



to: cfsme@nice.org
FAO Guideline Committee

Friday 26th February 2021

SUBJECT: Clinical Guideline in Development - Evidence Reviews

We are contacting the Guideline Committee (GC) after careful consideration.

Based on the draft that was circulated for consultation towards the end of last year, the guideline that will replace the highly contentious Clinical Guideline 53 may well prove to be a step in the right direction for ME patients, including the severely affected patients whom we represent.

At the same time, we wish to see the best outcome possible for people with ME, in keeping with the scope and breadth of evidence that is presently available, and given that it may well prove very difficult indeed to secure any improvements to the guidance after it is published.

The issue we are bringing to your attention today is this: we face the unavoidable conclusion that, in a number of respects, the GC have not been well served by the evidence reviews put before them.

Achieving a good standard throughout Evidence Reviews and related procedures is a fundamental issue in guideline development and members of a GC are entitled to expect a high standard in terms of the assessment and presentation of the evidence put before them. We are sure you will agree that the identification, assessment and presentation of evidence must be thorough, pertinent and accurate.

The enclosed reports set out issues we have identified. We have provided separate papers in respect of each evidence review (with the exception of Review I, which we have not appraised). They are by no means the result of a thorough and comprehensive consideration, and as such may represent the tip of an iceberg.

We consider that the draft for consultation was in fact remarkably good in many (but not all) respects, given the evidence that was - and, just as importantly, was not - put before the committee when developing the draft. We appreciate that the draft for consultation will have attracted a large volume of comment, which the GC are tasked with appraising. We take no satisfaction in adding to the load however the core principle for all concerned must be to serve the best interests of patients and assist professionals to do so through high quality guidance and for that the best time is now.

H. Brawley

P.P. Simon Lawrence
Chairperson

25% M.E. Group, 21 Church Street, Troon, Ayrshire KA10 6HT.

Office Telephone: **01292 318611**

Website: www.25megroup.org Email: enquiry@25megroup.org