatment or cure for ME/CFS."*

Interesting that nothing has changed since 2007 in terms of research and now NICE admit what patients have been saying since 2007.
What a waste of 13 years where the lives of people with ME have been compromised by poor NICE guidelines.

An apology from NICE might be in order.

The CONTEXT section, we feel, needs to be expanded upon and should be relocated to the beginning of this document in order to set the scene before reading whatever final guidelines are produced.
This comment needs to be highlighted in that introductory section -

> *"The committee reinforced there is no therapy based on physical activity or exercise that is effective as a treatment or cure for ME/CFS."*

NICE mentions major studies coming online yet gives no detail of what these are.
This is important to specify in order to determine what triggers a review of guidelines.

GDG Composition

We had doubts about the forming if the Guidelines Development Group – and we commented on this at the time -

Addendum 30 October 2018
After our statement was put out regarding the NICE Guidelines Development Working Group shenanigans we have been approached about forcing NICE to "address the balance" in the composition of this working group.

We feel this is a false idea. Any group calling for balance is continuing the same problem.

There should be no "balance". There need be no "balance".

As we wrote in our statement above -

It is astonishing that the ME/CFS NICE guideline discussion continues to revolve around two opposing viewpoints despite NICE, the Department of Health and the UK government all officially accepting ME as a neurological illness as classified by the WHO.

That should be a starting point for all accepted into the working group as well.

We have already stated that people with ME do not need a "balance" – they need proper science, proper investigations and educational offerings based on real data, and not on businesses or careers or DWP coercion.

Hearing of stories of certain parties "working behind the scenes" with NICE to "address the balance" is another alarm bell.
What is this collusion? Why is it hidden?

Drip-feeding the composition of the NICE working group to the public in order to deal with and then dissipate the anger of patients against certain selections for the working group, whilst leaving open three places in the working group that then get filled by superficially "ME-friendly" persons, just to assuage the anger of patients, is a cynical tactic.

A terrible indictment of this whole process, of NICE and of certain others operating "behind the scenes".

So much for NICE's commitment to transparency. [10]

NICE ADDITIONAL QUESTIONS

NICE asked for answers to some specific questions.
We supplied the following -

1. Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why.

   - Providing timely and correct diagnosis
     - Challenging for both patients and doctors as not enough doctors who understand ME/CFS
     - The document mentions the word "specialist" numerous times but does not define the specialist or where/how patients are going to be able to access them. There needs to be funding for specialists. This will be extremely challenging in the current environment and history dictates that ME will likely not receive the amount of funding for these specialists that is required.
     - Challenging for medical education as there is considerable effort needed to get rid of the thinking that ME/CFS is caused by childhood trauma, for example.

   - Providing ongoing care

  - Challenging to undo the harm that long-term patients have suffered as a consequence of the 2007 CG53 guideline recommendations and the apathetic approach to ME that governments, the NHS, MRC and NICE have taken toward ME.
  - Challenging to encourage commissioners to fund specialist care that satisfies the demand
  - Challenging to healthcare providers to get long-term patients to trust them and reconnect with healthcare as many have not seen a doctor for their ME/CFS for years.
  - Challenging to NHS to re-educate ME/CFS service providers that followed the information in the 2007 guidelines and the research that the public funders supported. Getting them to acknowledge that their care set ups need to be overhauled.

- Providing appropriate care and follow up for the very severely affected patients that have special needs.
  - Hospitals for example cannot guarantee isolation from noise, light, smells etc. How to accommodate for all the special requests and requirements in practice?
  - There are not enough knowledgeable healthcare staff to advice on problems with tube feeding and other dietary issues for example. Not enough dieticians in general and even less so those that understand ME/CFS.
  - Not enough healthcare professionals who do home visits

- Treating children with ME/CFS with respect and listening to them
  - Challenging for social services and paediatricians to understand that ME/CFS is a disease that does not require child protection orders to be implemented just because the child has been diagnosed with ME/CFS

2. Would implementation of any of the draft recommendations have significant cost implications?

- Medical education on ME/CFS needs to be standardised and updated as required. Needs funding.
- GPs need to follow up their ME/CFS patients just as they do any other of their chronically ill patients so that they can provide medical evidence for DWP assessments for example.
- ME/CFS services need to connect to research initiatives to foster learning and collaboration.
  Need funding.
- Very severely ill ME/CFS patients need in-patient facilities and respite care offered to carers that are often family members. Funding required.

3. What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.)

- There needs to be major investment in all areas of ME/CFS biomedical research to help provide good evidence for policies that guide patient care.
- Invest in ME Research has been involved in funding and initiating ME/CFS research at

Quadram Institute in Norwich since 2013. The charity initiated partnership involves the local East Coast Community Health ME/CFS clinic and is an example of good collaborative practice that has been initiated by patients and carers without any support from public funding.

9 Conclusions

Unlike the 2006 draft guidelines these current draft guidelines seemed to have no objectives mentioned and so there is no direct way of determining if they have achieved the required result.

The objectives of the 2007 guidelines were stated by NICE as follows –
- Increasing the recognition of CFS/ME
- Influencing practice in the 'real world'
- Improving access to appropriate services, and supporting consistent service provision
- Emphasising the need for multidisciplinary working
- Improving care for patients and particularly for those severely affected
- Providing guidance on 'best practice' for children with CFS/ME
- Balancing guidance with the flexibility and tailored management, based on the needs of the patients
- Facilitating communication between practitioners and patients, and their families or carers.

[4]

The 2020 guidelines site does state that this "guidance will fully update the 2007 CG53 Guidelines Chronic fatigue syndrome/myalgic encephalomyelitis: diagnosis and management (CG53)" so it would seem as though the same objectives should be realised – even though the 2007 guidelines did not achieve their objectives.
The nearest we could see was a sentence at the beginning – "It aims to improve awareness and understanding about ME/CFS and when to suspect it, so that people are diagnosed earlier."

It is too early to say if this aim will be met.
Yet we feel that this document will not, in itself, change much for patients

The evidence reviews contain a disclaimer –

> "When exercising their judgement, professionals are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or service users. The recommendations in this guideline **are not mandatory** and the guideline does not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and, where appropriate, their carer or guardian. Local commissioners and providers have a responsibility to enable the guideline to be applied **when individual health professionals and their patients or service users wish to use it**."

So these guidelines are not mandatory and open to interpretation or to usage according to individual health professionals!.
Why is this disclaimer not in the main guidelines document – the one that clinicians will read?

We have some doubts as to whether they will be effective in improving understanding in their present form or will be universally adopted after thirteen years of flawed NICE guidelines being left in place.

From reading these guidelines we feel somewhat underwhelmed – a chance to frame the future for clinical services has basically been squandered with a vague conflux of terms and somewhat ineffectual and nebulous recommendations that leaves in place the pre-determined NICE “balance” of opposing views for the disease.

These guidelines still leave much that is open to interpretation and therefore little that will change the landscape of ME in the near future.

In 2007 Guidelines the chapter 1 was entitled Guidance.
In 2020 Guidelines the chapter 1 is replaced by Recommendations.
A subtle difference but one that reinforces the view that the NICE document is open to interpretation and open to any decision to use it, or not.

Guidelines for any disease must surely be created for the benefit of patients and to assist clinicians (and researchers).
Yet the draft guidelines document is a cumbersome document to read and needs more clarity. It does not aid busy GPs or hard-pressed healthcare staff.
It should be easier and more concise to read.

Having separate sections for severely affected and children is an obvious necessity and would help everyone.

Much of the valid information that is in the Appendices relating to children and severely affected patients does not appear to have been well imparted to the main guidelines document.
As we have stated GPs and healthcare staff may mainly look at the central document – not through appendices and NICE seem to have created a sparse document which does not fully transfer the valuable information that may have come from patients and is in some of the Appendices.
Amalgamation of much of the Appendices data for children and severely affected needs to be made to transform the main document into a more valuable resource.

Professor Mark Baker stated to us in our correspondence with him [10] that –

> “The existing recommendations are carefully nuanced and crafted to give power and choice to patients.”

During the time that the existing guidelines were put into operation there have been many patients who have adversely been on the receiving end of these “nuances” and made worse due to the guidelines.
So we have asked NICE if the new draft guidelines contain any nuances that are hidden.
Guidelines should be clear and not open to interpretation by cryptic phraseology, or nuances.

The NICE press release of 10th November 2020 announced the likely removal of GET as a recommendation from the new NICE guidelines – something that has existed since the 2007 guidelines were published.
CBT, however, remains supported by NICE –even though they seem to “nuance” their recommendation by calling it supportive CBT rather than prescriptive CBT.

This was predictable and predicted – creating a balance of action and inaction, satisfying some of the demands from patients and retaining some of the status quo that merely props up previous flawed research.

The 2007 guidelines promoted GET and CBT as recommendations for treatment.
The 2020 guidelines now states –

> “…Only offer cognitive behavioural therapy (CBT) to people with ME/CFS who would like to use it to support them in managing their symptoms of ME/CFS and to reduce the psychological distress associated with having a chronic illness. Do not offer CBT as a treatment or cure for ME/CFS.
> …CBT should be only delivered by a healthcare professional with appropriate training and experience in CBT for ME/CFS, and under the clinical supervision of someone with expertise in CBT for ME/CFS”

Removing GET was always going to happen thanks to the age of social media where the paucity of any evidence base and the overwhelming rejection by patients meant that GET could never survive serious and constant scrutiny as a useful therapy for ME.

Leaving CBT was always going to happen. Continually emphasising it in the guidelines is a mistake and a rather insidious and disingenuous decision by NICE based on the flimsy evidence. Yet it satisfies the balance that NICE want to keep – for no good reason for patients.

Following the publication of the draft guidelines some seem happy just that GET is removed from NICE guidelines.
That may be understandable given the harm it has caused.

But is our bar set so low that this is all we expect – a flawed recommendation corrected after thirteen years of being left in place?

Should we not want more from guidelines – directions on what to do, how to correct missing prerequisites for real progress, methods to demolish all of the misinformation that still exists, a publicity effort to raise awareness of the real disease, a planned pathway to re-educate healthcare staff on the realities of ME/CFS?

Should we not call out the failure of NICE to do anything in thirteen years and leave flawed and harmful guidelines in place for healthcare staff to make wrong decisions or for insurance companies and those clinging to the BPS ideology to manipulate vulnerable patients?

It seems as though NICE produced a document to rectify errors and falsehoods in their previous guidelines – and yet have not admitted what harm their previous guidelines may have done.

Rather than looking to move things on for the future by recommending changes, it has instead used the past guidelines as a basis for the current draft, creating a "balance" of interests which was not necessary and failing to take a clean sheet.

It fails to include recommendations for changing the way ME is treated and perceived.

The coercion of ME patients to take CBT or other therapies will not necessarily disappear and the DWP will still likely perform their benefits assessments with no reference to any evidence in NICE and will continue their one size fits all approach to claimants?

As the disclaimer mentioned above states it does not enforce anything and is open to interpretation.

Patients justifiably lost trust in NICE to listen or to carry out any real attempt to understand patients or this disease. This draft document does not restore any trust in our eyes.

The NICE press release that accompanied the publication of the draft guidelines document stated that the draft guidelines

> "...stresses the need for a tailored, individualised approach to care based on establishing a partnership between the person with ME/CFS and those providing their care that allows joint decision making and informed choice."

It is an interesting statement but we do not believe this will change much for ME patients.

Early diagnosis of ME is to be welcomed though there is still no specialisation in ME so how effective this will be in practice is determined by attitudes of clinicians and consultants.

It would be nice to assume that properly trained professionals who are capable of administering the suggested care will have the requisite expertise or will be retrained.

The past 13 years of recommending CBT and GET has been based on a false illness belief model of ME which still resonates today in healthcare, so there is cause for concern.

IiMER hope that these changes to previous recommendations will filter through to insurance companies as soon as possible. Too many patients have lost their livelihoods and health on claims that CBT and GET are curative and necessary to go through before any claims could be made.
Of course, NICE have never been accountable for this damage.

We are happy to see a NICE Guidelines director acknowledge what Invest in ME Research has been stating for years, that everything has been

> ".. compounded further by a lack of effective treatments, wide variation in access to services, and by controversy over the use of graded exercise therapy and CBT that has served only to alienate many people with ME/CFS.."

something the charity pointed out when NICE formed their “balanced” working group in 2018 [11].

All of these points could have been taken on board in 2007 when patients took NICE to judicial review [6].
Yet NICE are only now deciding to take steps to remove these flaws in their previous guidelines

Tellingly, the NICE statement implicitly recognises the failure of national research councils (and the government) to fund and initiate adequate research into ME by including this observation –

> “The committee wasn’t able to make any recommendations for treatments because of a lack of evidence of effectiveness”

The reason for a lack of evidence is a result of a lack of funding for fundamental biomedical research – a task that has been taken up instead by patients and carers [24].
Thanks to patients it has been realised how important it is that the biomedical research needs to be performed that allows accumulation of scientific data, collaboration with other institutes and possibility of treatments being developed for ME.

Whilst NICE might well expect to be congratulated for giving the impression of finally listening, in part, to the needs of people with ME, then it would be premature to think that all is now well.

Did the draft document set new standards for health professionals and ensure that people with ME have access to the right care and support?
We doubt it.

The NICE document showed how little has changed for people with ME in UK over thirteen years as their press release was entitled “**..the continuing debate about the best approach to the diagnosis and management of myalgic encephalomyelitis..**”

The fact that NICE still feel the need to refer to a “continuing debate” illustrates that it is an organisation still compromised by vested interests and probably still has a lot to learn to get to where patients were some thirteen years ago – the lost years.

The magnitude of the failure of NICE is illustrated by the fact nothing has changed much for ME patients over the last thirteen years since the 2007 CG53 guidelines were published.
Yet NICE are walking back on the many flaws and errors in their 2007 guidelines to reveal a bare bones guideline that is short on evidence on which to base conclusions and recommendations.

So no, no reason for congratulations.

It took NICE thirteen years to document what we already knew thirteen years ago.

We doubt that this document will be enough to change views that have been engrained in the healthcare system for decades due to misinformation that has been produced – some by NICE itself.
We do not see much in the new guidelines to be optimistic that anything will be changed quickly regarding clinical care.

Yet we already see some organisations positioning themselves before the NICE draft guidelines were published, and certainly after.
These shapeshifting entities have never served ME patients well so we are not surprised how fluid they are when establishing positions.

In thirteen years will one look at these 2020 NICE guidelines and see them as a watermark for change?
We doubt it.

Diagnosis is important as it helps with education and benefits but will this document assist? It needs to be accurate and as early as possible but it needs knowledge and education about the disease.
We wrote before that NICE was pitting doctors against patients and it still has not rectified that with these new guidelines
Whilst retaining CBT to maintain a balance and while there is a lack of sufficient and appropriate research into the disease then there will be no effective treatments and we are left with the need for a common sense approach – something these guidelines fail to do with their continued peddling of CBT.

If there are no treatments then part of the reason for that has been the disastrous handling of research funding for ME by research funding agencies.
The lack of any effective recommendations for treatments ought to be seen as a judgement on the failure of past policies toward research into ME that have been maintained by the MRC, and a condemnation of those the individuals to whom the MRC gave responsibility and all of the “expert panels” and collaboratives that were touted as being progress, yet turned out to be failures.

COVID-19 is a disease that cannot so easily be misrepresented by a block of psychiatrists with vested interests as being a behavioural illness. Perhaps this knowledge will eventually force NICE and others to recognise that ME cannot be swept under the same carpet of obfuscation and falsehoods that has so characterised NICE policies and MRC funding for decades.

We do not feel that these guidelines have moved us forward. We feel they tried to correct some of the flaws in the irresponsible 2007 guidelines.
Yet we doubt all doctors will change views overnight – after all they have had thirteen years of NICE guidelines keeping ME in the medical wilderness.

The guidelines now show how the lack of any real strategy of research and clinical training has been allowed to exist – some might say fester

Can we see things changing – not from these guidelines.
There needs to be more done than just modifying flawed guidelines from the past.
The change will likely come from the fallout of the pandemic which has seen ME being seen in a different light by some in influential positions who had previously remained ignorant.

Would we recommend the NICE guidelines for other healthcare systems in other countries?
No.

Finally, although we are not impressed by the work of NICE over the last thirteen years, we feel it would be worthwhile for NICE to organise a publicity campaign to expel the myths that have permeated all levels of public policy about ME/CFS regarding the failed psychological therapies. They could draw attention to the lack of research and funding for research.
We all know that this is due to policy based evidence making where only biopsychosocial research teams have received public funding to promote their version of ME/CFS, despite patients and their families having suffered enormously due to flawed research forming basis for public policy.
This campaign could mention that new guidelines are replacing the old, flawed document and that in the interim period an addendum that was requested by IiMER has been added to the existing NICE guidelines page warning against use of GET (though we requested also that CBT be added)[16].

10 Appendices

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