

## **New Guideline on 'ME/CFS' in Development**

**The National Institute for Health and Care Excellence - commonly abbreviated to 'NICE' - is presently developing a new guideline on the diagnosis and management of 'ME/CFS' for use by health and social care professionals.**

The 25% ME Group, in common with many other M.E. organisations, is on record with the view that the existing guideline is unhelpful [Clinical Guideline 53, 2007 - which relates to 'CFS/ME']. So we are very much hoping that the replacement will prove to be a change for the better. However, as it will not appear until 2020, we are pressing for a 'health warning' on some of the advice contained in Clinical Guideline 53 in the meantime. We wrote to 'NICE' back in March regarding this: to date there has been no reply.

### **The guideline 'scope' will provide specific questions to address and set the context**

Getting the context right will be vital when developing the new guideline. Any guideline that is applied to M.E. patients must draw on information that is pertinent to M.E. patients, including when selecting research trials on which to base recommendations. Controlled trials are traditionally considered as high status evidence by NICE, with heavy reliance on their reported findings. However selecting only research that is pertinent to people with M.E. has manifestly not happened to date - greatly aided by the amorphous concept that is 'CFS' and in particular the now notorious 'Oxford' CFS research criteria that have been used to recruit participants to trials involving graded activity or exercise. The 25% ME Group's submission to a consultation on the new guideline's scope addresses this (<https://25megroup.org/nice-guidelines>).

In a nutshell, the overall coverage of the proposed questions is very similar to those set in respect of the existing guideline. In our view what is crucial is how the guideline development group will go about providing answers. What type of information is admissible as 'evidence'? And how robustly will this 'evidence' be interrogated? As we assert in our comments, the parameters set when CG53 developed are exactly what got us into the present mess.

NICE will provide a response to comments submitted publish a final scope.

### **The process of recruiting members of the Guideline Development Group is now underway.**

At present a chair and vice chair are already in place:

CHAIR: Dr Peter Barry, a Leicestershire based paediatrician with a clinical interest in paediatric intensive care. You can read about Dr Barry's academic research work at:

[https://www.researchgate.net/profile/Peter\\_Barry](https://www.researchgate.net/profile/Peter_Barry) and

<https://www.le.ac.uk/childhealth/staff/pwb1.html>

VICE CHAIR: Baroness Ilora Finlay, a Cardiff based consultant physician in palliative care and crossbench peer (member of the House of Lords with no party affiliation). Baroness Finlay lists her parliamentary interests as: health services & medicine; science & technology; and medical ethics. You can see her House of Lords profile at:

<https://www.parliament.uk/biographies/lords/baroness-finlay-of-llandaff/3609>

The 25% ME Group have contacted NICE requesting the involvement of a member of a specialist nutritional support team in guideline development. We did this in view of the very serious situations that a person with severe M.E. can face when faced with inability to swallow and/or undernourishment due to gastro intestinal problems. We have been informed that a dietician will be recruited to the guideline committee. However we will continue to press for a specialist nutritional support team member, such as an enteral feeding specialist.

24<sup>th</sup> August 2018

*Where to find further information:*

The draft scope and other information about the guideline replacement process can be found here: <https://www.nice.org.uk/guidance/indevelopment/gid-ng10091/documents>.

As well as our own submission, we contributed to comments drawn together by the Countess of Mar on behalf of Forward-ME (<http://www.forward-me.org.uk/Reports/NICE-comments-form-2.pdf>).

You can read submissions to the consultation on scope from other M.E. organisations at the ME Association website: <http://www.meassociation.org.uk/2017/07/the-nice-guideline-consultation-uk-stakeholder-submissions-27-july-2017/>.

NICE originally expressed the view that the present guideline does not require to be updated or replaced. If you would like to read about how the change of plan was secured you'll find a report in The Quarterly (Newsletter of the 25% ME Group), Issue 44, Winter 2017.

***NOTE: If clicking on a link in this article doesn't take you to the relevant webpage, please paste the link into your web browser.***