

David Coombs

From: Mark Baker
Sent: 28 October 2015 15:08
To: [REDACTED] (section 40)
Cc: Sarah Willett; [REDACTED]
Subject: RE: Report from NIH on CFS

Thanks. I've handled the correspondence with Countess Mar.

M

From: [REDACTED]
Sent: 28 October 2015 13:48
To: Mark Baker
Cc: Sarah Willett; [REDACTED]
Subject: RE: Report from NIH on CFS

Hi Mark,

I've finalised [REDACTED] paper after receiving feedback from [REDACTED]. Essentially he agreed with the approach to bring the surveillance review forward to 2017. [REDACTED] felt that by 2017 there is likely to be a clearer case definition and evidence on which categories of patients respond to the therapies now available.

Based on this piece of work we're proposing to keep the topic on the static list but bring the review forward. This topic is proposed to move to Q3 2015 (starting October 2017) and we will update the website with the new review date.

Will you respond to the enquirer or do you want us to respond and send them a copy of the document?

Many thanks,
[REDACTED] (section 40)

From: Mark Baker
Sent: 23 October 2015 15:08
To: [REDACTED] (section 40)
Cc: Sarah Willett; [REDACTED]
Subject: RE: Report from NIH on CFS

Thanks. I think the draft paper offers the right approach. [REDACTED]'s view will certainly be worth getting. [REDACTED]
[REDACTED] (section 40)

If the diagnostic criteria are not going to be signed off until late 2017, it is not obvious that bringing the review forward will have much traction. From your summary it seems that the NIH work is preparing the ground for the future rather than rewriting the past. We will still be left with a syndromic state with a broad spectrum of severity, little idea as to aetiology and not much to treat with. I'm not sure why the special interest groups think the guidance needs to change.

M

From: [REDACTED] (section 40)
Sent: 23 October 2015 14:37
To: Mark Baker

Cc: Sarah Willett; [REDACTED]
Subject: FW: Report from NIH on CFS

Dear Mark

Did you get chance to look at this? I'm away next week, so if you could let Sarah and [REDACTED] have your thoughts they can pursue getting a view from the GDG Chair.

Thanks

[REDACTED] (section 40)

[REDACTED]

From: [REDACTED] (section 40)
Sent: 16 October 2015 14:32
To: Mark Baker
Cc: Sarah Willett; [REDACTED]
Subject: RE: Report from NIH on CFS

Hi Mark

Here's my draft paper on CFS/ME. If you agree with the general thrust in it I will run it past [REDACTED].

In general, the proposed changes to diagnostic criteria seem to move to a tighter definition and the more severe end of the spectrum. I think it probably reflects an attempt to move from a syndrome to a disease, but will probably leave some people with symptoms excluded from this label.

Best wishes

[REDACTED] (section 40)

[REDACTED]

From: Mark Baker
Sent: 12 October 2015 13:10
To: [REDACTED]
Cc: Sarah Willett; [REDACTED]
Subject: RE: Report from NIH on CFS

Basically I think we remain in a world which is split down the middle between the advocates of CBT and GET, some without assumption as to aetiology, and the believers in a primary neurological condition. The former believe that the PACE trial supports their views, and the guideline. The latter believe that the PACE trial confirms their view that the guideline is harmful because it assumes a primary psychological cause and that GET is directly harmful (to some).

I wasn't sure but I think the NIH report is a Panel view rather than a primary research contribution and, as such, doesn't affect the status of the guideline. However, this field is so hamstrung by context and perspective that it is difficult to know how to make progress.

Removing the guideline from the static list would lead to an immediate demand for a rewrite whereas in fact I am suggesting that we give it priority within the static category. However, we could adopt either approach.

M

From: [REDACTED] (section 40)
Sent: 12 October 2015 13:02
To: Mark Baker
Cc: Sarah Willett; [REDACTED]
Subject: RE: Report from NIH on CFS

Dear Mark

I've had a look at the reports and letter and am drafting a 'challenge to static list' paper.

There are a lot of proposals in the US committee report, including changing the name of the condition and diagnostic criteria. The latter would clearly have implications for the guideline but they suggest a two year period of validation for the proposed criteria, so they are not likely to be stable till late 2017. There are some specific recommendations around treatment and care, but also a recommendation to develop guidelines, and I am not sure how well those two sit together.

There's a specific call for a Declaration that the disease is not the result of fear-based avoidance of activity and that cognitive behavioral therapy (CBT) and graded exercise therapy (GET) for this purpose are inappropriate. There's no further detail on this, but I think this is in relation to a 2015 secondary analysis of the PACE trial published in the Lancet Psychiatry, looking at factors mediating response or lack of it. In CG53's recommendations, we do not make any assumptions about causation in recommending individualised use of these interventions and I am not sure how we would change the recommendations. Assuming the diagnostic criteria do change, we will need to reassess the applicability of evidence on treatment to people meeting the new criteria, and GET and CBT will be no exception. I think, however, this would be better done when there is more clarity over the diagnostic criteria in a couple of years.

I understand you have already committed to bringing the full surveillance review forward anyway, and I think that is probably the appropriate action for now.

I will forward you the draft surveillance document when I have completed it.

Best wishes

[REDACTED] (section 40)

[REDACTED]

From: Sarah Willett
Sent: 23 September 2015 11:50
To: [REDACTED] (section 40)
Cc: [REDACTED]
Subject: FW: Report from NIH on CFS

Can we discuss tomorrow.

Thanks

Sarah

From: Mark Baker
Sent: 23 September 2015 11:36
To: Sarah Willett
Subject: FW: Report from NIH on CFS

Fyi

M

From: MAR, Countess [mailto:MARM@parliament.uk]

Sent: 23 September 2015 10:52

To: Mark Baker [REDACTED] (section 40)

Cc: [REDACTED]

Subject: RE: Report from NIH on CFS

Dear Mark

Many thanks for your helpful response. I attach the papers upon which the determination of the Health Committee report was based. The references are there. The ME Association is in the process of finalising the results of a large survey among its members. I will forward this to you as soon as it is available.

I entirely agree with you about the lack of clinical research is a major hindrance, but do you really think that it should be an excuse for continuing to recommend a practice which is known to be harmful? Unless someone takes a stand, nothing will ever be done to improve the situation for patients. I am also a little concerned that your reviewers might take the view that the findings of UK academics are necessarily superior to those of respected researchers in the USA and elsewhere. May I be reassured on that point, please?

With kind regards
Margaret

From: Mark Baker [REDACTED] (section 40)

Sent: 22 September 2015 09:39

To: MAR, Countess

Cc: 'McShane Martin (NHS ENGLAND)'

Subject: Report from NIH on CFS

Dear Margaret

Thank you for copying me into your response to Martin and for the hard copies of relevant papers.

Although we are not yet scheduling a formal review, we are going to conduct a critique of the US paper, which I note is not referenced, and consider whether it adds anything to what we already know. You will be aware that the British academic establishment holds an entirely different view, though not necessarily any better informed.

We are looking to bring forward the formal review of the guideline by a year but the lack of relevant clinical research, as especially highlighted in the US papers, is an obstacle to progress, and the absence of an agreed and reproducible pathophysiology over the last twenty years is a major obstacle to relevant research. It remains a tragedy that this serious and disabling condition has seen so little progress in a generation.

Best wishes

Mark

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