

25% Group

Sir Andrew Dillon,
Chief Executive,
National Institute for Health and Care Excellence
10 Spring Gardens
London
SW1A 2BU

6th November 2018

Re: ME/CFS Clinical Guideline

Dear Sir Andrew Dillon,

The 25% Group is concerned that with so few representatives on the GDG, who have a biomedical understanding of ME, that the new Guidelines will be as equally inappropriate and potentially harmful for people, as the current NICE guidance, perhaps even worse.

Patients with ME require a physiological explanation for their symptoms, genuine recognition of the seriousness of their illness and an honest and realistic prognosis. They do not understand why the the GDG appears to be so heavily biased toward a biopsychosocial (BPS) perspective of ME.

Based upon flawed logic, riddled with inconsistencies, misleading statements and glaring methodological problems, the BPS approach to ME has caused untold damage, harm to people with Severe ME, over many years of neglect.

Effectively abandoned by the NHS, people with Severe ME, under the influence of a powerful UK “psychiatric lobby” have been left to cope, on their own, often for decades on end, without proper testing or treatment, leaving them with no hope.

The ME community finds it incomprehensible that despite the National Academy of Medicine’s declaration that ME is an organic condition, requiring biomedical treatment, despite all the medical evidence, NICE has appointed a predominantly biopsychosocial GDG.

We need to know that the BPS approach, specifically recommending GET, CBT and Graded Activity Management, will no longer be applied to our disease, but how can this GDG, possibly bring that about ?

There is absolutely NO possible compromise between those who advocate a fatigue based therapy service and who are a majority on the GDG and those who are desperate for a full-blown biomedical pathway to be put in place instead.

There is no such thing as a “balanced” biopsychosocial / biomedical approach to ME; that is a contradiction in terms.

We appreciate that not all members have yet been appointed to the GDG, however that does little to alter the perception, in the ME Community, that NICE seems biased towards a BPS approach.

We also appreciate that Expert Witnesses will be appointed, who may have biomedical expertise. However, it is not certain how much influence they will have, nor how this will not lead to conflicting views and interpretations.

NICE has a unique opportunity to develop, at long last, a proper biomedical pathway, to issue a clear message that ME is not Chronic fatigue or MUS, but a WHO classified neurological disease with multi-system dysfunction..

It appears, however, to already have squandered that opportunity.

Can you please confirm, in line with international medical consensus that the intention is to produce a biomedical Guideline for people with ME?

If so, can you please outline how this will be possible under the current GDG? What reassurance can you give people with Severe ME that this Guideline is going to meet their urgent need for a comprehensive biomedical pathway ?

Yours sincerely,

Simon Lawrence