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New Parliamentary Inquiry into the work of NICE

Margaret Williams 8th February 2007

Many in the UK ME community will already be aware that the NICE Guideline on "CFS/ME" that was originally due for publication in April 2007 has been delayed until August 2007 due to the enormous amount of submissions received.

There are two more potentially significant developments, one relating to NICE and the other to the Department for Work and Pensions.

The DWP Guidance on "CFS/ME" which was scheduled for publication in February 2007 has now been delayed until June 2007.

Regarding NICE, attention is drawn to a Press Release dated 2nd February 2007 about the forthcoming Parliamentary Inquiry by the Health Select Committee into aspects of the work of the National Institute for Health and Clinical Excellence (NICE). The inquiry is scheduled as No.11 in Session 2006-2007. The Committee has the power to send for persons, papers and records.

Amongst other things, the Press Release states:

"The Committee has decided to undertake an inquiry into aspects of the work of the National Institute for Health and Clinical Excellence. Areas of specific interest include:

- why NICE's decisions are increasingly being challenged
- whether public confidence in the Institute is waning, and if so why
- NICE's evaluation process, and whether any particular groups are disadvantaged by the process
- the speed of publishing guidance
- the appeal system
- comparison with the work of the Scottish Intercollegiate Guidelines Network (SIGN)
- the implementation of NICE guidance, both technology appraisals and clinical guidelines (which guidance is acted upon, which is not, and the reasons for this).

Written evidence should, if possible, be in Word or rich text format –not in PDF – and sent by email to

healthcommem@parliament.uk

The body of the email must include a contact name, postal address and telephone number.

The deadline is Friday 23rd March 2007.

The postal address is House of Commons, Health Select Committee, 7 Millbank, London SW1P 3JA. The telephone number is 0207-219-6182.

Submissions must address the terms of reference (listed above) and should be no more then 3.000 words.

Paragraphs should be numbered for ease of reference and the document must include an executive summary.

Submissions should be original work and not previously circulated elsewhere. Once submitted, they become the property of the Committee and no public use should be made of (the submissions) unless permission has first been obtained from the Clerk of the Committee. The Committee normally, though not always, chooses to publish the written evidence it receives.

Evidence sessions are likely to commence after the Easter Recess and a later press notice will give details of these".

Immensely difficult though it is, every member of the UK ME community is urged to respond if at all possible, and to submit the many concerns about the NICE draft guideline on "CFS/ME".

The ME community is standing on the edge of a precipice and it is therefore vital to do so, as this may well be the last opportunity to influence the political position.