The development of the guideline for 'Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): diagnosis and management of chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy) in adults and children'

Who is involved in developing the guideline?

The guideline is being developed by a Guideline Development Group (GDG) under the auspices of the National Collaborating Centre for Primary Care. Patient representatives, healthcare professionals, and technical/project management staff from the National Collaborating Centre are all involved in the development of the guideline. (A full list of members is available on the NICE website http://www.nice.org.uk/page.aspx?o=guidelines.inprogress.cfsme)

How is the guideline developed?

The guideline is based on the best available evidence from the research literature. Briefly, the GDG first defined a number of key clinical questions that covered the clinical areas outlined in the scope (the document that sets out what the guideline will cover). Next, a search and review of the research evidence was performed, updating the earlier review that informed the Chief Medical Officer's report. This was done according to NICE methodology and was carried out by the University of York. The GDG considers all the evidence and will formulate its recommendations to the NHS. These draft recommendations and accompanying documents will be posted on the NICE website for an 8-week public consultation.

Why do we need to do consensus work, using techniques like a Delphi survey?

Sometimes there is not enough appropriate published research evidence to answer the key clinical questions. In these circumstances, GDG members may use their experience and expertise to formulate recommendations. In the CFS/ME guideline the GDG has identified several questions that are affected by variation in practice and a lack of appropriate research evidence. Therefore, the GDG has agreed to make recommendations using formal consensus methods. This includes constructing a questionnaire of statements to describe clinical circumstances. As part of this method,

they have decided to seek the views of a wider group on these statements to inform their decisions. (This is separate from the public consultation on the draft guideline, which is part of NICE's standard consultation process due to take place in the autumn of 2006.)

How will it be done?

The consensus development method we have chosen is called the Delphi technique, and it is being modified for this guideline. We have sought nominees (between 5 and 50) from each stakeholder organisation registered for this guideline, involving both patients and healthcare professionals. We have circulated a systematic review and a questionnaire to those nominees, and asked them to complete the questionnaire by 5 May 2006. The GDG will use the results to help them make decisions about the recommendations that NICE will publish for public consultation. The results will help to inform the GDG's decision-making, but as with all NICE guidelines, the final content of the guideline is the responsibility of the GDG.

Next Steps

Once the guideline recommendations have been formulated, the GDG will produce a draft document for stakeholder and public consultation. This document will list details of the process, and the pooled results of the formal consensus of the GDG and wider group questionnaire will be made available as appendices to the full guideline document. At this time, anyone who wishes to may comment on the draft through the formal stakeholder consultation process as set out in the Guidelines Manual on the NICE website (www.nice.org.uk/page.aspx?o=201977)

Following the consultation, all comments will be considered by the GDG and the final draft of the guideline will be presented to NICE for final approval before publication. The final documents will include the full methodology, and it is planned to publish a copy of the comments received, and the responses of the GDG, on the NICE website.