

Janet Fahie

Subject: FW: ME/CFS/SEID

Importance: High

From: Gillian Leng
Sent: 17 June 2015 19:49
To: Mark Baker
Subject: FW: ME/CFS/SEID
Importance: High

Mark

Do you have any thoughts on this query? I thought we'd decided not to review the CFS guideline? I had heard a new name was in the offing....

Please do respond directly to Martin!

Cheers Gill

From: McShane Martin (NHS ENGLAND) [REDACTED] (section 40)
Sent: 17 June 2015 09:32
To: Gillian Leng
Subject: FW: ME/CFS/SEID
Importance: High

Gillian
Could you help me with the second part of the query below at all??
I would be indebted!

Yours,

Martin

Dr Martin McShane
National Medical Director for Long Term Conditions



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Medical Directorate

NHS England

5W25 | Quarry House | Quarry Hill | Leeds | LS2 7UE

Executive assistant: [REDACTED] (section 40)

Direct Dial: [REDACTED]

Email Address: [REDACTED]

From: [REDACTED] (section 40)

Sent: 27 May 2015 13:59

To: Contactus England (HEALTH AND SOCIAL CARE INFORMATION CENTRE)

Cc: [REDACTED]

Subject: ME/CFS/SEID

Please could you tell me:

1. which organisations in England commission services for patients with ME/CFS?
CCGs?
or other?
2. what is the response of **NHS England** to the recent report, commissioned by the **US Institute of Medicine**, on ME/CFS?

The report recommends, among other things, a change of name of the illness to Systemic Exertion Intolerance Disease, and simplified criteria for diagnosis which any doctor could use effectively.

It is the most comprehensive report on the condition that I have seen, and was commissioned at the request of several US government agencies.

The IOM has yet to decide on its recommendations.

Has it been considered by the UK NHS?

[REDACTED] (section 40)

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Janet Fahie

Subject: CFS/ME

From: McShane Martin (NHS ENGLAND) [REDACTED] (section 40)
Sent: 18 June 2015 08:42
To: Mark Baker
Subject: Re: CFS/ME

Many thanks. Really helpful.

Dr Martin McShane
Director (Domain 2) Improving the quality of life for people with Long Term Conditions

NHS England
Medical Directorate (4N22)
Quarry House
Quarry Hill
LEEDS,
LS2 7UE
Work Mobile [REDACTED]
Office [REDACTED]

On 18 Jun 2015, at 08:27, Mark Baker [REDACTED] wrote:

Dear Martin

Gill has asked me to respond to your request to her for advice on the new classification of CFS/ME.

I had been made aware, probably by the same source as you, of the work commissioned in the US. What she didn't mention is the summary situation described in the BMJ recently of no real progress in twenty years, no agreement on causality or disease nature and little prospect of change in the next decade. In these circumstances, it doesn't really matter what we call it, the NICE guideline remains the best summary of effective treatments for most patients with CFS.

It is not really for the NHS to respond to a report commissioned in another country and not yet examined by its commissioner. We would take seriously the views of the relevant esteemed medical associations in the UK, principally the RCP and the RCPsych, when looking at reviewing this guidance around 2018. I am not aware of any reason to do anything before then unless some major new evidence on treatment emerges, and we know that no major studies are in progress.

Best wishes

Mark

Professor Mark R Baker
Director
Centre for Clinical Practice
The National Institute for Health and Care Excellence

10 Spring Gardens
Trafalgar Square
London SW1A 2BU

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Janet Fahie

From: NICE Mail
Subject: Re NICE guidance for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME)

From: McShane Martin (NHS ENGLAND) [REDACTED] (section 40)
Sent: 27 July 2015 11:55
To: Mark Baker
Cc: [REDACTED] (section 40)
Subject: RE: Re NICE guidance for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME)

Thanks Mark
 I will let you have sight of my response before I send it so you can let me know if you have any concerns.

Yours,

Martin

Dr Martin McShane
National Medical Director for Long Term Conditions



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 Executive assistant: [REDACTED]
 Direct Dial: [REDACTED]
 Email Address: [REDACTED] (section 40)

From: Mark Baker [REDACTED] (section 40)
Sent: 27 July 2015 11:07
To: McShane Martin (NHS ENGLAND)
Cc: Arnold Richard (NHS ENGLAND)
Subject: RE: Re NICE guidance for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME)

I can't think of any reason why not. It accords with what I have said and written to her before.

Mark

From: McShane Martin (NHS ENGLAND) [REDACTED] (section 40)
Sent: 27 July 2015 11:05
To: Mark Baker

Cc: Arnold Richard (NHS ENGLAND)

Subject: RE: Re NICE guidance for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME)

Mark

Are you content for me to let countess Marr see this response?

Yours,

Martin

Dr Martin McShane

National Medical Director for Long Term Conditions



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Medical Directorate

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Executive assistant: [REDACTED]

Direct Dial: [REDACTED]

Email Address: [REDACTED] (section 40)

From: Mark Baker [REDACTED] (section 40)

Sent: 27 July 2015 09:53

To: McShane Martin (NHS ENGLAND)

Cc: Arnold Richard (NHS ENGLAND)

Subject: RE: Re NICE guidance for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME)

Dear Martin

Thank you for your letter.

As you know, we have a formal and regular surveillance programme for guidelines in which we review all the literature covering the guideline scope since the publication or previous update. CFS has been fully reviewed twice and no evidence was found which would justify updating the guideline. It is now on our static list and unlikely to be looked at again before 2018.

As there is no Quality Standard on CFS in the Library, we would not be giving priority to updating this guideline, even if evidence was found. Of course, that status is within the control of NHSE.

With special reference to GET and CBT, I am aware that some members of the Forward ME Group persistently claim that these treatments make some patients worse. However, we have looked specifically for evidence of this and have found none.

The situation therefore is that in the absence of new compelling evidence, and/or the inclusion of CFS in the Quality Standards library, we are unlikely to review this guideline for update before 2018.

Best wishes

Mark

From: McShane Martin (NHS ENGLAND) [REDACTED]
Sent: 21 July 2015 15:47
To: Mark Baker
Cc: Arnold Richard (NHS ENGLAND); McShane Martin (NHS ENGLAND)
Subject: Re NICE guidance for Chronic Fatigue Syndrome/Myalgic Encphalomyelitis (CFS/ME)

Dear Mark

Please find attached letter from Martin regarding NICE guidance for(CFS/ME).

With many thanks

[REDACTED]
Executive Assistant to Dr Martin McShane
Medical Director for Long Term Conditions
Medical Directorate
NHS England
5W25 | Quarry House | Quarry Hill | Leeds | LS2 7UE

Direct Dial: [REDACTED]
Email Address: [REDACTED]

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Janet Fahie

Subject: Report from NIH on CFS
Attachments: 2014 AHRQ Evidence Report Diagnosis and Treatment of Myalgic Encephalomyelitis-Chronic Fatigue Syndrome.pdf; 2015 NIH Beyond Myalgic Encephalomyelitis-Chronic Fatigue Syndrome. Redefining an Illness. Final report.pdf; 2015-08-18-19-recommendations CFS AC HHS.pdf; Mar re CFS 170915.pdf

Attachments 1 – 3 are exempt – section 21

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

Professor Mark R Baker
Director
Centre for Clinical Practice
The National Institute for Health and Care Excellence
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Trafalgar Square
London SW1A 2BU

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Medical Director for Long Term Conditions
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17 September 2015

Dr Martin McShane

US HHS chronic Fatigue Syndrome ADVISORY COMMITTEE – August 2015

On the basis of the principle that persistence is frequently the only way to make changes, may I draw your attention to this document – copy enclosed. I would particularly draw your attention to the Recommendations on pages 19 to 21. Paragraph e. on page 21 – “Clarification that counseling therapies are not treatments but may be helpful coping mechanisms; Declaration that the disease is not the result of fear-based avoidance of activity and that cognitive behaviour therapy (CBT) and graded exercise therapy (GET) for this purpose *are inappropriate* (my italics); Clear warning about the potential harms of graded exercise therapyFurther, treatment recommendations and clinical findings based on Oxford or Reeves definitions should no longer be applied to these patients.”

This report is the result of reports from the reports of two very widely respected US institutions. It is absolutely clear CBT and GET are inappropriate as treatments for ME/CFS. It is also clear that clinical findings on the basis of the Oxford criteria, those upon which the PACE trial was based, should not be applied to patients.

I have to assume that you must agree that patients with ME/CFS are very much the same wherever they are in the world, and that there will be no difference between UK and US patients. I also assume that you must agree that very many more resources have been applied to this issue in the US than in the UK. Professor Baker reiterates his belief that there is no evidence that GET makes some patients worse. Absence of evidence is not evidence of

COPY.

absence, and there is plenty of evidence from the two major charities in the UK – Action for ME and the ME Association, which have both done major surveys of their members, as well as the evidence quoted in my last letter.

I recognise that neither NHS England nor NICE have the resources to perform a complete review of CG 53. In the circumstances, I do not think it unreasonable that I ask you to consider that the Guideline CG53 be withdrawn before they do any further harm to patients.

I look forward to hearing from you.

Yours sincerely
Baroness

Countess of Mar

Copy to: Professor Mark Baker, NICE

Evidence Report/Technology Assessment

Number 219



Diagnosis and Treatment of Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome



Agency for Healthcare Research and Quality
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Evidence-Based
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Chronic Fatigue Syndrome Advisory Committee

The Chronic Fatigue Syndrome Advisory Committee (CFSAC) provides advice and recommendations to the Secretary of Health and Human Services (HHS) through the Assistant Secretary for Health on issues related to Myalgic Encephalomyelitis and Chronic Fatigue Syndrome (ME/CFS).

August 2015

Recommendations

From the

HHS Chronic Fatigue Syndrome ADVISORY COMMITTEE

Following Publication of:

INSTITUTE OF MEDICINE OF THE NATIONAL ACADEMIES BEYOND MYALGIC ENCEPHALOMYELITIS/CHRONIC FATIGUE SYNDROME: Redefining an Illness

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Sponsored by the U.S. Department of Health and Human Services Office on Women's Health, the National Institutes of Health, the Centers for Disease Control and Prevention, the Food and Drug Administration, the Agency for Healthcare Research and Quality, and the Social Security Administration

and

NATIONAL INSTITUTES OF HEALTH Pathways to Prevention Workshop: Advancing the Research on Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome

Co-sponsored by the NIH Office of Disease Prevention and the Trans-NIH Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) Research Working Group

Note: The term "ME/CFS" is used herein to correspond with terminology used in both reports.





Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness


ISBN
978-0-309-31689-7

330 pages
6 x 9
PAPERBACK (2015)

Committee on the Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome; Board on the Health of Select Populations; Institute of Medicine

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Surveillance Management Catch-up

24 September 2015

Decisions and actions

Attendees: SW, [REDACTED]

Apologies: [REDACTED]

1. Update on actions from last meeting - all actions are ongoing or were completed apart from the following:

Information removed – not within the scope of this FOI request

2. Report from NIH on CFS (SW)

- a. It was agreed that [REDACTED] would take a look at the information submitted by NIH to assess if it is enough to trigger a review and take the topic off the static list.

- b. **Action:** [REDACTED] *to review CFS challenge.*

Information in points 3 – 8 removed – not within the scope of the FOI request

Janet Fahie

Subject: Report from NIH on CFS

From: MAR, Countess [mailto:MARM@parliament.uk]
Sent: 25 September 2015 11:39
To: Mark Baker
Cc: Charles Shepherd
Subject: RE: Report from NIH on CFS

Dear Mark

Thank you.

I am sure that you are finding this to and fro correspondence as tedious as I do. There are matters that I would wish to raise with you that aren't really suited to this form of exchange. Do you think that it would help if we were to meet and get it all over in one go? I would like Dr Charles Shepherd of the ME Association to join us, if you agree. We are both available at 4.30 pm on Tuesday 3 November for tea in the Lords. If that is not suitable for you, I am sure we can find another mutually acceptable date.

I look forward to hearing from you.

With kind regards
Margaret

From: Mark Baker [REDACTED] (section 40)
Sent: 23 September 2015 11:21
To: MAR, Countess
Cc: [REDACTED]
Subject: RE: Report from NIH on CFS

Dear Margaret

We consider all English language research. We judge the research on a range of crib terra including relevance to the UK population and health care system. There is certainly no agreement within the UK that the currently recommended treatments are harmful.

Best wishes

Mark

From: MAR, Countess [mailto:MARM@parliament.uk]
Sent: 23 September 2015 10:52
To: Mark Baker [REDACTED] (section 40)
Cc: [REDACTED]

[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

Professor Mark R Baker
Director
Centre for Clinical Practice
The National Institute for Health and Care Excellence
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Janet Fahie

Subject: Report from NIH on CFS

From: Sarah Willett
Sent: 28 September 2015 08:19
To: [REDACTED]
Cc: [REDACTED]
Subject: RE: Report from NIH on CFS

Thanks [REDACTED]. We'll stick on agenda for next week.

S

From: [REDACTED]
Sent: 25 September 2015 13:05
To: Sarah Willett
Cc: [REDACTED]
Subject: RE: Report from NIH on CFS

Dear Sarah

I've had a look at this. There is a report from AHRQ (Dec 2014), which is a form of evidence review, a report from a committee established by IOM, that largely considered diagnostic criteria, and then a response to the latter report by a Health and Human Services cttee.

The key recommendations in the latter for us to think about are:

- Proposed diagnostic criteria, which differ significantly from the ones used in our guideline. In many ways these are more restrictive than our guideline, as part of the concern has been too many people being labelled as having ME/CFS
- However, they also recommend that these need to be used and validated within the next two years, so we cannot assume that they will automatically become a US or international consensus.
- Changing the name of the condition to SEID 'systemic exertion intolerance disease'. I don't know if their name will stick, it doesn't seem particularly memorable or specific to me.
- They make some statements about CBT and GET and this rec that I don't fully understand. **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.** I can't find a clear link back to the rationale for this, and I think it is a bit ambiguous. I think it means guidelines should be clear that the interventions are not aimed at altering something caused by fear-based avoidance of exercise, which presumably sufferers feel is something they are accused of.
- Perhaps the biggest challenge is that if the diagnostic criteria change then the inclusion criteria in research to date may not match, and so the evidence becomes less applicable. That would need careful consideration, but is hard to do until the criteria have undergone their 2 year validation and are universally accepted or revised.

Can we discuss what all this means for surveillance at a management catch up?

[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

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Cc: 'McShane Martin (NHS ENGLAND)'
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Best wishes

Mark

Professor Mark R Baker

Director

Centre for Clinical Practice

The National Institute for Health and Care Excellence

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Surveillance Management Catch-up

6 October 2015

Decisions and actions

Attendees: SW, [REDACTED] (note taker)

Apologies: none

1. Update on actions from last meeting - all actions are ongoing or were completed apart from the following:

Information removed – not within the scope of this FOI request

2. Report from NIH on CFS and what this means for surveillance – [REDACTED]

[REDACTED] had circulated his comments on the NIH report with the agenda. It was agreed that a full review was not required at this time as the proposed diagnostic criteria needed to undergo evaluation for 2 years. It was noted that CG53 CFS is on the static list and not due to be reviewed until Q4 2018-19. It was agreed that it should be checked in 2017 to see if any further information on the diagnostic criteria had been published.

Action: [REDACTED] to advise Mark Baker that a full review would not be required at this time.

Action: [REDACTED] to send the standard template for the response to [REDACTED]

Action: [REDACTED] to update the master spreadsheet to trigger a review in 2017.

Information in points 3 – 8 removed – not within the scope of the FOI request

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Surveillance programme

Clinical guideline

CG53: Chronic fatigue syndrome/myalgic encephalomyelitis

Publication date

August 2007

Previous review dates

August 2010

Current status

On static list (since February 2014)

Challenge to surveillance decision

A letter to the Centre for Clinical Practice Centre Director raised the 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.

Action taken

The Surveillance Team Clinical Adviser reviewed the three reports alongside the guideline and the current recommendations. A view on the impact of the reports on the guideline recommendations can be found in [Appendix 1](#). Feedback was also sought from the GDG Chair who indicated that they agreed with the approach to bring the surveillance review forward to 2017. They 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.

Surveillance recommendation

Through the evaluation of the US reports cited above, 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.

The Director of CCP had already decided that the surveillance review for CG53 should be brought forward to 2017. The proposal is to continue with that plan.

Key findings

		Potential impact on guidance	
		Yes	No
Evidence identified through challenge to surveillance decision		✓	
Feedback from Guideline Development Group Chair		✓	
Remain on static list	Transfer to active list	Change review cycle	
✓		✓	

Appendix 1

Summary of evidence	Impact on guideline recommendations
<p>The AHRQ report¹ concluded that:</p> <ul style="list-style-type: none"> • None of the current diagnostic methods have been adequately tested to identify patients with ME/CFS when diagnostic uncertainty exists. • Rintatolimod improves exercise performance in some patients (low strength of evidence) • counselling therapies and GET have broader benefit but have not been adequately tested in more disabled populations (low to moderate strength of evidence) • other treatments and harms have been inadequately studied (insufficient evidence). More definitive studies are needed to fill the many research gaps in diagnosing and treating ME/CFS. 	<p>There is no clear impact on the guideline recommendations for the following reasons:</p> <ul style="list-style-type: none"> • Changes to diagnostic criteria might have implications for the applicability of any research used to inform the current guideline. This report did not recommend a particular change. • Rintatolimod has been granted orphan designation (EU/3/15/1480) for the treatment of Ebola virus disease but has no license for the treatment of CFS/ME and would not usually be considered in a clinical guideline. • CG53 recommends individualised psychological therapy, and GET for people with mild or moderate CFS/ME.
<p>The IOM report² considered the diagnostic criteria for CFS/ME and proposed the following:</p> <p>Diagnosis requires that the patient have the following three symptoms:</p> <ol style="list-style-type: none"> 1. A substantial reduction or impairment in the ability to engage in preillness levels of occupational, educational, social, or personal activities that persists for more than 6 months and is accompanied by fatigue, which is often profound, is of new or definite onset (not lifelong), is not the result of ongoing excessive exertion, and is not substantially alleviated by rest, 2. Post-exertional malaise,* and 3. Unrefreshing sleep* <p>At least one of the two following manifestations is also required:</p> <ol style="list-style-type: none"> 1. Cognitive impairment* or 2. Orthostatic intolerance <p>* Frequency and severity of symptoms should be assessed. The diagnosis of ME/CFS should be questioned if patients do not have these symptoms at least half of the time with moderate, substantial, or severe intensity.</p>	<p>The proposals differ from the recommendations for features suggesting the possibility of ME/CFS in CG53 and from the approach to diagnosis in CG53. It is likely that the proposed criteria would also differ from the inclusion criteria for studies of interventions for people with ME/CFS. It is difficult to predict the effect this might have on the recommendations in CG53. However, it is worth noting that this is a proposal, and must be interpreted alongside the subsequent recommendations of the HHS Chronic Fatigue Syndrome Advisory Committee.</p>
<p>The report³ of the HHS Chronic Fatigue</p>	<p>If the recommendations of the report are</p>

<p>Syndrome Advisory Committee made a number of recommendations for a US audience on the need for further research in this field, particularly around</p> <ul style="list-style-type: none"> • biomarkers and objective diagnostic tests • gaps in basic, translational, clinical and epidemiological research to improve the understanding of the condition(s) • research on treatments for people meeting newly proposed diagnostic characteristics • standardised assessment and measurement tools <p>The Committee also made some amendments to the proposed diagnostic criteria in the IOM report, including changing “unrefreshing sleep” to “sleep disturbances”, added some features, expanded definitions, and recommended a period of two years’ validation of these.</p> <p>The report made a number of recommendations regarding treatment and care, but also recommended that clinical practice guidelines be developed.</p>	<p>followed, the proposed diagnostic criteria will have been evaluated by the end of 2017. It may be too early to try to interpret the implications of the proposed changes until then. Noting that the Committee recommendations differ from the proposal made by the IOM, it seems quite possible that further changes may occur as a result of validation.</p> <p>One of the recommendations on treatment and care called for a “Declaration that the disease is not the result of fear-based avoidance of activity and that cognitive behavioural therapy (CBT) and graded exercise therapy (GET) for this purpose are inappropriate”. CG53 recommends individualised use of these interventions, and does not recommend any particular assumptions about the cause of the disease. Therefore the impact of this statement is unclear.</p>
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Overall Impact

Taken together, these three reports may have important implications for the CFS/ME guideline, but there is a suggested two year validation of the proposed changes to diagnostic criteria and it would be premature to update the guidance until there is a consensus in the UK and preferably internationally about the adoption of the proposed changes. The new criteria may affect the interpretation of all preceding evidence that may have used different inclusion criteria for study participants. It is not possible to tell how this might affect the recommendations.

1. 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.
2. IOM (Institute of Medicine). 2015. Beyond myalgic encephalomyelitis/chronic fatigue syndrome: Redefining an illness. Washington, DC: The National Academies Press.
3. Recommendations from the HHS Chronic Fatigue Syndrome Advisory Committee. August 2015.

Janet Fahie

Subject: NICE guideline CG53: Chronic fatigue syndrome

From: [REDACTED] (section 40)

Sent: 28 October 2015 08:54

To: [REDACTED]

Subject: RE: NICE guideline CG53: Chronic fatigue syndrome

[REDACTED]

[REDACTED]

[REDACTED] (section 40)

Best wishes

[REDACTED]

[REDACTED] (section 40)

From: [REDACTED] (section 40)

Sent: 26 October 2015 07:50

To: [REDACTED] (section 40)

Subject: RE: NICE guideline CG53: Chronic fatigue syndrome

Dear [REDACTED],

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,

[redacted] (section 40)

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

Tel: [redacted]

Web: <http://nice.org.uk>

From: [redacted] (section 40)

Sent: 28 April 2015 13:37

To: [redacted]

Subject: RE: NICE guideline CG53: Chronic fatigue syndrome

[redacted]

[redacted]
(section 40)

[redacted]

[redacted]
(section 40)

[redacted]

[redacted] (section 40)

Best wishes

[redacted]

[redacted] (section 40)

From: [redacted] (section 40)

Sent: 21 April 2015 09:06

To: [redacted]

Subject: NICE guideline CG53: Chronic fatigue syndrome

Dear [REDACTED], (section 40)

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 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,
[REDACTED] (section 40)

[REDACTED]
National Institute for Health and Care Excellence
Level 1A | City Tower | Piccadilly Plaza | Manchester M1 4BD | United Kingdom
Tel: [REDACTED]
Web: <http://nice.org.uk>

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Janet Fahie

Subject: Report from NIH on CFS

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.

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)

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)

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

Professor Mark R Baker
Director
Centre for Clinical Practice
The National Institute for Health and Care Excellence
10 Spring Gardens
Trafalgar Square
London SW1A 2BU

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Janet Fahie

Subject: More from the US AHRQ

From: Sarah Willett
Sent: 05 September 2016 13:14
To: [REDACTED] (section 40)
Subject: RE: More from the US AHRQ

Thanks [REDACTED], can you log this.

Cheers

S

From: [REDACTED] (section 40)
Sent: 05 September 2016 12:11
To: Sarah Willett; [REDACTED]
Subject: RE: More from the US AHRQ

Hello

I've just responded on another CG53 enquiry to say that we will publish the update decision between October and December 2017 and work will start somewhere between January and March 2017.

Thanks
[REDACTED]

From: Sarah Willett
Sent: 05 September 2016 12:06
To: [REDACTED] (section 40)
Subject: RE: More from the US AHRQ

Thanks [REDACTED] If we have it already on the books for next year (which is bring it off the SL to look at early) then I think that's ok and Mark can respond that we will pick it up then. I don't think we need to bring it any more forward as you say.

[REDACTED] - can you confirm likely timing?

Thanks

S

From: [REDACTED] (section 40)
Sent: 05 September 2016 12:03
To: Sarah Willett; [REDACTED]
Subject: RE: More from the US AHRQ

It was the main report we looked at as part of the challenge. I see there's a new addendum. Want me to have a read? Not sure we can change our decision to speed up any more?

[REDACTED]

From: Sarah Willett
Sent: 05 September 2016 11:57
To: [REDACTED] (section 40)
Cc: [REDACTED]
Subject: FW: More from the US AHRQ

I think we said we would bring this forward and do a review next year haven't we because of all the noise and Mark previous suggestion. Can you confirm?

If not do we need to based on the enclosed.

Thanks

Sarah

From: Mark Baker
Sent: 05 September 2016 09:01
To: Sarah Willett
Subject: FW: More from the US AHRQ

Would this affect our decision on surveillance?

M

From: MAR, Countess [<mailto:MARM@parliament.uk>]
Sent: 26 August 2016 11:08
To: Mark Baker
Subject: More from the US AHRQ

Dear Mark

The AHRQ have added an annex to the report that I sent you earlier. They have conducted a systematic review of the evidence for CBT and GET and have withdrawn their advice on GET.

I hope that you are summering well. I hear you mentioned on a variety of topics on the radio, so clearly you are being kept busy.

Kind regards

Margaret

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Janet Fahie

Subject: FW: FOI enq ref EH73066 re CFS/ME guideline

From: [REDACTED]
Sent: 16 September 2016 11:58
To: [REDACTED]
Subject: RE: FOI enq ref EH73066 re CFS/ME guideline

Hi,

Amendments/discussions/impact of the biomedical findings in people with ME/CFS as detailed in the Canadian Consensus Criteria-2003, and the International Consensus Criteria-2011

An article was alluded to in the initial questionnaire asking whether there is new evidence suggesting that practice as recommended in the current guideline may not be best practice (*Jason et al. The development of a revised Canadian myalgic encephalomyelitis chronic fatigue syndrome case definition. American Journal of Biochemistry and Biotechnology, 2010; 6(2): 120-135*). The aim of this article was to specify explicit rules for determining whether critical symptoms meet ME/CFS criteria using a revised Canadian case definition. As we only looked at the abstract, the rules were not described and the study was not considered to impact on guideline recommendations.

I couldn't find anything specific on the Canadian Consensus Criteria-2003 or the International Consensus Criteria-2011 through a review of the audit document, consultation document or GE paper for the surveillance review. Stakeholders highlighted that a future review of the guideline should consider the diagnosis of CFS/ME (in particular, relating to case definitions, clinical utility of diagnostic tests and recommended blood tests) and this was noted in the GE paper.

Thanks,
[REDACTED]

From: [REDACTED]
Sent: 15 September 2016 18:06
To: [REDACTED]
Subject: RE: FOI enq ref EH73066 re CFS/ME guideline

Hello
Just a reminder on the following before you go on leave.
Cheers
[REDACTED]

From: [REDACTED]
Sent: 13 September 2016 12:08
To: Mark Baker; [REDACTED]
Cc: Sarah Willett
Subject: FW: FOI enq ref EH73066 re CFS/ME guideline
Importance: High

Dear all
Please see below. Can you please forward me any emails and documents relevant to the evidence listed below by 20 September. I'll sort the notes from our management meeting. I'll then collate/de-duplicate for Janet. If you need more time please let me know.

Thanks

2

As I don't have a feel for how many documents could be included I'm not sure how much time to allow for the identification of the information within the scope of the request. If you could let me have a general idea of the potential number of documents and time that it'll take to identify and retrieve them **by 20 September** I'd appreciate it.

Best wishes
Janet

Janet Fahie
Communications Executive, Corporate Communications
[REDACTED]

