David Coombs

From: 1

(section 40)

(section 40)

Sent: 28 October 2015 08:54

To:

Cultingto DE NICE

Subject: RE: NICE guideline CG53: Chronic fatigue syndrome

I've had a look at these reports. It is encouraging to see developments in thinking about CFS/ME, and that there is growing attention to the problem in the US. It would be very good news if they were to fund new research into its diagnosis and management.

I agree with your proposed decision on updating the guideline, but do believe that a review of the guideline will be necessary by 2017. By then, there is likely to be a clearer case definition and evidence on which categories of patients respond to the therapies now available. There is also a case for supporting the development of an international consensus on case definitions; I'm not sure how this could be done, but encouragement from NICE for the establishment of an international group to address this question could well be helpful.

Best wishes

(section 40)

From:

Sent: 26 October 2015 07:50

To: (section 40)

Subject: RE: NICE quideline CG53: Chronic fatigue syndrome

Dear

We have received some new information relating to the CFS/ME guideline. We were made aware of publication of the following three reports in the USA that might have implications for the CFS/ME guideline:

- Smith MEB, Nelson HD, Haney E, Pappas M, Daeges M, Wasson N, McDonagh M. Diagnosis and Treatment of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. Evidence Report/Technology Assessment No. 219. (Prepared by the Pacific Northwest Evidence-based Practice Center under Contract No. 290-2012-00014-I.) AHRQ Publication No. 15-E001-EF. Rockville, MD: Agency for Healthcare Research and Quality; December 2014. www.effectivehealthcare.ahrq.gov/reports/final.cfm.
- IOM (Institute of Medicine). 2015. Beyond myalgic encephalomyelitis/chronic fatigue syndrome: Redefining an illness. Washington, DC: The National Academies Press.
- Recommendations from the HHS Chronic Fatigue Syndrome Advisory Committee. August 2015.

Our Clinical Adviser has reviewed these reports and his view is that there are likely to be changes in the diagnostic criteria in this field that will have implications for the guideline in the future, but not until after the proposed 2 year validation of the diagnostic criteria is completed. As such, we are proposing to keep the guideline on the static list for the moment however, our review to determine whether it should come off the static list will be brought forward to coincide with the validation of this diagnostic criteria (likely to be 2017/18 financial year).

Do you have any views on that proposal? Feedback by Monday 2 November would be greatly appreciated. Best wishes. (section 40) National Institute for Health and Care Excellence Level 1A | City Tower | Piccadilly Plaza | Manchester M1 4BD | United Kingdom Tel: i Web: http://nice.org.uk From: (section 40) Sent: 28 April 2015 13:37 Subject: RE: NICE guideline CG53: Chronic fatigue syndrome My apologies for the delay in responding. and emails can get overlooked. Today is a work day. (section 40) The Cochrane review is an update of its 2004 review; that review included 5 studies, and the update has added 3 new trials. The 2004 review would have been taken into account in the guideline (I haven't checked that it was reference in the guideline, but assume so). Here is an extract from the text of the discussion section of the new review: 'This update provides valuable additional information when compared with the original review, and results reported in the original review are largely confirmed in this update. Moreover, the results reported here correspond well with those of other systematic reviews (Bagnall 2002; Larun 2011; Prins 2006) and with existing guidelines (NICE 2007).' The new review seems to provide greater confidence in the conclusions of the 2004 review, but does not really change them. Therefore, I tend to agree with the decision that the guideline should remain static. Best wishes (section 40) From: (section 40) Sent: 21 April 2015 09:06 To: Subject: NICE guideline CG53: Chronic fatigue syndrome

The clinical guideline CG53: Chronic fatigue syndrome / myalgic encephalomyelitis was placed on the static list in February 2014 which means that we check the need to update the guideline less regularly than guidelines on the

(section 40)

Dear

active list. Recently we had an enquiry challenging the guideline's position on the static list due to publication of a Cochrane review.

We have evaluated the results of the Cochrane review (see attached paper) and feel that they would not impact on the guideline recommendations. We feel that the static list position for CG53 remains justified.

Do you have any views on our proposal? Feedback by Friday 24 April would be greatly appreciated.

As the attached paper is an internal document we would appreciate it if you do not circulate further.

Best wishes, (section 40)

National Institute for Health and Care Excellence
Level 1A | City Tower | Piccadilly Plaza | Manchester M1 4BD | United Kingdom

Tel:

Web: http://nice.org.uk

The information contained in this message and any attachments is intended for the addressee(s) only. If you are not the addressee, you may not disclose, reproduce or distribute this message. If you have received this message in error, please advise the sender and delete it from your system. Any personal data sent in reply to this message will be used in accordance with provisions of the Data Protection Act 1998 and only for the purposes of the Institute's work.

All messages sent by NICE are checked for viruses, but we recommend that you carry out your own checks on any attachment to this message. We cannot accept liability for any loss or damage caused by software viruses.

http://www.nice.org.uk

Delivered via MessageLabs

The information contained in this message and any attachments is intended for the addressee(s) only. If you are not the addressee, you may not disclose, reproduce or distribute this message. If you have received this message in error, please advise the sender and delete it from your system. Any personal data sent in reply to this message will be used in accordance with provisions of the Data Protection Act 1998 and only for the purposes of the Institute's work.

All messages sent by NICE are checked for viruses, but we recommend that you carry out your own checks on any attachment to this message. We cannot accept liability for any loss or damage caused by software viruses.

http://www.nice.org.uk