National Institute for Health and Care Excellence

Final

Myalgic encephalomyelitis (or encephalopathy) / chronic fatigue syndrome: diagnosis and management

[J] Monitoring and reviewing people with ME/CFS

NICE guideline NG206

Evidence reviews underpinning recommendations and research recommendations in the NICE guideline

October 2021

Final

These evidence reviews were developed by the National Guideline Centre

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1 Monitoring and Review

1.1 Review question

What is the most clinically and cost-effective method of monitoring and reviewing people with ME/CFS?

1.1.1 Introduction

ME/CFS is a chronic complex, multisystem condition. Symptoms and clinical course can fluctuate with or without treatment interventions, making it difficult to have a fixed regime for the review of people with the illness. There is no established frequency, methodology or recording of monitoring or reviewing people with ME/CFS. Furthermore, the availability of ME/CFS specialist services in England and Wales means that review protocols are not consistent in the two countries. There is also a lack of consistency in recommendations for the diagnosis and management of the condition across European countries. Currently people are seen in ME/CFS specialist services for limited periods of time (usually 6 months to a year) and then discharged back to primary care. There is no clear guidance for primary care on follow up or monitoring. The current opportunistic approach for people with ME/CFS increases the risk that people will not be seen and in particular, that people most severally affected by ME/CFS will not be reviewed.

1.1.2 Summary of the protocol

For full details see the review protocol in Appendix A.

Table 1: PICO characteristics of review question

Population	Inclusion: Adults, children and young people who are diagnosed as having ME/CFS. Exclusion: Adults, children and young people with suspected ME/CFS
Interventions and comparisons	Any monitoring or reviewing strategies. These can be compared to each other or to a suitable comparator (i.e. no monitoring/review).
Outcomes	Longest follow up available: CRITICAL OUTCOMES: • Quality of life (any validated scales, for example, EQ-5D, SF-36) • Pain (VAS/NRS) • Fatigue/fatigability (any validated scales) • Physical functioning / exercise tolerance / ADL (any validated scales) • Cognitive functioning (any validated scales) • Sleep quality (any validated scales) • Adverse effects (any reported by the studies) • Psychological outcomes • Patient satisfaction • Benefit status/employment/school attendance/school absences • Update of diagnostic status • Comorbidities • Activity monitoring • Post exertional Malaise (PEM)/Post exertional symptom exacerbation (PESE)
Study design	• Systematic reviews • RCTs

	Non-randomised studies will be excluded unless no RCTs are found. If no RCTs are found non-randomised comparative trials will be considered (including prospective cohort studies) if they have attempted to detect, and if necessary adjust for, confounding.

1.1.3 Methods and process

This evidence review was developed using the methods and process described in Developing NICE guidelines: the manual. Methods specific to this review question are described in the review protocol in appendix A and the methods document.

Declarations of interest were recorded according to NICE's conflicts of interest policy.

1.1.4 Effectiveness evidence

1.1.4.1 Included studies

A search was conducted for randomised trials and non-randomised comparative studies comparing the effectiveness of monitoring and review strategies versus each other or a suitable comparator (that is,. no monitoring and review).

No relevant studies were identified.

1.1.4.2 Excluded studies

See the excluded studies list in Appendix L.

1.1.5 Summary of studies included in the effectiveness evidence

No relevant studies were identified.

1.1.6 Summary of the effectiveness evidence

No evidence was identified.

1.1.7 Call for evidence

See the methods document for detail on the process and methods for the call for evidence.

The committee identified monitoring and review as an area of the scope with a lack of published evidence and proposed a call for evidence to identify any relevant literature not identified in the searches. Submissions were received from 42 separate organisations or individuals, consisting of 508 reports or references to publications (after removal of duplicates). Of the submissions considered to be potentially relevant to this review question, all were excluded. For details why submitted evidence was not relevant see call for evidence excluded studies list in Appendix L.

1.1.8 Economic evidence

1.1.8.1 Included studies

No health economic studies were included.

1.1.8.2 Excluded studies

No relevant health economic studies were excluded due to assessment of limited applicability or methodological limitations.

See also the health economic study selection flow chart in Appendix I.

1.1.9 Economic model

This area was highlighted as a potential priority for new cost-effectiveness analysis. However, no clinical evidence was found on which to base a model.

1.1.10 Evidence statements

1.1.10.1 Effectiveness

- No relevant published evidence was identified.

1.1.10.2 Economic

- No relevant economic evaluations were identified.

1.2 The committee's discussion and interpretation of the evidence

The committee discussed this evidence with the findings from the reviews on Information for people with ME/CFS and their families and carers (report A), Information and Support for health and social care professionals (report B), access to care (report C), multidisciplinary care (report I) and the reports on Children and Young people (Appendix 1) and people with severe ME/CFS (Appendix 2). Where relevant, this is noted.

1.2.1 The outcomes that matter most

Quality of life, pain, fatigue/fatigability, physical functioning, cognitive functioning, sleep quality, adverse effects, psychological outcomes, patient satisfaction, benefit status, employment and educational attendance, diagnostic status, co-morbidities, activity monitoring and post exertional malaise were all agreed by the committee to be critical outcomes for decision making.

These outcomes reflect the direct impact ME/CFS symptoms have on a person (specifically levels of pain, fatigue, physical functioning cognitive functioning, sleep quality, psychological outcomes, post exertional malaise (PEM) , and in turn the impact on quality of life (specifically benefit status, employment and educational attendance).

The impact of the monitoring and review strategies can be measured by the outcomes listed above, if a strategy is successful symptoms would be managed appropriately and the impact on a person's life would be minimised compared to a strategy (including no review) that did not identify worsening symptoms.

The effectiveness of a strategy is also reflected in these outcomes: diagnostic status, co-morbidity identification, adverse effects and patient satisfaction. Diagnostic status and

comorbidity review and identification are key to ensuring that someone is receiving the correct intervention and management for their condition. If this is not picked up in a review this would have a detrimental impact on the person.

Any intervention for people with ME/CFS requiring contact with health and social care services is likely to affect their physical and emotional energy levels. It is key that any strategy should not make people with ME/CFS worse and strategies should ensure that they are able to access the service successfully. Measuring adverse effects and patient satisfaction address these concerns.

The committee acknowledged the lack of existing objective outcome measures of effectiveness of interventions for ME/CFS and the limitations of subjective measures (see Professor Edwards expert testimony – Appendix 3: Expert testimonies). Only validated outcome measurement scales were included in the evidence review.

1.2.2 The quality of the evidence

No evidence was identified in the review or the call for evidence.

1.2.3 Benefits and harms

The committee acknowledged there is a lack of evidence on monitoring and review strategies. However, the area is important to people with ME/CFS and providing guidance on monitoring and review is likely to improve the care delivered to people with ME/CFS. The committee made consensus recommendations informed by their own experience and evidence in other areas of the guideline.

Stakeholders in the scoping consultation highlighted that people with ME/CFS need to have regular monitoring and scheduled reviews of their health like all other people with a long term condition. This was described as an area of care that is inadequate and neglected in people with ME/CFS, people are lost to follow-up and do not receive appropriate support and care.

The committee noted that people with ME/CFS report little or no follow up care, monitoring or scheduled reviews. This is reflected in Evidence review C: Access to care and the reports on children and young people with ME/CFS (Appendix 1: Children and Young people), and people with severe ME/CFS (Appendix 2: People with severe ME/CFS). The majority of respondents with severe ME/CFS (41/60) reported not having any regular monitoring by any healthcare profession and 92% (55/60) have not had ongoing medical support for an illness (related or not related to ME/CFS). Poor experience of health and social care and lack of trust in health and social care services has resulted in people with ME/CFS not engaging with services and not receiving appropriate care or follow-up (see Evidence review C: Access to care).

The committee emphasised that inadequate or inappropriate follow up and review impacts not only on care related to ME/CFS but screening and assessment for other conditions and preventative care. This has the potential consequence of worsening of symptoms and overall deterioration in health.

Principles of monitoring and review

The committee agreed that although all adults with ME/CFS should be seen by specialist services initially to confirm diagnosis and the development of a personalised care and support plan, most will be primarily monitored and reviewed in primary care and this was reflected in the recommendations (section 1.15 Review in primary care). The committee noted that healthcare professionals reported a lack of confidence and ability to manage people with ME/CFS (see Evidence review B: Information for health and social care professionals and Dr Muirhead's related expert testimony in appendix 3), to address this they recommended training in this area but also noted that within primary care settings where

people with ME/CFS are not commonly seen that care across a primary care network might be appropriate.

The committee agreed a copy of the care and support plan and clinical communications from the ME/CFS specialist team, including (if relevant) discharge letters should be sent to the person's GP. These should be comprehensive and have a detailed plan for monitoring and review in primary care. Specialist input may be needed for some people on an ongoing basis, or intermittently, but the committee are aware of the significant delays that people can experience in accessing specialist services after re-referral from primary services.

The committee noted that written assessments, and reassessments, are important for accessing disability support. A scheduled review with a healthcare professional is an opportunity to provide people with ME/CFS medical evidence of disability for the purpose of claiming benefits and accessing support. Access to written assessments by healthcare professionals is essential in supporting communication between educational providers and a child or young person's family. Evidence from assessments increases understanding of the child or young person's capabilities and provides information on adjustments to help them stay in education. It is also important in providing information to a local authority about why a child or young person may have reduced or no school attendance.

The committee noted as with any part of providing care for people with ME/CFS it is vital to consider and discuss with the person the most appropriate way for them to participate in a review of their care. The ME/CFS population is underserved by health and social care services and this is explored in Evidence review C: Access to care and information and Evidence review A: Information and support for people with ME/CFS. The committee have made recommendations on accessing services (see section 1.3 of the guideline) and providing information for people with ME/CFS (see section 1.4 of the guideline).

The committee noted that review of care may be required by more than one professional depending on the person's situation, for example someone with severe or very severe ME/CFS and who is immobile will need assessments for contractures, and pressure ulcers as well as other more general aspects of review.

The committee considered that a scheduled review alongside advice on self-management and advice on who to contact in periods of worsening health could help people with ME/CFS to feel more supported and able to better self-manage in between reviews.

Review process

The committee considered that adults with ME/CFS would benefit from having a review of all aspects of their care at least annually. They acknowledged that not everyone might accept this and the need for an annual review will depend on the person's circumstances. Some people may not accept an annual review in primary care for various reasons, including involvement of secondary care services and attendance at other reviews or that the risk from the interaction is too great but the committee agreed it was important that people with ME/CFS were offered the opportunity to have care related to their ME/CFS reviewed at least once a year in line with other long term conditions.

The committee were clear that scheduled reviews (for both adults and children and young people) do not override the need for regular monitoring of symptoms and additional reviews in response to changing needs or episodes of acute illness. ME/CFS is a fluctuating medical condition that affects each person differently and can vary in symptom presentation and severity during the course of a day, week or longer. The impact of fluctuations can vary widely and can range from being severely debilitating to people being able to carry out most aspects of daily living. Additional monitoring and reviews may be needed for people with severe or very severe ME/CFS.

The committee added specific examples to the recommendations for children and young people. The committee discussed the needs of children and young people with ME/CFS

recognising that additional scheduled reviews may be necessary. They noted that when children and young people reach developmental milestones the understanding of their condition and management changes. During significant life changes (for example, school and college transitions, exam periods) more emotional and practical support may be required. After considering this the committee recommended that children and young people are offered a review of their care at least every six months.

The committee members working with children and young people with ME/CFS agreed that the process for monitoring and review is different from adults and needs to address the changing needs of children and young people as they develop. Supportive models of care, with primary care working alongside a specialist centre was described as one model of care that worked well. The committee members agreed that scheduled reviews for children and young people should be carried out by or overseen by a paediatrician with expertise in ME/CFS.

With particular reference to scheduled reviews, the committee observed that healthcare professionals should understand they are unlikely to see people at their worst because of the debilitating impact of their symptoms. These may prevent people from leaving their home, and if they have cognitive difficulties they may wait until they are able to speak and explain clearly before contacting services. Contacting services can cause symptoms to worsen, and people may not have the energy to expend on communication even when health or social care professionals are receptive. They may not contact professionals once they have improved because of the risk of making their symptoms worse. A comment in the report on People with severe ME/CFS (Appendix 2: People with severe ME/CFS) illustrates this: “any doctor visit makes me ill (even a home visit), so it is only worthwhile for a specific purpose.”

Content of a scheduled review

The committee reflected on the evidence (see Evidence review B: Information for health and social care professionals and Dr Muirhead’s related expert testimony in appendix 3) that health care professionals lack the knowledge and training to confidently manage the care of people with ME/CFS and agreed to provide guidance on areas that should be considered during a scheduled review. The committee considered this could also be a useful resource for carers and families when monitoring a person’s symptoms and health between scheduled reviews (see evidence report A: information for people with ME/CFS).

The committee were hesitant to recommend specific tools or checklists, as evidence for their use in the monitoring and review of people with ME/CFS has not been reviewed. They noted there are scales being developed to use with people with ME/CFS to evaluate symptoms.

The committee agreed that as a minimum providing guidance of areas to assess would ensure that relevant topics are discussed with people with ME/CFS. The committee considered this guidance works best as a framework. A list could make a consultation constrained and rigid and not responsive to the person and their needs. A list that takes a long time to complete may be counterproductive, people with ME/CFS may find the time and energy to complete a long assessment prohibitive and even damaging to their health. In addition, the committee were aware that primary care consultation appointments are commonly limited to 10 minutes and any assessment has to be realistic within these time frames.

The committee were keen to reinforce that any review of care should be personalised and take into account the person’s own experience of ME/CFS. The committee observed it was important that any review or assessment should not be done in isolation and there should be access to the person’s care and support plan and any related clinical communications from their ME/CFS specialised team this should be reviewed with the person considering the assessment.

The committee used their experience of undertaking assessments and reviews to recommend areas for discussion under the following headings.

Current condition and self-management

People should be asked about changes in their condition and the impact of any changes including what can and cannot be achieved. This is important to assess if someone has experienced any flare ups or relapses and if their condition is worsening impacting on their life. It is important to look at any self-management strategies, in particular those for energy management to see if the strategies are effective or need revising.

Symptoms

As well as asking about someone's current condition the committee considered it was important to ask directly about current symptoms and if these had changed or if any new ones had developed. Then the current management of symptoms should be assessed to see if any changes are needed. Th committee also considered that it is important to assess if any new symptoms or change in symptoms have been attributed to ME/CFS and evaluate if these need further investigation for other causes and conditions.

Current support

The committee noted that when people are asked how they are managing, they may respond they are managing well, for example carrying out activities of daily living, but not explain that these are only possible with support from family members. The committee considered this was particularly relevant in children and young people that may require considerable support from their parents but need further questioning to assess accurately how they are managing. This is important in identifying how much support a family may need. The committee were aware that the level of care provided by family members is often unrecognised or are they seen as partners in the healthcare team.

Psychological, emotional and social wellbeing

The committee considered that as part of any assessment someone should be asked about their psychological, emotional and social wellbeing and the impact of ME/CFS on their lives.

Any future plans

People should be asked if they are considering any changes in their lives, or there are any expected challenges anticipated. This can support effective planning with the aim of preventing any flare ups and relapses.

The committee discussed how other areas of health can be forgotten when reviewing someone with ME/CS. Aspects of care such as bone health and skin care may be neglected if there is a focus on specific disease processes only. This is particularly pertinent to people with ME/CFS and reduced mobility who should be assessed for osteoporosis, pressure sores and relevant NICE guidelines are referenced in the recommendations.

In addition to this list the committee wanted to raise awareness that if the scheduled review identified any issues for concern related to a person's ME/CFS then a referral to their contact in their ME/CFS specialist team should be made. The committee noted that some of the symptoms of ME/CFS are similar to other those in other conditions and can be erroneously put down to ME/CFS (for example, dizziness). They were aware of conditions that had been undiagnosed or misdiagnosed and as a consequence treatment had been neglected causing harm. The committee made a recommendation in the suspecting ME/CFS section of the guideline raising the awareness of the possibility of other conditions. The committee made a similar recommendation here to remind health care professionals to refer any issues identified in the scheduled review to appropriate specialists for evaluation.

1.2.4 Cost effectiveness and resource use

No economic evidence on monitoring and reviewing people with ME/CFS was found.

There was no quantitative evidence for the frequency of review and so cost effectiveness is uncertain.

ME/CFS is often a fluctuating condition and the impact on quality of life is considerable.[154] In the committee's experience and in line with the qualitative evidence, a lack of monitoring can be a barrier to the effective management of ME/CFS. Therefore, the committee agreed that offering follow up yearly for adults and twice yearly for children would be important for assessing worsening or changing of symptoms and modifying the patients' care plan and would be commensurate with other long-term conditions.

An analysis of general practice records found that people with ME/CFS have an average of 7 GP consultations a year,[97] so these recommendations are unlikely to have a substantial resource impact. However, the qualitative evidence in this guideline suggests that some people with ME/CFS, including those with severe or very severe ME/CFS, do not get a clinical review routinely, so for some this will be a change in practice.

The committee decided that it would be helpful to provide guidance on topics that may need review for people with ME/CFS.

Appendices

Appendix A Review protocol

Table 2: Review protocol for monitoring and review

ID	Field	Content
	Scope	Monitoring and review
	Draft review questions	What is the most clinically and cost-effective method of reviewing people with ME/CFS? What is the most clinically and cost-effective method of monitoring people with ME/CFS?
0.	PROSPERO registration number	-
1.	Review title	What is the most clinically and cost-effective method of monitoring/reviewing people with ME/CFS?
2.	Review question	What is the most clinically and cost-effective method of monitoring/reviewing people with ME/CFS?
3.	Objective	To identify the most clinically and cost effective form of monitoring/reviewing to improve outcomes in adults and children with a diagnosis of ME/CFS.
4.	Searches	The following databases will be searched: • Cochrane Central Register of Controlled Trials (CENTRAL) • Cochrane Database of Systematic Reviews (CDSR) • Embase

		• MEDLINE • Cinahl Searches will be restricted by: • English language studies • Human studies • Letters and comments are excluded. Other searches: • Inclusion lists of relevant systematic reviews will be checked by the reviewer. The searches may be re-run 6 weeks before final committee meeting and further studies retrieved for inclusion if relevant. The full search strategies will be published in the final review.
5.	Condition or domain being studied	ME / CFS
6.	Population	Inclusion: Adults, children and young people who are diagnosed as having ME/CFS. Exclusion: Adults, children and young people with suspected ME/CFS
7.	Intervention/Exposure/Test	

8.	Comparator/Reference standard/Confounding factors	Any monitoring/reviewing strategies evaluated by the eligible literature. These can be compared to each other or to a suitable comparator (i.e. no monitoring/review).
9.	Types of study to be included	• Systematic reviews • RCTs Non-randomised studies will be excluded unless no RCTs are found. If no RCTs are found non-randomised comparative trials will be considered (including prospective cohort studies) if they have attempted to detect, and if necessary adjust for, confounding.
10.	Other exclusion criteria	Non-English language studies. Conference abstracts will be excluded as it is expected there will be sufficient full text published studies available.
11.	Context	N/A
12.	Primary outcomes (critical outcomes)	Longest follow up available: CRITICAL OUTCOMES: • Quality of life (any validated scales, for example, EQ-5D, SF-36) • Pain (VAS/NRS) • Fatigue (any validated scales) • Physical functioning / exercise tolerance / ADL (any validated scales) • Cognitive functioning (any validated scales) • Sleep quality (any validated scales) • Adverse effects (any reported by the studies) • Psychological outcomes • Patient satisfaction • Benefit status/employment/school attendance/school absences

		• Update of diagnostic status • Comorbidities • Activity monitoring • post exertional symptom exacerbation
13.	Secondary outcomes (important outcomes)	• Care needs • Impact on the carer/family
14.	Data extraction (selection and coding)	EndNote will be used for reference management, sifting, citations and bibliographies. Titles and/or abstracts of studies retrieved using the search strategy and those from additional sources will be screened for inclusion. The full text of potentially eligible studies will be retrieved and will be assessed for eligibility in line with the criteria outlined above. 10% of the abstracts will be reviewed by two reviewers, with any disagreements resolved by discussion or, if necessary, a third independent reviewer. An in-house developed database; EviBase, will be used for data extraction. A standardised form is followed to extract data from studies (see Developing NICE guidelines: the manual section 6.4) and for undertaking assessment of study quality. Summary evidence tables will be produced including information on: study setting; study population and participant demographics and baseline characteristics; details of the intervention and control interventions; study methodology' recruitment and missing data rates; outcomes and times of measurement; critical appraisal ratings.
15.	Risk of bias (quality) assessment	Risk of bias will be assessed using the appropriate checklist as described in Developing NICE guidelines: the manual.

		For Intervention reviews the following checklist will be used according to study design being assessed: • Systematic reviews: Risk of Bias in Systematic Reviews (ROBIS) • Randomised Controlled Trial: Cochrane RoB (2.0) 10% of all evidence reviews are quality assured by a senior research fellow. This includes checking: papers were included /excluded appropriately a sample of the data extractions correct methods are used to synthesise data a sample of the risk of bias assessments Disagreements between the review authors over the risk of bias in particular studies will be resolved by discussion, with involvement of a third review author where necessary.
16.	Strategy for data synthesis	Where possible, data will be meta-analysed. Pairwise meta-analyses will be performed using Cochrane Review Manager (RevMan5) to combine the data given in all studies for each of the outcomes stated above. A fixed effect meta-analysis, with weighted mean differences for continuous outcomes and risk ratios for binary outcomes will be used, and 95% confidence intervals will be calculated for each outcome. Heterogeneity between the studies in effect measures will be assessed using the I^2 statistic and visually inspected. We will consider an I^2 value greater than 50% indicative of substantial heterogeneity. Sensitivity analyses will be conducted based on pre-specified subgroups using stratified meta-analysis to explore the heterogeneity in effect estimates. If this does not explain the heterogeneity, the results will be presented using random-effects.

		GRADE pro will be used to assess the quality of each outcome, taking into account individual study quality and the meta-analysis results. The 4 main quality elements (risk of bias, indirectness, inconsistency and imprecision) will be appraised for each outcome. If the population included in an individual study includes children aged under 12, it will be included if the majority of the population is aged over 12, and downgraded for indirectness if the overlap into those aged less than 12 is greater than 20%. Publication bias is tested for when there are more than 5 studies for an outcome. Other bias will only be taken into consideration in the quality assessment if it is apparent. Where meta-analysis is not possible, data will be presented and quality assessed individually per outcome. If sufficient data is available to make a network of treatments, WinBUGS will be used for network meta-analysis.
17.	Analysis of sub-groups	Stratification: • Age: children vs young people vs adults • Severity: severe vs not severe Subgroups to investigate if heterogeneity is present: • post infectious onset / no post infectious onset • Duration of illness (<3 months symptoms/3-36 months/>36 months) • Gender • When study was done (pre 2000/post 2000)

18.	Type and method of review	☒ Intervention ☐ Diagnostic ☐ Prognostic ☐ Qualitative ☐ Epidemiologic ☐ Service Delivery ☐ Other (please specify)		
19.	Language	English		
20.	Country	England		
21.	Anticipated or actual start date	01/01/20		
22.	Anticipated completion date	01/01/21		
23.	Stage of review at time of this submission	**Review stage**	**Started**	**Completed**
		Preliminary searches	☑	☐
		Piloting of the study selection process	☑	☐
		Formal screening of search results	☐	☐

		against eligibility criteria		
		Data extraction	☐	☐
		Risk of bias (quality) assessment	☐	☐
		Data analysis	☐	☐
24.	Named contact	**5a. Named contact** National Guideline Centre **5b Named contact e-mail** **5e Organisational affiliation of the review** National Institute for Health and Care Excellence (NICE) and the National Guideline Centre		
25.	Review team members	From the National Guideline Centre: • Dr Kate Kelley [Guideline lead] • Ms Maria Smyth [Senior systematic reviewer] • Ms Melina Vasileiou [Systematic reviewer] • Dr Richard Clubbe [Systematic reviewer] • Dr Karin van Bart [Systematic reviewer]		

		• Mr David Wonderling [Health economist] • Ms Agnes Cuyas [Information specialist] • Ms Kate Ashmore [Project manager]
26.	Funding sources/sponsor	This systematic review is being completed by the National Guideline Centre which receives funding from NICE.
27.	Conflicts of interest	All guideline committee members and anyone who has direct input into NICE guidelines (including the evidence review team and expert witnesses) must declare any potential conflicts of interest in line with NICE's code of practice for declaring and dealing with conflicts of interest. Any relevant interests, or changes to interests, will also be declared publicly at the start of each guideline committee meeting. Before each meeting, any potential conflicts of interest will be considered by the guideline committee Chair and a senior member of the development team. Any decisions to exclude a person from all or part of a meeting will be documented. Any changes to a member's declaration of interests will be recorded in the minutes of the meeting. Declarations of interests will be published with the final guideline.
28.	Collaborators	Development of this systematic review will be overseen by an advisory committee who will use the review to inform the development of evidence-based recommendations in line with section 3 of Developing NICE guidelines: the manual. Members of the guideline committee are available on the NICE website: https://www.nice.org.uk/guidance/indevelopment/gid-ng10091
29.	Other registration details	
30.	Reference/URL for published protocol	
31.	Dissemination plans	NICE may use a range of different methods to raise awareness of the guideline. These include standard approaches such as: • notifying registered stakeholders of publication

		• publicising the guideline through NICE's newsletter and alerts • issuing a press release or briefing as appropriate, posting news articles on the NICE website, using social media channels, and publicising the guideline within NICE.
32.	Keywords	
33.	Details of existing review of same topic by same authors	N/A
34.	Current review status	☒ Ongoing ☐ Completed but not published ☐ Completed and published ☐ Completed, published and being updated ☐ Discontinued
35..	Additional information	N/A
36.	Details of final publication	www.nice.org.uk

Table 3: Health economic review protocol

Review question	All questions – health economic evidence

Objectives	To identify health economic studies relevant to any of the review questions.
Search criteria	• Populations, interventions and comparators must be as specified in the clinical review protocol above. • Studies must be of a relevant health economic study design (cost–utility analysis, cost-effectiveness analysis, cost–benefit analysis, cost–consequences analysis, comparative cost analysis). • Studies must not be a letter, editorial or commentary, or a review of health economic evaluations. (Recent reviews will be ordered although not reviewed. The bibliographies will be checked for relevant studies, which will then be ordered.) • Unpublished reports will not be considered unless submitted as part of a call for evidence. • Studies must be in English.
Search strategy	A health economic study search will be undertaken using population-specific terms and a health economic study filter – see appendix B below.
Review strategy	Studies not meeting any of the search criteria above will be excluded. Studies published before 2004, abstract-only studies and studies from non-OECD countries or the USA will also be excluded. Each remaining study will be assessed for applicability and methodological limitations using the NICE economic evaluation checklist which can be found in appendix H of Developing NICE guidelines: the manual (2014).[319] **Inclusion and exclusion criteria** • If a study is rated as both 'Directly applicable' and with 'Minor limitations' then it will be included in the guideline. A health economic evidence table will be completed and it will be included in the health economic evidence profile. • If a study is rated as either 'Not applicable' or with 'Very serious limitations' then it will usually be excluded from the guideline. If it is excluded then a health economic evidence table will not be completed and it will not be included in the health economic evidence profile. • If a study is rated as 'Partially applicable', with 'Potentially serious limitations' or both then there is discretion over whether it should be included. **Where there is discretion** The health economist will make a decision based on the relative applicability and quality of the available evidence for that question, in discussion with the guideline committee if required. The ultimate aim is to include health economic studies that are helpful for decision-making in the context of the guideline and the current NHS setting. If several studies are considered of sufficiently high applicability and methodological quality that they could all be included, then the health economist, in discussion with the committee if required, may decide to include only the most applicable studies and to selectively exclude the remaining studies. All studies excluded on the basis of applicability or methodological limitations will be listed with explanation in the excluded health economic studies appendix below. The health economist will be guided by the following hierarchies.

	Setting: • UK NHS (most applicable). • OECD countries with predominantly public health insurance systems (for example, France, Germany, Sweden). • OECD countries with predominantly private health insurance systems (for example, Switzerland). • Studies set in non-OECD countries or in the USA will be excluded before being assessed for applicability and methodological limitations. *Health economic study type:* • Cost–utility analysis (most applicable). • Other type of full economic evaluation (cost–benefit analysis, cost-effectiveness analysis, cost–consequences analysis). • Comparative cost analysis. • Non-comparative cost analyses including cost-of-illness studies will be excluded before being assessed for applicability and methodological limitations. *Year of analysis:* • The more recent the study, the more applicable it will be. • Studies published in 2004 or later but that depend on unit costs and resource data entirely or predominantly from before 2004 will be rated as 'Not applicable'. • Studies published before 2004 will be excluded before being assessed for applicability and methodological limitations. *Quality and relevance of effectiveness data used in the health economic analysis:* • The more closely the clinical effectiveness data used in the health economic analysis match with the outcomes of the studies included in the clinical review the more useful the analysis will be for decision-making in the guideline.

Appendix B Literature search strategies

This literature search strategy was used for the following review question:

- What is the most clinically and cost-effective method of monitoring and reviewing people with ME/CFS?

The literature searches for this review are detailed below and complied with the methodology outlined in Developing NICE guidelines: the manual.[319]

For more information, please see the Methodology review published as part of the accompanying documents for this guideline.

B.1 Clinical search literature search strategy

Searches were constructed using a PICO framework where population (P) terms were combined with Intervention (I) and in some cases Comparison (C) terms. Outcomes (O) are rarely used in search strategies for interventions as these concepts may not be well described in title, abstract or indexes and therefore difficult to retrieve.

Searches for patient views were run in Medline (OVID), Embase (OVID), CINAHL, and PsycINFO (ProQuest).

Table 4: Database date parameters and filters used

Database	Dates searched	Search filter used
Medline (OVID)	1946 – 23 June 2020	Exclusions
Embase (OVID)	1974 – 23 June 2020	Exclusions
The Cochrane Library (Wiley)	Cochrane Reviews to 2020 Issue 6 of 12 CENTRAL to 2020 Issue 6 of 12	None
CINAHL, Current Nursing and Allied Health Literature (EBSCO)	Inception – 23 June 2020	None
PsycINFO (ProQuest)	Inception – 23 June 2020	Exclusions
Epistemonikos (The Epistemonikos Foundation)	Inception - 23 June 2020	None

Medline (Ovid) search terms

1.	Fatigue Syndrome, Chronic/
2.	chronic* fatigue*.ti,ab.
3.	(fatigue* adj2 (disorder* or syndrome* or post viral or postviral or immune dysfunction* or post infection* or postinfection*)).ti,ab.
4.	((myalgic or post infection* or postinfection*) adj (encephalomyelitis or encephalopathy)).ti,ab.
5.	((ME adj CFS) or (CFS adj ME) or CFIDS or PVFS).ti,ab.
6.	(Systemic Exertion Intolerance Disease or SEID).ti,ab.
7.	((CFS adj SEID) or (SEID adj CFS) or (ME adj CFS adj SEID) or (ME adj SEID) or (SEID adj ME)).ti,ab.
8.	((Orthostatic intolerance or postural orthostatic tachycardia syndrome or postural tachycardia syndrome or POTS) adj6 (CFS or chronic* fatigue* or ME or myalgic or SEID or systemic exertion)).ti,ab.

9.	((Post-exertional or postexertional) adj2 malaise).ti,ab.
10.	(neurasthenic neuroses or epidemic neuromyasthenia or neurataxia or neuroasthenia or neurasthenia).ti,ab.
11.	((atypical or simulating or resembling) adj poliomyelitis).ti,ab.
12.	((chronic adj2 epstein Barr virus) or CEBV or CAEBV or chronic mononucleosis).ti,ab.
13.	xenotropic murine leukemia virus-related virus.ti,ab.
14.	effort syndrome*.ti,ab.
15.	(((akureyri or iceland or tapanui or royal free or royal free hospital) adj disease*) or ((yuppie or yuppy or tapanui) adj flu)).ti,ab.
16.	or/1-15
17.	letter/
18.	editorial/
19.	news/
20.	exp historical article/
21.	Anecdotes as Topic/
22.	comment/
23.	case report/
24.	(letter or comment*).ti.
25.	or/17-24
26.	randomized controlled trial/ or random*.ti,ab.
27.	25 not 26
28.	animals/ not humans/
29.	exp Animals, Laboratory/
30.	exp Animal Experimentation/
31.	exp Models, Animal/
32.	exp Rodentia/
33.	(rat or rats or mouse or mice).ti.
34.	or/27-33
35.	16 not 34
36.	limit 35 to English language

Embase (Ovid) search terms

1.	chronic fatigue syndrome/
2.	chronic* fatigue*.ti,ab.
3.	(fatigue* adj2 (disorder* or syndrome* or post viral or postviral or immune dysfunction* or post infection* or postinfection*)).ti,ab.
4.	((myalgic or post infection* or postinfection*) adj (encephalomyelitis or encephalopathy)).ti,ab.
5.	((ME adj CFS) or (CFS adj ME) or CFIDS or PVFS).ti,ab.
6.	(Systemic Exertion Intolerance Disease or SEID).ti,ab.
7.	((CFS adj SEID) or (SEID adj CFS) or (ME adj CFS adj SEID) or (ME adj SEID) or (SEID adj ME)).ti,ab.
8.	((Orthostatic intolerance or postural orthostatic tachycardia syndrome or postural tachycardia syndrome or POTS) adj6 (CFS or chronic* fatigue* or ME or myalgic or SEID or systemic exertion)).ti,ab.
9.	((Post-exertional or postexertional) adj2 malaise).ti,ab.
10.	(neurasthenic neuroses or epidemic neuromyasthenia or neurataxia or neuroasthenia or neurasthenia).ti,ab.

11.	((atypical or simulating or resembling) adj poliomyelitis).ti,ab.
12.	((chronic adj2 epstein Barr virus) or CEBV or CAEBV or chronic mononucleosis).ti,ab.
13.	xenotropic murine leukemia virus-related virus.ti,ab.
14.	effort syndrome*.ti,ab.
15.	(((akureyri or iceland or tapanui or royal free or royal free hospital) adj disease*) or ((yuppie or yuppy or tapanui) adj flu)).ti,ab.
16.	or/1-15
17.	letter.pt. or letter/
18.	note.pt.
19.	editorial.pt.
20.	case report/ or case study/
21.	(letter or comment*).ti.
22.	or/17-21
23.	randomized controlled trial/ or random*.ti,ab.
24.	22 not 23
25.	animal/ not human/
26.	nonhuman/
27.	exp Animal Experiment/
28.	exp Experimental Animal/
29.	animal model/
30.	exp Rodent/
31.	(rat or rats or mouse or mice).ti.
32.	or/24-31
33.	16 not 32
34.	limit 33 to English language

Cochrane Library (Wiley) search terms

#1.	MeSH descriptor: [Fatigue Syndrome, Chronic] this term only
#2.	chronic* fatigue*:ti,ab
#3.	(fatigue* near/2 (disorder* or syndrome* or post viral or postviral or immune dysfunction* or post infection* or postinfection*)):ti,ab
#4.	((myalgic or post infection* or postinfection*) near/1 (encephalomyelitis or encephalopathy)):ti,ab
#5.	((ME near/1 CFS) or (CFS near/1 ME) or CFIDS or PVFS):ti,ab
#6.	(Systemic Exertion Intolerance Disease or SEID):ti,ab
#7.	((CFS near/1 SEID) or (SEID near/1 CFS) or (ME near/1 CFS near/1 SEID) or (ME near/1 SEID) or (SEID near/1 ME)):ti,ab
#8.	(Orthostatic intolerance or postural orthostatic tachycardia syndrome or postural tachycardia syndrome or POTS)
#9.	((Post-exertional or postexertional) near/2 malaise):ti,ab
#10.	(neurasthenic neuroses or epidemic neuromyasthenia or neurataxia or neuroasthenia or neurasthenia):ti,ab
#11.	((atypical or simulating or resembling) near/1 poliomyelitis):ti,ab
#12.	((chronic epstein Barr virus) or CEBV or CAEBV or chronic mononucleosis):ti,ab
#13.	xenotropic murine leukemia virus-related virus:ti,ab
#14.	effort syndrome*:ti,ab
#15.	((akureyri or iceland or tapanui or "royal free" or "royal free hospital") near/1 disease*):ti,ab

#16.	((yuppie or yuppy or tapanui) near flu):ti,ab
#17.	(or #1-#16)

CINAHL (EBSCO) search terms

S1.	(MH "Fatigue Syndrome, Chronic")
S2.	chronic* fatigue*
S3.	(fatigue* n2 (disorder* or syndrome* or post viral or postviral or immune dysfunction* or post infection* or postinfection*))
S4.	((myalgic or post infection* or postinfection*) and (encephalomyelitis or encephalopathy))
S5.	((ME and CFS) or (CFS and ME) or CFIDS or PVFS)
S6.	(Systemic Exertion Intolerance Disease or SEID)
S7.	((CFS and SEID) or (SEID and CFS) or (ME and CFS and SEID) or (CFS and ME and SEID) or (ME and SEID) or (SEID and ME))
S8.	((Orthostatic intolerance or postural orthostatic tachycardia syndrome or postural tachycardia syndrome) and (CFS or chronic* fatigue* or ME or myalgic or SEID or systemic exertion))
S9.	((Post-exertional or postexertional) n2 malaise)
S10.	(neurasthenic neuroses or epidemic neuromyasthenia or neurataxia or neuroasthenia)
S11.	((atypical or simulating or resembling) and poliomyelitis)
S12.	(chronic epstein Barr virus or chronic mononucleosis)
S13.	xenotropic murine leukemia virus-related virus
S14.	effort syndrome*
S15.	(((akureyri or iceland or tapanui or royal free or royal free hospital) and disease*) or ((yuppie or yuppy or tapanui) and flu))
S16.	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15

PsycINFO (ProQuest) search terms

1.	((((chronic* fatigue*) OR (fatigue* NEAR2 (disorder* OR syndrome* OR post viral OR postviral OR immune dysfunction* OR post infection* OR postinfection*)) OR ((myalgic OR post infection* OR postinfection*) NEAR1 (encephalomyelitis OR encephalopathy)) OR ((ME NEAR1 CFS) OR (CFS NEAR1 ME) OR CFIDS OR PVFS) OR (Systemic Exertion Intolerance Disease OR SEID) OR ((CFS NEAR1 SEID) OR (SEID NEAR1 CFS)) OR ((ME NEAR1 CFS NEAR1 SEID) OR (ME NEAR1 SEID) OR (SEID NEAR1 ME)) OR ((Orthostatic intolerance OR postural orthostatic tachycardia syndrome OR postural tachycardia syndrome OR POTS) NEAR6 (CFS OR chronic* fatigue* OR ME OR myalgic OR SEID OR systemic exertion)) OR (neurasthenic neuroses OR epidemic neuromyasthenia OR neurataxia OR neuroasthenia OR neurasthenia) OR ((atypical OR simulating OR resembling) NEAR1 poliomyelitis)) OR (((chronic NEAR2 epstein Barr virus) OR CEBV OR CAEBV OR chronic mononucleosis) OR (xenotropic murine leukemia virus-related virus) OR (effort syndrome*) OR ((akureyri OR iceland OR tapanui OR royal free OR royal free hospital) NEAR1 disease*) OR ((yuppie OR yuppy OR tapanui) NEAR1 flu) OR MAINSUBJECT.EXACT.EXPLODE("Chronic Fatigue Syndrome"))) AND (stype.exact("Scholarly Journals") AND la.exact("ENG") AND po.exact("Human") NOT (me.exact("Empirical Study" OR "Quantitative Study" OR "Longitudinal Study" OR "Clinical Trial" OR "Qualitative Study" OR "Prospective Study" OR "Followup Study" OR "Literature Review" OR "Retrospective Study" OR "Systematic Review" OR "Meta Analysis") AND po.exact("Human"))

Epistemonikos search terms

1.	(advanced_title_en:((advanced_title_en:((chronic* fatigue* syndrome*) OR (fatigue* syndrome* OR fatigue* disorder* OR postviral fatigue* OR post viral fatigue* OR fatigue* immune dysfunction OR post infection fatigue* OR postinfection fatigue*) OR (encephalomyelitis OR encephalopathy) OR ("ME/CFS" OR "CFS/ME" OR "CFIDS"

	OR "PVFS") OR (Systemic Exertion Intolerance Disease OR SEID) OR ((CFS AND SEID) OR (SEID AND CFS) OR (ME AND CFS AND SEID) OR (ME AND SEID) OR (SEID AND ME)) OR (Orthostatic intolerance OR postural orthostatic tachycardia syndrome OR postural tachycardia syndrome OR POTS) OR ((Post-exertional OR postexertional) AND malaise) OR (neurasthenic neuroses OR epidemic neuromyasthenia OR neurataxia OR neuroasthenia OR neurasthenia) OR (atypical poliomyelitis OR simulating poliomyelitis OR resembling poliomyelitis) OR (chronic epstein Barr virus OR CEBV OR CAEBV OR chronic mononucleosis) OR (xenotropic murine leukemia virus-related virus) OR (effort syndrome*) OR (akureyri OR iceland disease OR tapanui OR royal free disease) OR (yuppie flu OR yuppy flu OR tapanui flu)) OR advanced_abstract_en:((chronic* fatigue* syndrome*) OR (fatigue* syndrome* OR fatigue* disorder* OR postviral fatigue* OR post viral fatigue* OR fatigue* immune dysfunction OR post infection fatigue* OR postinfection fatigue*) OR (encephalomyelitis OR encephalopathy) OR ("ME/CFS" OR "CFS/ME" OR "CFIDS" OR "PVFS") OR (Systemic Exertion Intolerance Disease OR SEID) OR ((CFS AND SEID) OR (SEID AND CFS) OR (ME AND CFS AND SEID) OR (ME AND SEID) OR (SEID AND ME)) OR (Orthostatic intolerance OR postural orthostatic tachycardia syndrome OR postural tachycardia syndrome OR POTS) OR ((Post-exertional OR postexertional) AND malaise) OR (neurasthenic neuroses OR epidemic neuromyasthenia OR neurataxia OR neuroasthenia OR neurasthenia) OR (atypical poliomyelitis OR simulating poliomyelitis OR resembling poliomyelitis) OR (chronic epstein Barr virus OR CEBV OR CAEBV OR chronic mononucleosis) OR (xenotropic murine leukemia virus-related virus) OR (effort syndrome*) OR (akureyri OR iceland disease OR tapanui OR royal free disease) OR (yuppie flu OR yuppy flu OR tapanui flu)))) OR advanced_abstract_en:((advanced_title_en:((chronic* fatigue* syndrome*) OR (fatigue* syndrome* OR fatigue* disorder* OR postviral fatigue* OR post viral fatigue* OR fatigue* immune dysfunction OR post infection fatigue* OR postinfection fatigue*) OR (encephalomyelitis OR encephalopathy) OR ("ME/CFS" OR "CFS/ME" OR "CFIDS" OR "PVFS") OR (Systemic Exertion Intolerance Disease OR SEID) OR ((CFS AND SEID) OR (SEID AND CFS) OR (ME AND CFS AND SEID) OR (ME AND SEID) OR (SEID AND ME)) OR (Orthostatic intolerance OR postural orthostatic tachycardia syndrome OR postural tachycardia syndrome OR POTS) OR ((Post-exertional OR postexertional) AND malaise) OR (neurasthenic neuroses OR epidemic neuromyasthenia OR neurataxia OR neuroasthenia OR neurasthenia) OR (atypical poliomyelitis OR simulating poliomyelitis OR resembling poliomyelitis) OR (chronic epstein Barr virus OR CEBV OR CAEBV OR chronic mononucleosis) OR (xenotropic murine leukemia virus-related virus) OR (effort syndrome*) OR (akureyri OR iceland disease OR tapanui OR royal free disease) OR (yuppie flu OR yuppy flu OR tapanui flu)) OR advanced_abstract_en:((chronic* fatigue* syndrome*) OR (fatigue* syndrome* OR fatigue* disorder* OR postviral fatigue* OR post viral fatigue* OR fatigue* immune dysfunction OR post infection fatigue* OR postinfection fatigue*) OR (encephalomyelitis OR encephalopathy) OR ("ME/CFS" OR "CFS/ME" OR "CFIDS" OR "PVFS") OR (Systemic Exertion Intolerance Disease OR SEID) OR ((CFS AND SEID) OR (SEID AND CFS) OR (ME AND CFS AND SEID) OR (ME AND SEID) OR (SEID AND ME)) OR (Orthostatic intolerance OR postural orthostatic tachycardia syndrome OR postural tachycardia syndrome OR POTS) OR ((Post-exertional OR postexertional) AND malaise) OR (neurasthenic neuroses OR epidemic neuromyasthenia OR neurataxia OR neuroasthenia OR neurasthenia) OR (atypical poliomyelitis OR simulating poliomyelitis OR resembling poliomyelitis) OR (chronic epstein Barr virus OR CEBV OR CAEBV OR chronic mononucleosis) OR (xenotropic murine leukemia virus-related virus) OR (effort syndrome*) OR (akureyri OR iceland disease OR tapanui OR royal free disease) OR (yuppie flu OR yuppy flu OR tapanui flu)))))

B.2 Health economics literature search strategy

Health economic evidence was identified by conducting a broad search relating to ME/CFS population in NHS Economic Evaluation Database (NHS EED – this ceased to be updated after March 2015) and the Health Technology Assessment database (HTA – this ceased to be updated after March 2018), with no date restrictions. NHS EED and HTA databases are

hosted by the Centre for Research and Dissemination (CRD). Additional searches were run on Medline and Embase for health economics.

Table 5: Database date parameters and filters used

Database	Dates searched	Search filter used
Medline	2014 – 30 June 2020	Exclusions Health economics studies
Embase	2014 –30 June 2020	Exclusions Health economics studies
Centre for Research and Dissemination (CRD)	HTA - 2003 – 31 March 2018 NHSEED - 2003 to 31 March 2015	None

Medline (Ovid) search terms

1.	Fatigue Syndrome, Chronic/
2.	chronic* fatigue*.ti,ab.
3.	(fatigue* adj2 (disorder* or syndrome* or post viral or postviral or immune dysfunction* or post infection* or postinfection*)).ti,ab.
4.	((myalgic or post infection* or postinfection*) adj (encephalomyelitis or encephalopathy)).ti,ab.
5.	((ME adj CFS) or (CFS adj ME) or CFIDS or PVFS).ti,ab.
6.	(Systemic Exertion Intolerance Disease or SEID).ti,ab.
7.	((CFS adj SEID) or (SEID adj CFS) or (ME adj CFS adj SEID) or (ME adj SEID) or (SEID adj ME)).ti,ab.
8.	((Orthostatic intolerance or postural orthostatic tachycardia syndrome or postural tachycardia syndrome or POTS) adj6 (CFS or chronic* fatigue* or ME or myalgic or SEID or systemic exertion)).ti,ab.
9.	((Post-exertional or postexertional) adj2 malaise).ti,ab.
10.	(neurasthenic neuroses or epidemic neuromyasthenia or neurataxia or neuroasthenia or neurasthenia).ti,ab.
11.	((atypical or simulating or resembling) adj poliomyelitis).ti,ab.
12.	((chronic adj2 epstein Barr virus) or CEBV or CAEBV or chronic mononucleosis).ti,ab.
13.	xenotropic murine leukemia virus-related virus.ti,ab.
14.	effort syndrome*.ti,ab.
15.	(((akureyri or iceland or tapanui or royal free or royal free hospital) adj disease*) or ((yuppie or yuppy or tapanui) adj flu)).ti,ab.
16.	or/1-15
17.	letter/
18.	editorial/
19.	news/
20.	exp historical article/
21.	Anecdotes as Topic/
22.	comment/
23.	case report/
24.	(letter or comment*).ti.
25.	or/17-24
26.	randomized controlled trial/ or random*.ti,ab.

27.	25 not 26
28.	animals/ not humans/
29.	exp Animals, Laboratory/
30.	exp Animal Experimentation/
31.	exp Models, Animal/
32.	exp Rodentia/
33.	(rat or rats or mouse or mice).ti.
34.	or/27-33
35.	16 not 34
36.	limit 35 to English language
37.	Economics/
38.	Value of life/
39.	exp "Costs and Cost Analysis"/
40.	exp Economics, Hospital/
41.	exp Economics, Medical/
42.	Economics, Nursing/
43.	Economics, Pharmaceutical/
44.	exp "Fees and Charges"/
45.	exp Budgets/
46.	budget*.ti,ab.
47.	cost*.ti.
48.	(economic* or pharmaco?economic*).ti.
49.	(price* or pricing*).ti,ab.
50.	(cost* adj2 (effective* or utilit* or benefit* or minimi* or unit* or estimat* or variable*)).ab.
51.	(financ* or fee or fees).ti,ab.
52.	(value adj2 (money or monetary)).ti,ab.
53.	or/37-52
54.	36 and 53

Embase (Ovid) search terms

1.	chronic fatigue syndrome/
2.	chronic* fatigue*.ti,ab.
3.	(fatigue* adj2 (disorder* or syndrome* or post viral or postviral or immune dysfunction* or post infection* or postinfection*)).ti,ab.
4.	((myalgic or post infection* or postinfection*) adj (encephalomyelitis or encephalopathy)).ti,ab.
5.	((ME adj CFS) or (CFS adj ME) or CFIDS or PVFS).ti,ab.
6.	(Systemic Exertion Intolerance Disease or SEID).ti,ab.
7.	((CFS adj SEID) or (SEID adj CFS) or (ME adj CFS adj SEID) or (ME adj SEID) or (SEID adj ME)).ti,ab.
8.	((Orthostatic intolerance or postural orthostatic tachycardia syndrome or postural tachycardia syndrome or POTS) adj6 (CFS or chronic* fatigue* or ME or myalgic or SEID or systemic exertion)).ti,ab.
9.	((Post-exertional or postexertional) adj2 malaise).ti,ab.
10.	(neurasthenic neuroses or epidemic neuromyasthenia or neurataxia or neuroasthenia or neurasthenia).ti,ab.

11.	((atypical or simulating or resembling) adj poliomyelitis).ti,ab.
12.	((chronic adj2 epstein Barr virus) or CEBV or CAEBV or chronic mononucleosis).ti,ab.
13.	xenotropic murine leukemia virus-related virus.ti,ab.
14.	effort syndrome*.ti,ab.
15.	(((akureyri or iceland or tapanui or royal free or royal free hospital) adj disease*) or ((yuppie or yuppy or tapanui) adj flu)).ti,ab.
16.	or/1-15
17.	letter.pt. or letter/
18.	note.pt.
19.	editorial.pt.
20.	case report/ or case study/
21.	(letter or comment*).ti.
22.	or/17-21
23.	randomized controlled trial/ or random*.ti,ab.
24.	22 not 23
25.	animal/ not human/
26.	nonhuman/
27.	exp Animal Experiment/
28.	exp Experimental Animal/
29.	animal model/
30.	exp Rodent/
31.	(rat or rats or mouse or mice).ti.
32.	or/24-31
33.	16 not 32
34.	limit 33 to English language
35.	health economics/
36.	exp economic evaluation/
37.	exp health care cost/
38.	exp fee/
39.	budget/
40.	funding/
41.	budget*.ti,ab.
42.	cost*.ti.
43.	(economic* or pharmaco?economic*).ti.
44.	(price* or pricing*).ti,ab.
45.	(cost* adj2 (effective* or utilit* or benefit* or minimi* or unit* or estimat* or variable*)).ab.
46.	(financ* or fee or fees).ti,ab.
47.	(value adj2 (money or monetary)).ti,ab.
48.	or/35-47
49.	34 and 48

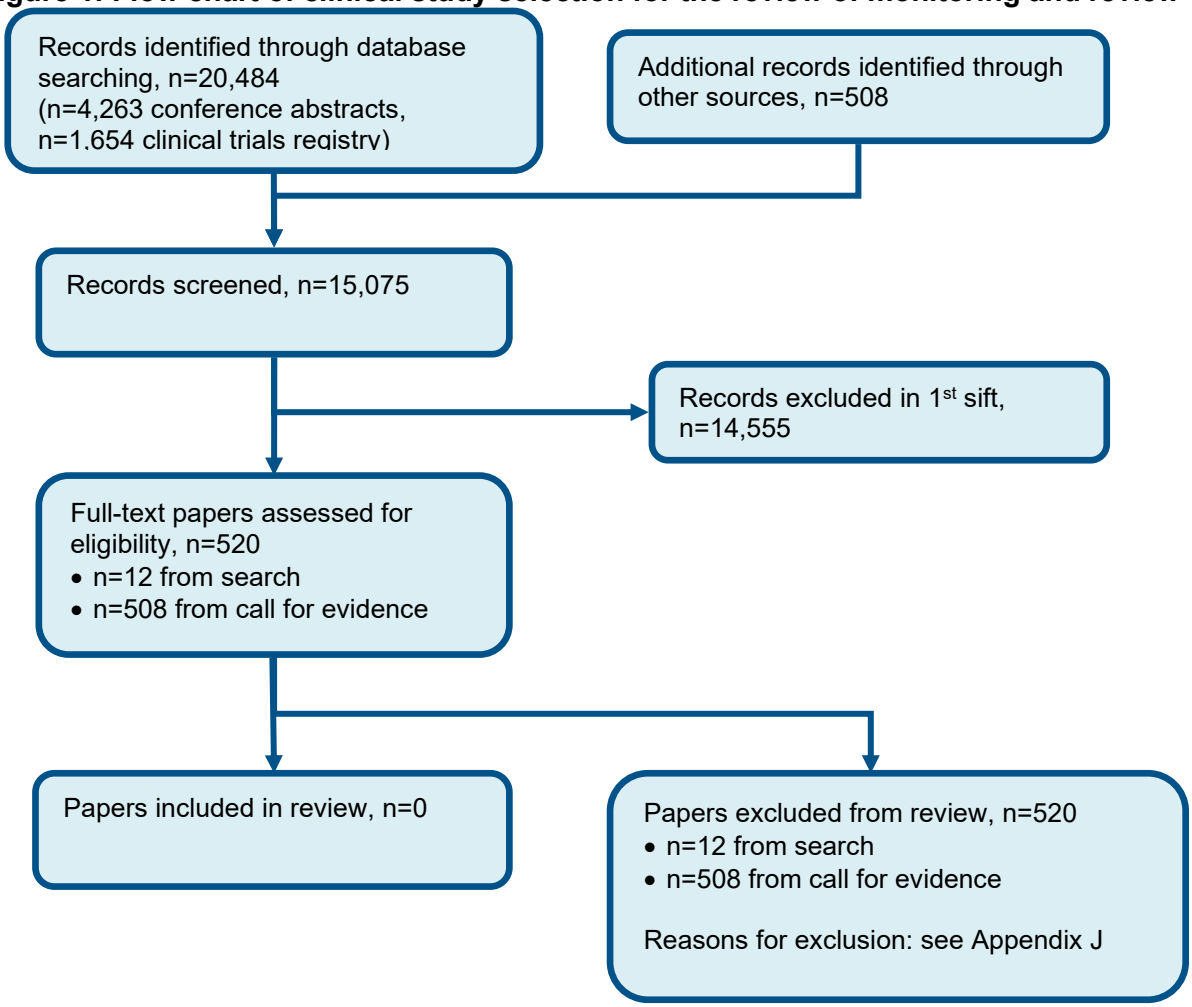
NHS EED and HTA (CRD) search terms

#1.	MeSH DESCRIPTOR Fatigue Syndrome, Chronic
#2.	(chronic fatigue or fatigue syndrome*)

#3.	((myalgic adj (encephalomyelitis or encephalopathy)))
#4.	(((ME adj CFS) or (CFS adj ME)))
#5.	(post viral fatigue or post viral syndrome* or viral fatigue syndrome* or PVFS)
#6.	#1 OR #2 OR #3 OR #4 OR #5
#7.	(neurasthenic neuroses or epidemic neuromyasthenia or post infectious encephalomyelitis or neurataxia or neuroasthenia)
#8.	(((atypical or simulating or resembling) adj poliomyelitis))
#9.	(chronic epstein Barr virus or chronic mononucleosis)
#10.	(xenotropic murine leukemia virus-related virus)
#11.	(((chronic fatigue and immune dysfunction syndrome*) or cfids or chronic fatigue-fibromyalgia syndrome* or chronic fatigue disorder* or Systemic Exertion Intolerance Disease or SEID or effort syndrome or post infectious fatigue))
#12.	((((akureyri or iceland or tapanui or royal free or royal free hospital) adj disease*) or ((yuppie or yuppy or tapanui) adj flu)))
#13.	#7 OR #8 OR #9 OR #10 OR #11 OR #12
#14.	#6 or #13

Appendix C Effectiveness evidence study selection

Figure 1: Flow chart of clinical study selection for the review of monitoring and review



Appendix D Effectiveness evidence

None.

Appendix E Forest plots

None.

Appendix F Effectiveness evidence

None.

Appendix G Forest plots

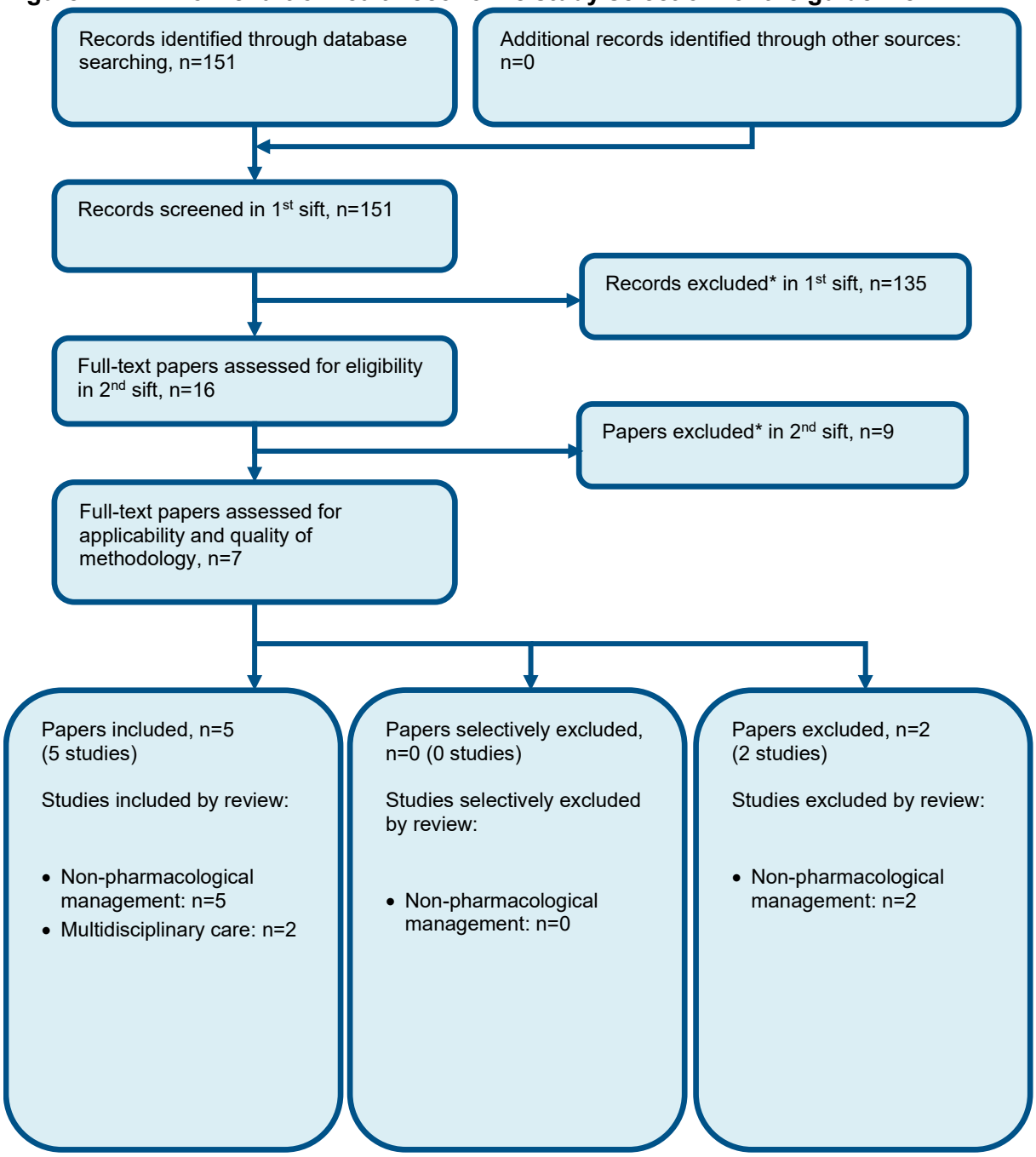
None.

Appendix H GRADE and/or GRADE-CERQual tables

None.

Appendix I Economic evidence study selection

Figure 2: Flow chart of health economic study selection for the guideline



* Non-relevant population, intervention, comparison, design or setting; non-English language

NB. Two papers were included in both the non-pharma and the multidisciplinary care reviews, in parallel with the review of clinical effectiveness.

Appendix J Economic evidence tables

None.

Appendix K Health economic model

No original economic modelling was undertaken.

Appendix L Excluded studies

L.1 Clinical studies

Table 6: Studies excluded from the clinical review

Study	Exclusion reason
Allen 2008[10]	Incorrect study design - not an intervention study (literature review and expert opinion on the treatment/care of women with ME/CFS during pregnancy/postpartum period)
Brown 1999[57]	Incorrect study design - not an intervention study (describes a treatment programme used at a hospital)
Bryan 1992[58]	Incorrect study design - not an intervention study (describes an approach to treatment/management and monitoring/review in people with ME/CFS)
Christley 2012[90]	Incorrect study design - not an intervention study (literature review on reproductive and pregnancy related issues and management in people with ME/CFS)
Jason 1994[215]	Incorrect study design - not an intervention study (case study describing the use of a symptom rating scale to monitor fluctuation in symptoms over time)
Jason 2000[212]	Incorrect study design - not an intervention study (descibes a model which aims to measure illness stage/progression in people with ME/CFS)
Jason 2009[216]	Incorrect study design - non-comparative study with no relevant outcomes (study used activity log to examine patterns, intensity and qualitative nature of activity in people with ME/CFS)
Kuehn 2018[254]	Incorrect study design - not a research article (news article describing ME/CFS)
Roor 2020[385]	Incorrect study design (assesses efficacy of intervention on the validity of cognitive performance measure results)
Ross 2004[386]	Incorrect study design/intervention - no relevant monitoring/reviewing interventions (systematic review on interventions, patient characteristics, neuropsychological test reliability and comorbid psychiatric conditions in people with ME/CFS)
Tillett 2000[456]	Incorrect study design - not an intervention study (study examines school attendance, management, and nature of follow-up in a cohort of school children diagnosed with ME/CFS)
Weatherburn 2007[499]	Incorrect study design - non-comparative study and no relevant outcomes (study examining the feasibility of teleconference distance review in a group of patients with ME/CFS)

A call for evidence was sent out for three review questions for which the committee anticipated that there would be limited published evidence. Some articles were submitted with a clear indication of which of the three review questions they related to, but for many there was no clear indication. Regardless, all articles were assessed for eligibility for inclusion in all three reviews and one main table was created for all studies/articles submitted that were subsequently excluded. For some articles, there were multiple reasons for exclusion across the three review questions. The exclusion reason listed is the main reason for exclusion from the review that the article was judged to be most relevant to. For example, a quantitative study on the effectiveness of an intervention in people diagnosed with ME/CFS was considered to be most relevant to the experiences of interventions question, but the review protocol specified only qualitative studies to be included, so the main reason for

exclusion would be incorrect study design. Some articles were relevant to the guideline in general but did not specifically attempt to answer any of the three review questions.

Table 7: Studies excluded from call for evidence

Study	Exclusion reason
Action for ME 2001[2]	Incorrect study design (quantitative survey)
Action for ME 2014[345]	No relevant themes
Action for ME 2019 Results from our big survey[1] (unpublished)	Incorrect study design (quantitative survey)
Action for ME and Association of Young People with ME (UK) 2008[3]	Incorrect study design (qualitative survey)
Adamowicz 2014[4]	Systematic review with different PICO
Adamson[5] (unpublished)	Incorrect study design (cohort)
Adedeji 2012[6]	Study/article does not address any of the call for evidence review questions
Adelakun[7]	No useable data - qualitative data reported as most frequently occurring words
Ahmed 2020[8]	Incorrect study design (systematic review; no qualitative data)
All-Party Parliamentary Group on ME 2010[9]	Not a qualitative study
Allwright 2019[11]	No relevant themes
Anderson 1997[13]	Mixed method study design with no extractable themes
Anderson[12] (unpublished)	Incorrect study design (qualitative)
Anon[429]	Incorrect study design (quantitative survey)
Anon[398]	Incorrect study design (non-comparative intervention study)
Anon[14]	Incorrect study design (non-comparative intervention study with quantitative outcomes)
Anon 2013[346] (unpublished)	Incorrect study design (quantitative survey)
Anon 2015[95]	Trial registry record; no results posted
Anon 2015[399]	Incorrect study design (quantitative)
Anon 2015[15]	Unable to obtain
Anon 2016[28] (unpublished)	Letter/commentary/expert opinion
Anon 2016[372]	Study/article does not address any of the call for evidence review questions
Anon 2017[152]	Study/article does not address any of the call for evidence review questions
Anon 2018[363]	Not research article
Antcliff 2019[16]	Incorrect population (HCPs)
Antiel 2011[17]	Incorrect interventions (no intervention)
Armstrong 2012[18]	Study/article does not address any of the call for evidence review questions
Arnold 2015[19]	Incorrect study design (RCT)
Ates 2016[20]	Study/article does not address any of the call for evidence review questions
Augusto 2018[21]	Study/article does not address any of the call for evidence review questions
BACME 2019[22]	Incorrect population (survey of CFS/ME services)

Study	Exclusion reason
Balaguru 2012[23]	Study/article does not address any of the call for evidence review questions
Baos 2019[24]	RCT protocol
Baraniuk 2017[26]	Study/article does not address any of the call for evidence review questions
Baraniuk 2018[25]	Study/article does not address any of the call for evidence review questions (BMJ best practice)
Barnden 2016[27]	Study/article does not address any of the call for evidence review questions
Bazelmans 2004[29]	Incorrect population (therapists)
Bazelmans 2005[30]	Incorrect study design (quantitative)
Bazilevskaya 2006[31]	Study/article does not address any of the call for evidence review questions
Beasant[32] (unpublished)	Incorrect study design (qualitative)
Belgian Ministry of Social Affairs, Public Health and Environment 2000[33]	Guidelines including systematic review of the evidence (unclear source of data on patient experience of CBT)
Bell 2016[34]	Letter/commentary/expert opinion
Berkovitz 2009[35]	Incorrect interventions (no intervention)
Blease 2017[36]	Incorrect study design (review article)
Bloot 2015[37]	Incorrect study design (quantitative)
Blue Ribbon for the Awareness of Myalgic Encephalomyelitis 2010[38] (unpublished)	Incorrect study design (quantitative survey; no qualitative data)
Boneva 2019[39]	Incorrect interventions (no intervention)
Bould 2011[41]	Review
Bould 2013[40]	Not relevant to any call for evidence questions
Bowers 2019[42]	Study/article does not address any of the call for evidence review questions
Brigden[46] (unpublished)	Incorrect study design (qualitative)
Brigden 2018[45]	No intervention
Brigden 2018[43]	No relevant themes
Brigden 2016[44]	RCT protocol
Bringsli 2014[47]	Incorrect study design (quantitative survey)
Bristol CFS/ME Service[49]	Incorrect study design (survey)
Bristol CFS/ME Service[48] (unpublished)	Incorrect study design (qualitative)
Britain 2019[50]	Conference abstract
Brooks 2011[51]	Incorrect study design (quantitative)
Broughton 2017[52]	Incorrect interventions (specialist services rather than specific interventions)
Brouwers 2002[53]	Incorrect study design (RCT)
Brown 2012[55]	Study/article does not address any of the call for evidence review questions
Brown 2005[56]	Study/article does not address any of the call for evidence review questions
Brown 2015[54]	Study/article does not address any of the call for evidence review questions

Study	Exclusion reason
Buchachenko 2013[63]	Study/article does not address any of the call for evidence review questions
Buchachenko 2005[61]	Study/article does not address any of the call for evidence review questions
Buchachenko 2006[62]	Study/article does not address any of the call for evidence review questions
Buchachenko 2017[60]	Study/article does not address any of the call for evidence review questions
Buchachenko 2019[59]	Study/article does not address any of the call for evidence review questions
Burgess 2012[64]	Incorrect study design (RCT)
Burke 1986[65]	Study/article does not address any of the call for evidence review questions
Butland 1982[66]	Study/article does not address any of the call for evidence review questions
Calello 2018[67]	Study/article does not address any of the call for evidence review questions
Carpenter 2013[68]	Study/article does not address any of the call for evidence review questions
Carruthers 2011[71]	Study/article does not address any of the call for evidence review questions
Carruthers 2012[70]	Study/article does not address any of the call for evidence review questions
Carruthers 2003[69]	Guidelines
Casanova 2011[72]	Study/article does not address any of the call for evidence review questions
Castro-Marrero 2016[74]	Incorrect study design (RCT)
Castro-Marrero 2017[73]	Study/article does not address any of the call for evidence review questions
Cella 2011[76]	Incorrect study design (quantitative)
Cella 2011[75]	Incorrect study design (quantitative)
Centers for Disease Control and Prevention 2019[77]	Study/article does not address any of the call for evidence review questions
CFS/ME National Outcomes Database Team 2016[78]	Incorrect study design (non-comparative observational study)
CFS/ME Service for South Yorkshire and North Derbyshire 2019[79]	Incorrect study design (quantitative survey)
CFS/ME Service for South Yorkshire and North Derbyshire[80]	Incorrect study design (quantitative survey)
CFS/ME Working Group 2002[81] (unpublished)	No relevant themes
Chaudhuri 2003[88]	Study/article does not address any of the call for evidence review questions
Chalder 1993[83]	Study/article does not address any of the call for evidence review questions
Chalder 2010[84]	Incorrect study design (RCT)
Chalder 2010[82]	Incorrect study design (review, not qualitative)
Chalder 2015[85]	Incorrect study design (quantitative)
Chan 2019[86]	Not a qualitative study

Study	Exclusion reason
Chang 2012[87]	Incorrect interventions (no intervention)
Childs 2019[89]	Incorrect study design (quantitative survey); no qualitative data
Chu 2018[91]	Study/article does not address any of the call for evidence review questions
Claypoole 2007[92]	Incorrect interventions (no intervention)
Cleare 2004[93]	Incorrect study design (quantitative)
Cliff 2019[94]	Study/article does not address any of the call for evidence review questions
Cockshell 2010[96]	Incorrect interventions (no intervention)
Collin 2018[101]	Study/article does not address any of the call for evidence review questions
Collin 2017[99]	Incorrect study design (non-comparative cohort study)
Collin 2017[97]	Incorrect study design (case-control)
Collin 2017[98]	Study/article does not address any of the call for evidence review questions
Collin 2016[102]	Study/article does not address any of the call for evidence review questions
Collin 2015[103]	Study/article does not address any of the call for evidence review questions
Collin 2012[104]	Incorrect study design (quantitative survey)
Collin 2011[100]	Study/article does not address any of the call for evidence review questions
Comhaire 2018[105]	Incorrect study design (quantitative)
Cook 2017[106]	Incorrect interventions (no intervention)
Cooper 2019[107]	No relevant themes (qualitative data on an ME/CFS service, not specific interventions)
Corsius 2019[108]	Report summary; full report in Dutch
Costa 1995[109]	Study/article does not address any of the call for evidence review questions
Crawford 2010[111]	Study/article does not address any of the call for evidence review questions
Crawford 2012[110]	Letter/commentary/expert opinion
Crawford 2012[112]	Study advertisement
Crawley 2018[118]	Not relevant to monitoring/review question
Crawley 2013[115]	Incorrect interventions
Crawley 2013[113]	No relevant outcomes
Crawley 2011[117]	No intervention
Crawley 2009[114]	Study/article does not address any of the call for evidence review questions
Crawley 2009[116]	Study/article does not address any of the call for evidence review questions
Crowhurst 2005[119]	Letter/commentary/expert opinion
Crowhurst 2007[120]	No relevant themes
Currell[121]	No relevant themes (qualitative data on a specialist service, not specific interventions)
DARPA 2017[122]	Study/article does not address any of the call for evidence review questions
Davenport 2010[127]	Incorrect study design (conceptual model; not qualitative)

Study	Exclusion reason
Davenport 2019[123]	Study/article does not address any of the call for evidence review questions
Davenport 2011[125]	Study/article does not address any of the call for evidence review questions
Davenport 2011[124]	Incorrect study design (quantitative)
Davenport 2019[126]	Letter/commentary/expert opinion
Davies 2008[128]	Study/article does not address any of the call for evidence review questions
Dawes 2019[153]	Executive summary of an excluded survey
Deale 2001[136]	Incorrect study design (RCT)
Deale 1998[135]	Incorrect study design (quantitative)
Deale 1997[134]	Incorrect study design (RCT)
De Becker 2000[130]	Study/article does not address any of the call for evidence review questions
De Becker 2001[129]	Study/article does not address any of the call for evidence review questions
de Carvalho 2011[131]	Study/article does not address any of the call for evidence review questions
Deftereos 2016[137]	Incorrect population (expert clinicians)
de Lange 2008[132]	Incorrect study design (quantitative)
DeLuca 2004[138]	Incorrect interventions (no intervention)
de Vega 2017[133]	Study/article does not address any of the call for evidence review questions
Devasahayam 2012[139]	Study/article does not address any of the call for evidence review questions
Diao 2017[140]	Study/article does not address any of the call for evidence review questions
Dobson 2007[141]	Study/article does not address any of the call for evidence review questions
Dougall 2014[142]	Incorrect study design (RCT)
Doukrou 2019[143]	Incorrect study design (no qualitative data)
Dowsett 1997[144]	Study/article does not address any of the call for evidence review questions
Duyn 2017[145]	Study/article does not address any of the call for evidence review questions
Dyda 2018[146]	Study/article does not address any of the call for evidence review questions
Effective Health Care Program: Agency for Healthcare Research and Quality[147]	Systematic review protocol
Emerge Australia 2018[148]	Incorrect study design (quantitative survey)
Emerge Australia 2019[149]	Incorrect study design (quantitative survey)
Encephalitis Society 2017[150]	Study/article does not address any of the call for evidence review questions (website information)
Eroshenko 2004[151]	Study/article does not address any of the call for evidence review questions
Falk Hvidberg 2015[154]	Incorrect interventions (no intervention)
Faulkner 2016[155]	Letter/commentary/expert opinion
Fisher 2013[156]	No relevant themes

Study	Exclusion reason
Fisk 1994[157]	Not relevant to any call for evidence questions
Flo 2014[158]	Incorrect study design (quantitative)
Fluge 2019[160]	Incorrect study design (RCT)
Fluge 2015[161]	Incorrect study design (quantitative)
Fluge 2016[159]	Study/article does not address any of the call for evidence review questions
Forward ME Survey 2019[336]	Incorrect study design (survey)
Franklin 2018[162]	Incorrect study design (quantitative)
Fukuda 2016[163]	Incorrect study design (RCT)
Garner 2019[164]	Study/article does not address any of the call for evidence review questions
Geraghty 2018[168]	Incorrect study design (narrative review)
Geraghty 2016[170]	Incorrect study design (debate article)
Geraghty 2019[169]	Incorrect study design (literature review)
Geraghty 2019[166]	Letter/commentary/expert opinion
Geraghty 2017[165]	Incorrect study design (analysis of quantitative survey data)
Geraghty 2019[167]	Study/article does not address any of the call for evidence review questions
Ghatineh 2017[171]	Review of an RCT
Gielissen 2007[172]	Study/article does not address any of the call for evidence review questions
Gieré 2016[173]	Study/article does not address any of the call for evidence review questions
Gilder 2018[174]	Study/article does not address any of the call for evidence review questions
Gladwell 2013[175]	Incorrect study design (survey)
Goedendorp 2009[176]	Study/article does not address any of the call for evidence review questions
Haig-Ferguson 2019[177]	No relevant themes
Haig-Ferguson 2009[178]	No relevant themes
Halapy 2017[179]	Letter/commentary/expert opinion
Harada 1999[180]	Study/article does not address any of the call for evidence review questions
Haywood 2012[182]	Study/article does not address any of the call for evidence review questions
Haywood 2014[181]	Systematic review with different PICO
Heald 2019[183]	Study/article does not address any of the call for evidence review questions
Healthwatch Trafford 2017[185]	No relevant themes
Healthwatch Lancashire 2017[184]	Different focus to review question
Heins 2013[187]	Incorrect study design (quantitative)
Heins 2013[186]	Incorrect study design (quantitative)
Heins 2011[188]	Incorrect study design (quantitative)
Heins 2010[189]	Incorrect study design (quantitative)
Hives 2017[190]	Incorrect study design (diagnostic accuracy study)
Hodges 2018[191]	Incorrect interventions (no intervention)

Study	Exclusion reason
Holtzman 2019[192]	Study/article does not address any of the call for evidence review questions
Hughes 2002[194]	Review article
Hughes 2018[193]	Study/article does not address any of the call for evidence review questions
Huibers 2004[195]	Incorrect population (some met criteria for CFS, some did not and results not reported separately
Ickmans 2014[196]	Incorrect interventions (no intervention)
ICNIRP Project Group 2017[197]	Study/article does not address any of the call for evidence review questions
Ingman 2016[200]	Incorrect study design (quantitative)
Ingman[199]	Unable to obtain
Ingman[198]	Unable to obtain
Institute of Medicine 2015[201]	Study/article does not address any of the call for evidence review questions
ISRCTN Registry 2015[202]	Study/article does not address any of the call for evidence review questions
Jackson 2012[203]	Study/article does not address any of the call for evidence review questions
Janse 2019[204]	Prognostic study looking at predictors of outcome of CBT - none relevant to CFE questions
Janse 2019[206]	Incorrect study design (non-randomised quantitative study)
Janse 2018[208]	Incorrect study design (RCT)
Janse 2017[205]	Incorrect study design (RCT)
Janse 2016[207]	Incorrect population (idiopathic chronic fatigue); incorrect study design (RCT)
Janse 2015[209]	RCT protocol
Jason 2006[211]	Study/article does not address any of the call for evidence review questions
Jason 2008[217]	Study/article does not address any of the call for evidence review questions
Jason 2009[210]	Incorrect study design (quantitative)
Jason 2009[213]	Study/article does not address any of the call for evidence review questions
Jason 2015[218]	Review article
Jason 2018[214]	Not relevant to any call for evidence question
Jelinek 2001[219]	Study/article does not address any of the call for evidence review questions
Jenkins 2005[220]	Study/article does not address any of the call for evidence review questions
Jones 2012[221]	Incorrect study design (quantitative)
Josev 2019[222]	Incorrect interventions (no intervention)
Juutilainen 2018[223]	Study/article does not address any of the call for evidence review questions
Kapitein 2015[224]	Study/article does not address any of the call for evidence review questions
Kasevich 2002[225]	Study/article does not address any of the call for evidence review questions
Keller 2014[226]	Incorrect interventions (no intervention)

Study	Exclusion reason
Kempke 2013[227]	Study/article does not address any of the call for evidence review questions
Kenyon 2019[228]	Incorrect study design (quantitative)
Kim 2019[229]	Study/article does not address any of the call for evidence review questions
Kindlon 2011[237]	Letter/commentary/expert opinion
Kindlon 2017[231]	Letter/commentary/expert opinion
Kindlon 2009[230]	Letter/commentary/expert opinion
Kindlon 2010[239]	Letter/commentary/expert opinion
Kindlon 2010[241]	Letter/commentary/expert opinion
Kindlon 2011[233]	Letter/commentary/expert opinion
Kindlon 2012[234]	Letter/commentary/expert opinion
Kindlon 2012[235]	Letter/commentary/expert opinion
Kindlon 2015[232]	Letter/commentary/expert opinion
Kindlon 2015[240]	Letter/commentary/expert opinion
Kindlon 2015[242]	Letter/commentary/expert opinion
Kindlon 2011[236]	Letter/commentary/expert opinion
Kindlon 2009[238]	Letter/commentary/expert opinion
Kingdon 2018[243]	Study/article does not address any of the call for evidence review questions
Knoester 2019[244]	Study/article does not address any of the call for evidence review questions
Knoop 2008[249]	Incorrect study design (RCT)
Knoop 2007[248]	Incorrect study design (quantitative)
Knoop 2007[246]	Incorrect study design (quantitative)
Knoop 2007[245]	Incorrect study design (quantitative)
Knoop 2008[247]	Incorrect study design (RCT)
Knudsen 2011[250]	Study/article does not address any of the call for evidence review questions
Kodama 2013[251]	Study/article does not address any of the call for evidence review questions
Kreyberg 2007[252]	Guidelines
Kreyberg 2007[253]	Incorrect population (nursing staff)
Lacerda 2018[255]	Study/article does not address any of the call for evidence review questions
Lacerda 2019[256]	No relevant themes
LaManca 1998[257]	Incorrect interventions (no intervention)
Lapp 2019[258]	Letter/commentary/expert opinion
Larun 2014[259]	Incorrect study design (systematic review of RCTs)
Leaman 1997[260]	Study/article does not address any of the call for evidence review questions
Leone 2006[262]	Not relevant to any call for evidence question
Lewis 2013[263]	Incorrect interventions (no intervention)
Lien 2019[264]	Study/article does not address any of the call for evidence review questions
Light 2009[265]	Incorrect study design (quantitative)
Lincolnshire Partnership 2019[266]	Qualitative data in the form of quotes - no thematic analysis

Study	Exclusion reason
Liu 2018[267]	Study/article does not address any of the call for evidence review questions
Lloyd 2012[269]	Incorrect study design (quantitative)
Lloyd 2012[268]	Incorrect study design (RCT)
Loades 2016[273]	Systematic review with different PICO
Loades 2019[270] (unpublished)	Incorrect population (already diagnosed with ME/CFS); incorrect study design (cross-sectional epidemiological study with no interventions)
Loades 2019[274]	Incorrect study design (qualitative); also excluded from experiences of interventions review due incorrect population (healthcare professionals)
Loades 2019[271]	Incorrect study design (quantitative)
Loades 2018[272]	Study/article does not address any of the call for evidence review questions
Loy 2016[275]	Incorrect study design (quantitative)
Lyshevski 2001[276]	Study/article does not address any of the call for evidence review questions
Maes 2006[279]	Study/article does not address any of the call for evidence review questions
Maes 2009[280]	Study/article does not address any of the call for evidence review questions
Maes 2012[281]	Study/article does not address any of the call for evidence review questions
Marshall 1997[282]	Not relevant to any call for evidence question
Marshall 1996[283]	Incorrect study design (quantitative)
Mathew 2009[284]	Study/article does not address any of the call for evidence review questions
May 2010[285]	Study/article does not address any of the call for evidence review questions
McCourt 2019[286]	Study/article does not address any of the call for evidence review questions
McDermott 2006[287]	Study/article does not address any of the call for evidence review questions
McGregor 2016[288]	Study/article does not address any of the call for evidence review questions
McGregor 2019[289]	Study/article does not address any of the call for evidence review questions
McManimen 2016[291]	Study/article does not address any of the call for evidence review questions
McManimen 2019[290]	Incorrect study design (qualitative)
McPhee 2019[292]	Qualitative section was related to information given to patients about possible harms, data about harm was quantitative
ME Action 2019[261]	Incorrect study design (survey)
ME/cvs Vereniging 2016[293]	Report summary; full report in Dutch
Meeus 2015[294]	Incorrect study design (RCT)
ME Group 2019[278]	No qualitative findings/data analysis reported
ME Group 2014[277]	No qualitative findings/data analysis reported
Melamed 2019[295]	Study/article does not address any of the call for evidence review questions

Study	Exclusion reason
Mihelicova 2016[296]	Study/article does not address any of the call for evidence review questions
Miller 2015[297]	Study/article does not address any of the call for evidence review questions
Millions Missing Canada 2017[298]	Incorrect study design (quantitative survey)
Missen 2012[299]	No relevant outcomes
Moneghetti 2018[300]	Incorrect interventions (no intervention)
Montoya 2018[301]	Incorrect study design (RCT)
Montoya 2013[302]	Incorrect study design (RCT)
Moore 2000[303]	Study/article does not address any of the call for evidence review questions
Moore 2015[304]	Study/article does not address any of the call for evidence review questions
Morens 2019[305]	Study/article does not address any of the call for evidence review questions
Morris 2014[306]	Study/article does not address any of the call for evidence review questions
Murdock 2017[307]	Study/article does not address any of the call for evidence review questions
Myalgic Encephalomyelitis / Chronic Fatigue Syndrome Advisory Committee 2019[308]	Study/article does not address any of the call for evidence review questions
Nacul 2011[311]	Study/article does not address any of the call for evidence review questions
Nacul 2011[312]	Study/article does not address any of the call for evidence review questions
Nacul 2018[313]	Study/article does not address any of the call for evidence review questions
Nacul 2019[310]	Study/article does not address any of the call for evidence review questions
Nacul 2019[309]	Study/article does not address any of the call for evidence review questions
Nagy-Szakal 2018[314]	Study/article does not address any of the call for evidence review questions
Natelson 2017[316]	Study/article does not address any of the call for evidence review questions
Natelson 2017[315]	Study/article does not address any of the call for evidence review questions
National Centers for Environmental Information[317]	Study/article does not address any of the call for evidence review questions
National Collaborating Centre for Primary Care 2007[318]	Study/article does not address any of the call for evidence review questions
Naviaux 2016[321]	Study/article does not address any of the call for evidence review questions
Naviaux 2017[320]	Study/article does not address any of the call for evidence review questions
Newberry 2018[322]	Study/article does not address any of the call for evidence review questions
Newton 2010[323]	Study/article does not address any of the call for evidence review questions

Study	Exclusion reason
NHS North Bristol 2019[324]	No relevant themes (qualitative data on specialist services, not specific interventions)
Nijhof 2014[328]	Incorrect study design (quantitative)
Nijhof 2013[327]	Incorrect study design (quantitative)
Nijhof 2012[325]	Incorrect study design (RCT)
Nijhof 2011[326]	RCT protocol
Norfolk and Suffolk Service 2009[329]	Unable to obtain (web link unavailable)
Norris 2017[330]	Incorrect study design (cross-sectional analysis of quantitative data)
Ocon 2012[331]	Study/article does not address any of the call for evidence review questions
Odoom 2018[332]	Study/article does not address any of the call for evidence review questions
Office for National Statistics 2018[333]	Not relevant to any call for evidence questions
Ojo-Amaize 1994[334]	Study/article does not address any of the call for evidence review questions
Oliver 2018[335]	Incorrect study design (quantitative survey)
PACE Trial participant dataset[337]	Study/article does not address any of the call for evidence review questions
Packer 1997[338]	Study/article does not address any of the call for evidence review questions
Pakpoor 2017[339]	Study/article does not address any of the call for evidence review questions
Parslow 2018[341]	No relevant themes
Parslow 2017[343]	Incorrect study design (qualitative)
Parslow 2017[342]	Systematic review with different PICO
Parslow 2015[340]	Incorrect study design (qualitative; assessed for monitoring and review question)
Pastula 2014[344]	Study/article does not address any of the call for evidence review questions
Patrick Neary 2008[347]	Incorrect interventions (no intervention)
Peci 2015[348]	Study/article does not address any of the call for evidence review questions
Peckerman 2003[349]	Study/article does not address any of the call for evidence review questions
Pemberton 2014[351]	No relevant themes
Pemberton 2014[350]	No relevant themes
Peterson 1991[356]	Not relevant to any call for evidence question
Peterson 1994[357]	Incorrect interventions (no intervention)
Perrin 1993[353]	Review; study/article does not address any of the call for evidence review questions
Perrin 1998[354]	Incorrect study design (non-randomised quantitative study)
Perrin 2011[355]	Incorrect study design (non-randomised quantitative study)
Pheby 2009[358]	Incorrect study design (survey) and no useable data
Physios for M.E[359] (unpublished)	Incorrect study design (qualitative)

Study	Exclusion reason
Plascencia-Villa 2016[360]	Study/article does not address any of the call for evidence review questions
Polli 2019[361]	Incorrect study design (quantitative)
Polo 2019[362]	Incorrect study design (no qualitative data)
Prins 2005[364]	Incorrect study design (quantitative)
Prins 2001[365]	Incorrect study design (RCT)
Prokhorov 2016[366]	Study/article does not address any of the call for evidence review questions
Puri 2011[367]	Incorrect study design (diagnostic accuracy study)
Quarmby 2007[368]	Incorrect study design (quantitative)
Raine 2004[369]	Incorrect population (GPs)
Rand Corporation[370]	Study/article does not address any of the call for evidence review questions
Rawlins 2008[371]	Study/article does not address any of the call for evidence review questions
Regland 2015[373]	Incorrect study design (quantitative)
Reynolds 2014[374]	Incorrect interventions (no intervention)
Richardson 2002[375]	Review article
Rimes 2014[376]	Incorrect study design (quantitative)
Roberts 2016[379]	Study/article does not address any of the call for evidence review questions
Roberts 2009[377]	Incorrect study design (quantitative)
Roberts 2018[378]	Study/article does not address any of the call for evidence review questions
Roe[380]	No relevant themes (qualitative data on a specialist service, not specific interventions)
Roerink 2017[383]	Study/article does not address any of the call for evidence review questions
Roerink 2017[381]	Incorrect study design (RCT)
Roerink 2015[382]	RCT protocol
Roma 2019[384]	Incorrect interventions (no intervention)
Rowe 2019[387]	No relevant themes
Rowe 2017[388]	Review article
Ruggieri 2017[389]	Study/article does not address any of the call for evidence review questions
Santini 2018[390]	Study/article does not address any of the call for evidence review questions
Ŝarić 2016[391]	Study/article does not address any of the call for evidence review questions
Scheeres 2009[392]	Study/article does not address any of the call for evidence review questions
Scheeres 2008[394]	Incorrect study design (quantitative)
Scheeres 2008[393]	Incorrect study design (quantitative)
Scheeres 2007[395]	Study/article does not address any of the call for evidence review questions
Schmaling 2019[396]	Study/article does not address any of the call for evidence review questions
Schweitzer 1995[397]	Not relevant to any call for evidence question
Severens 2004[400]	Letter/commentary/expert opinion

Study	Exclusion reason
Shakespeare 2017[401]	Study/article does not address any of the call for evidence review questions
Shan 2018[402]	Study/article does not address any of the call for evidence review questions
Sharpe 1991[404]	Study/article does not address any of the call for evidence review questions
Sharpe 2015[403]	Incorrect study design (RCT)
Shukla 2015[405]	Incorrect study design (quantitative)
Shungu 2012[406]	Study/article does not address any of the call for evidence review questions
Smith 2014[408]	Incorrect study design (systematic review of RCTs)
Smith 2013[409]	Systematic review with different PICO
Smith 2015[407]	Incorrect study design (systematic review of RCTs)
Snell 2013[410]	Study/article does not address any of the call for evidence review questions
Snounou 2019[411]	Incorrect study design (qualitative)
Solomon-Moore 2019[412]	Incorrect study design (baseline cross-sectional data from an RCT)
Stahl 2014[413]	Incorrect study design (quantitative)
Staud 2017[415]	Incorrect study design (RCT)
Staud 2018[414]	Incorrect study design (quantitative)
Steffen 2002[416]	Study/article does not address any of the call for evidence review questions
Stevelink 2019[417]	Study/article does not address any of the call for evidence review questions
Stevens 2018[418]	Study/article does not address any of the call for evidence review questions
Stevens 2010[419]	Incorrect study design (case study)
Stoll 2017[420]	Systematic review with different PICO
Stordeur 2008[421]	Study/article does not address any of the call for evidence review questions
Strassheim 2018[422]	Study/article does not address any of the call for evidence review questions
Strawbridge 2019[423]	Not relevant to any call for evidence question
Strayer 2012[424]	Incorrect study design (RCT)
Strbak 2011[425]	Study/article does not address any of the call for evidence review questions
Stulemeijer 2005[426]	Incorrect study design (RCT)
Sumathipala 2008[427]	Incorrect population (medically unexplained symptoms)
Sunnquist 2018[428]	Incorrect study design (quantitative)
Suvorov 1998[430]	Study/article does not address any of the call for evidence review questions
Swinscow 1997[431]	Study/article does not address any of the call for evidence review questions
Taylor 2004[434]	Incorrect study design (RCT)
Taylor 2019 Leeds and York CFS/ME Service[433] (unpublished)	No qualitative data
Taylor 2016[432]	Study/article does not address any of the call for evidence review questions

Study	Exclusion reason
Teitelbaum 2001[435]	Incorrect study design (RCT)
Terzi 2016[436]	Study/article does not address any of the call for evidence review questions
The 2010[449]	Incorrect study design (RCT)
The 2007[450]	Incorrect study design (RCT)
The Consortium of Multiple Sclerosis Centers Health Services Research Subcommittee 1997[448]	Not relevant to any call for evidence questions
The 25% ME Group 2010[437]	Different focus to review question
The 25% ME Group 2014[438] (unpublished)	Report on a research presentation; no qualitative data from people with ME/CFS
The 25% ME Group 2004[447]	Incorrect study design (quantitative survey)
The 25% ME Group 2000[444]	Incorrect study design (quantitative survey)
The 25% ME Group 2001[439]	Incorrect study design (quantitative survey)
The 25% ME Group[446]	Article; no qualitative data from people with ME/CFS
The 25% ME Group 2002[443] (unpublished)	Incorrect study design (quantitative survey)
The 25% ME Group 2017[441]	Not relevant to any call for evidence questions
The 25% ME Group 2018[440]	Not relevant to any call for evidence questions
The 25% ME Group 2001[442]	Incorrect study design (quantitative survey)
The 25% ME Group 2016[445]	Study/article does not address any of the call for evidence review questions (newsletter)
The ME Association 2010[451]	Incorrect study design (quantitative survey)
The ME Association 2015[452]	Survey including quantitative and qualitative data, but no analysis on the qualitative data
The Neurological Alliance 2019[453]	Incorrect study design (quantitative survey)
Thomas 2009[454]	Incorrect interventions (no intervention)
Tiersky 2001[455]	Incorrect study design (quantitative)
Timbol 2019[457]	No relevant themes
Togo 2015[458]	Incorrect interventions (no intervention)
Trabal 2012[459]	Study/article does not address any of the call for evidence review questions
Tummers 2013[462]	Incorrect study design (quantitative)
Tummers 2012[461]	Incorrect study design (RCT)
Tummers 2010[460]	Incorrect study design (quantitative)
Twisk 2014[467]	Letter/commentary/expert opinion
Twisk 2017[464]	Letter/commentary/expert opinion
Twisk 2018[463]	Report summary; full report in Dutch
Twisk 2015[466]	Study/article does not address any of the call for evidence review questions
Twisk 2015[465]	Incorrect study design (review article)
Van Campen 2018[468]	Incorrect interventions (no intervention)
Van Campen 2018[470]	Study/article does not address any of the call for evidence review questions
Van Campen 2019[469]	Incorrect study design (quantitative)

Study	Exclusion reason
Van Den Eede 2011[471]	Study/article does not address any of the call for evidence review questions
Van Der Schaaf 2015[473]	RCT protocol
Van Der Schaaf 2017[472]	Study/article does not address any of the call for evidence review questions
Van Der Werf 2002[474]	Study/article does not address any of the call for evidence review questions
Van Konynenburg 2010[475]	Conference abstract
Van Kuppeveld 2010[476]	Study/article does not address any of the call for evidence review questions
VanNess 2007[477]	Incorrect interventions (no intervention)
VanNess 2010[478]	Incorrect intervention (exercise test)
Velleman 2016[479]	Incorrect population (siblings) and no relevant themes
Vercoulen 1996[481]	Incorrect study design (RCT)
Vercoulen 1996[480]	Study/article does not address any of the call for evidence review questions
Vermeulen 2010[482]	Study/article does not address any of the call for evidence review questions
Vermeulen 2014[483]	Study/article does not address any of the call for evidence review questions
Vernon 2004[484]	Unable to obtain
Verspaandonk 2015[485]	Incorrect study design (quantitative)
Vink 2017[486]	Incorrect study design (quantitative)
Vink 2018[489]	Review of an RCT
Vink 2018[488]	Incorrect study design (reanalysis of a Cochrane review); no qualitative data
Vink 2019[490]	Review article
Vink 2019[487]	Incorrect study design (reanalysis of a Cochrane review); no qualitative data
Wallis 2016[492]	Study/article does not address any of the call for evidence review questions
Wallis 2018[491]	Incorrect study design (quantitative)
Wang 2017[494]	Study/article does not address any of the call for evidence review questions
Watt 2012[495]	Incorrect study design (quantitative)
Wearden 2006[498]	Study/article does not address any of the call for evidence review questions
Wearden 2010[496]	Incorrect study design (RCT)
Wearden 2013[497]	Incorrect study design (prognostic)
Webb 2011[500]	No relevant themes
Werbach 2000[501]	Incorrect study design (literature review)
White 2007[504]	RCT protocol
White 2011[503]	Incorrect study design (RCT)
White 2013[502]	Study/article does not address any of the call for evidence review questions
Whitehead 2009[505]	Study/article does not address any of the call for evidence review questions
Whitehead 2002[506]	Study/article does not address any of the call for evidence review questions

Study	Exclusion reason
Wiborg 2010[508]	Incorrect study design (reanalysis of RCTs)
Wiborg 2014[510]	Incorrect study design (quantitative)
Wiborg 2015[509]	Incorrect study design (RCT)
Wiborg 2011[507]	Incorrect study design (quantitative)
Wieczorek 2017[493]	Study/article does not address any of the call for evidence review questions
Wilshire 2018[514]	Incorrect study design (reanalysis of an RCT)
Wilshire 2019[513]	Letter/commentary/expert opinion
Wilshire 2017[511]	Incorrect study design (critical commentary and reanalysis of an RCT)
Wilshire 2017[512]	Letter/commentary/expert opinion
Worm-Smeitink 2019[516]	Incorrect study design (RCT)
Worm-Smeitink 2017[515]	Study/article does not address any of the call for evidence review questions
Worm-Smeitink 2016[517]	Incorrect study design (quantitative)
Yorkshire Fatigue Clinic 2019[352]	Incorrect study design (survey)
Zablotskii 2016[518]	Study/article does not address any of the call for evidence review questions
Zablotskii 2018[519]	Study/article does not address any of the call for evidence review questions
Zhi 2017[520]	Study/article does not address any of the call for evidence review questions
Zielinski 2019[521]	Study/article does not address any of the call for evidence review questions

L.2 Health economic studies

Published health economic studies that met the inclusion criteria (relevant population, comparators, economic study design, published 2004 or later and not from non-OECD country or USA) but that were excluded following appraisal of applicability and methodological quality are listed below. See the health economic protocol for more details.

None.

References

1. Action for ME. Results from our Big Survey [Unpublished]. 2019.

2. Action for ME. Severely neglected: M.E. in the UK. Membership survey. London. Action for ME, 2001.

3. Action for ME, Association of Young People with ME. Action for M.E. and AYME survey 2008 - results. 2008. Available from: https://afme.wordpress.com/ Last accessed: 29/11/2019.

4. Adamowicz JL, Caikauskaite I, Friedberg F. Defining recovery in chronic fatigue syndrome: A critical review. Quality of Life Research. 2014; 23(9):2407-2416

5. Adamson J, Ali S, Santhouse A, Wessely S, Chalder T. Routine clinic outcomes after cognitive behavior therapy (CBT) and graded exercise therapy (GET) from South London and Maudsley NHS Trust & King's College London service compared to trials of CBT and GET respectively [Unpublished].

6. Adedeji AO, Okonko IO, Adu FD. Sabin and wild type polioviruses from children who presented with acute flaccid paralysis in Nigeria. African Health Sciences. 2012; 12(3):345-354

7. Adelakun S, Meriwoode J. An evaluation of CFS/ME group members' experience of engaging in a self management treatment programme in an NHS specialist CFS/ME service in the UK. Specialist Occupational Therapist Sussex-wide CFS/ME Service, 2019.

8. Ahmed SA, Mewes JC, Vrijhoef H. Assessment of the scientific rigour of randomized controlled trials on the effectiveness of cognitive behavioural therapy and graded exercise therapy for patients with myalgic encephalomyelitis/chronic fatigue syndrome: A systematic review. Journal of Health Psychology. 2020; 25(2):240-255

9. All-Party Parliamentary Group on ME. Inquiry into NHS Service Provision for ME/CFS. 2010. Available from: https://www.meassociation.org.uk/wp-content/uploads/2013/02/APPG-Report-v3.pdf

10. Allen PR. Chronic fatigue syndrome: implications for women and their health care providers during the childbearing years. Journal of Midwifery & Women's Health. 2008; 53(4):289-301; quiz 399

11. Allwright E, Murihead N. Understanding the role of the general practitioner in caring for patients with myalgic encephalomyelitis/chronic fatigue syndrome in the community. 2019.

12. Anderson E, Parslow R, Hollingworth W, Mills N, Beasant L, Gaunt D et al. Testing the feasibility of recruiting adolescents with CFS/ME to internet-delivered therapy: internal pilot within a randomised controlled trial investigating online cognitive behavioural therapy (Fatigue In Teenagers on the interNET in the NHS – "FITNET-NHS") compared to skype-delivered activity management for adolescents with CFS/ME [Unpublished].

13. Anderson JS, Ferrans CE. The quality of life of persons with chronic fatigue syndrome. Journal of Nervous and Mental Disease. 1997; 185(6):359-367

14. Anonymous. Evaluating the effects of change in the content and format of a lifestyle management group on standardized outcome measures of chronic fatigue syndrome/myalgic encephalomyelitis. University of Surrey.

15. Anonymous. Neuropsychological performance in myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and Gulf war illness (GWI). Implications for interventions and patient management. [Submission for Doctoral level Qualification in Counselling Psychology]. 2015.

16. Antcliff D, Keenan AM, Keeley P, Woby S, McGowan L. Survey of activity pacing across healthcare professionals informs a new activity pacing framework for chronic pain/fatigue. Musculoskeletal Care. 2019; 17(4):335-345

17. Antiel RM, Caudill JS, Burkhardt BE, Brands CK, Fischer PR. Iron insufficiency and hypovitaminosis D in adolescents with chronic fatigue and orthostatic intolerance. Southern Medical Journal. 2011; 104(8):609-611

18. Armstrong CW, McGregor NR, Sheedy JR, Buttfield I, Butt HL, Gooley PR. NMR metabolic profiling of serum identifies amino acid disturbances in chronic fatigue syndrome. Clinica Chimica Acta. 2012; 413(19-20):1525-1531

19. Arnold LM, Blom TJ, Welge JA, Mariutto E, Heller A. A randomized, placebo-controlled, double-blinded trial of duloxetine in the treatment of general fatigue in patients with chronic fatigue syndrome. Psychosomatics. 2015; 56(3):242-253

20. Ates K, Carlak HF, Ozen S. Magnetic field exposures due to underground power cables: A simulation study. Proceedings of the 2nd World Congress on Electrical Engineering and Computer Systems and Science. 2016:EEE 133

21. Augusto CRA, Navia CE, de Oliveira MN, Nepomuceno AA, Fauth AC, Kopenkin V et al. Relativistic proton levels from region AR 12673 (GLE #72) and the heliospheric current sheet as a sun–earth magnetic connection. Publications of the Astronomical Society of the Pacific. 2018; 131(996):024401

22. BACME. CFS/ME national services survey February 2018. 2019. Available from: https://www.bacme.info/sites/bacme.info/files/BACME%20CFS%20ME%20National%20services%20survey%20March19.pdf

23. Balaguru S, Uppal R, Vaid RP, Kumar BP. Investigation of the spinal cord as a natural receptor antenna for incident electromagnetic waves and possible impact on the central nervous system. Electromagnetic Biology and Medicine. 2012; 31(2):101-111

24. Baos S, Brigden A, Anderson E, Hollingworth W, Price S, Mills N et al. Investigating the effectiveness and cost-effectiveness of FITNET-NHS (Fatigue In Teenagers on the interNET in the NHS) compared to Activity Management to treat paediatric chronic fatigue syndrome (CFS)/myalgic encephalomyelitis (ME): Protocol for a randomised controlled trial. Trials. 2018; 19(1):136

25. Baraniuk JN. BMJ Best Practice: Chronic fatigue syndrome/Myalgic encephalomyelitis. 2018. Available from: https://bestpractice.bmj.com/topics/en-gb/277 Last accessed: 29/11/2019.

26. Baraniuk JN, Shivapurkar N. Exercise - induced changes in cerebrospinal fluid miRNAs in Gulf War Illness, Chronic Fatigue Syndrome and sedentary control subjects. Scientific Reports. 2017; 7:15338

27. Barnden LR, Kwiatek R, Crouch B, Burnet R, Del Fante P. Autonomic correlations with MRI are abnormal in the brainstem vasomotor centre in chronic fatigue syndrome. NeuroImage Clinical. 2016; 11:530-537

28. Barriers to access to social care for patients very severely affected by myalgic encephalomyelitis (ME). Submission to APPG on ME April 19th 2016 Roundtable Meeting on Social Care, chaired by Daniel Zeichner MP. 2016.

29. Bazelmans E, Prins JB, Hoogveld S, Bleijenberg G. Manual-based cognitive behaviour therapy for chronic fatigue syndrome: Therapists' adherence and perceptions. Cognitive Behaviour Therapy. 2004; 33(3):143-150

30. Bazelmans E, Prins JB, Lulofs R, van der Meer JW, Bleijenberg G, Netherlands Fatigue Research Group N. Cognitive behaviour group therapy for chronic fatigue syndrome: A non-randomised waiting list controlled study. Psychotherapy and Psychosomatics. 2005; 74(4):218-224

31. Bazilevskaya GA, Makhmutov VS, Sladkova AI. Gnevyshev gap effects in solar energetic particle activity. Advances in Space Research. 2006; 38(3):484-488

32. Beasant L, Brigden A, Anderson E, Mills N, Trist A, Crawley E. “All the programmes are designed around you”: Families views on graded exercise therapy for paediatric CFS/ME [Unpublished].

33. Belgian Ministry of Social Affairs, Public Health and Environment. Aanbevelingen betreffende de medischsociale, economische en juridische aspecten voor patienten met syndroom van chronische vermoeidheid. 2000. Available from: https://tinyurl.com/belgiumreportpdf

34. Bell DS. Prognosis of ME/CFS. 2016. Available from: https://www.omf.ngo/2016/08/01/prognosis-of-mecfs/ Last accessed: 26/11/2019.

35. Berkovitz S, Ambler G, Jenkins M, Thurgood S. Serum 25-hydroxy vitamin D levels in chronic fatigue syndrome: A retrospective survey. International Journal for Vitamin and Nutrition Research. 2009; 79(4):250-254

36. Blease C, Carel H, Geraghty K. Epistemic injustice in healthcare encounters: evidence from chronic fatigue syndrome. Journal of Medical Ethics. 2017; 43(8):549-557

37. Bloot L, Heins MJ, Donders R, Bleijenberg G, Knoop H. The process of change in pain during cognitive-behavior therapy for chronic fatigue syndrome. Clinical Journal of Pain. 2015; 31(10):914-921

38. Blue Ribbon for the Awareness of Myalgic Encephalomyelitis. Results of recent patient surveys on CBT, GET, PACING, REST [Unpublished]. 2010.

39. Boneva RS, Lin JS, Wieser F, Nater UM, Ditzen B, Taylor RN et al. Endometriosis as a comorbid condition in chronic fatigue syndrome (CFS): Secondary analysis of data from a CFS case-control study. Frontiers in Pediatrics. 2019; 7:195

40. Bould H, Collin SM, Lewis G, Rimes K, Crawley E. Depression in paediatric chronic fatigue syndrome. Archives of Disease in Childhood. 2013; 98(6):425-428

41. Bould H, Lewis G, Emond A, Crawley E. Depression and anxiety in children with CFS/ME: Cause or effect? Archives of Disease in Childhood. 2011; 96(3):211-214

42. Bowers JR, Valentine M, Harrison V, Fofanov VY, Gillece J, Delisle J et al. Genomic analyses of acute flaccid myelitis cases among a cluster in arizona provide further evidence of enterovirus D68 role. mBio. 2019; 10(1):e02262-02218

43. Brigden A, Barnett J, Parslow RM, Beasant L, Crawley E. Using the internet to cope with chronic fatigue syndrome/myalgic encephalomyelitis in adolescence: A qualitative study. BMJ Paediatrics Open. 2018; 2:e000299

44. Brigden A, Beasant L, Hollingworth W, Metcalfe C, Gaunt D, Mills N et al. Managed Activity Graded Exercise iN Teenagers and pre-Adolescents (MAGENTA) feasibility randomised controlled trial: Study protocol. BMJ Open. 2016; 6:e011255

45. Brigden A, Parslow RM, Gaunt D, Collin SM, Jones A, Crawley E. Defining the minimally clinically important difference of the SF-36 physical function subscale for paediatric CFS/ME: Triangulation using three different methods. Health & Quality of Life Outcomes. 2018; 16(1):202

46. Brigden AB, Beasant LB, Gaunt DG, Hollingworth WH, Mills NM, Solomon-Moore E et al. Results of the feasibility phase of the Managed Activity Graded Exercise iN Teenagers and Pre-Adolescents (MAGENTA) randomised controlled trial of treatments for chronic fatigue syndrome/myalgic encephalomyelitis [Unpublished].

47. Bringsli GJ, Gilje AM, Getz Wold BK. The Norwegian ME Association National Survey 2014. Oslo. 2014. Available from: http://www.me-foreningen.info/wp-content/uploads/2016/09/ME-Nat-Norwegian-Survey-Abr-Eng-Ver.pdf

48. Bristol CFS/ME Service. A qualitative evaluation of the Foundation Phase seminars [Unpublished].

49. Bristol CFS/ME Service. Survey of patients attending NHS specialist CFS/ME Services conducted April-July 2019. 2019.

50. Britain E, Muirhead NL, Finlay AY, Vyas J. The impact of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) on the family: measuring quality of life (QOL) using the WHOQOL-BREF and from-16 questionnaires. Journal of liMER,. 2019; 13(1):21

51. Brooks SK, Rimes KA, Chalder T. The role of acceptance in chronic fatigue syndrome. Journal of Psychosomatic Research. 2011; 71(6):411-415

52. Broughton J, Harris S, Beasant L, Crawley E, Collin SM. Adult patients' experiences of NHS specialist services for chronic fatigue syndrome (CFS/ME): A qualitative study in England. BMC Health Services Research. 2017; 17:384

53. Brouwers FM, Van Der Werf S, Bleijenberg G, Van Der Zee L, Van Der Meer JW. The effect of a polynutrient supplement on fatigue and physical activity of patients with chronic fatigue syndrome: A double-blind randomized controlled trial. QJM. 2002; 95(10):677-683

54. Brown AE, Jones DE, Walker M, Newton JL. Abnormalities of AMPK activation and glucose uptake in cultured skeletal muscle cells from individuals with chronic fatigue syndrome. PloS One. 2015; 10(4):e0122982

55. Brown MM, Bell DS, Jason LA, Christos C, Bell DE. Understanding long-term outcomes of chronic fatigue syndrome. Journal of Clinical Psychology. 2012; 68(9):1028-1035

56. Brown RC, Lockwood AH, Sonawane BR. Neurodegenerative diseases: An overview of environmental risk factors. Environmental Health Perspectives. 2005; 113(9):1250-1256

57. Brown S, Cox DL. Supporting pupils with chronic fatigue syndrome. Educational Psychology in Practice. 1999; 15(3):183-189

58. Bryan CS. Managing chronic fatigue syndrome: what's practical, and what isn't. Consultant. 1992; 32(4):33-40

59. Buchachenko A, Bukhvostov A, Ermakov K, Kuznetsov D. Nuclear spin selectivity in enzymatic catalysis: A caution for applied biophysics. Archives of Biochemistry and Biophysics. 2019; 667:30-35

60. Buchachenko A, Lawler RG. New possibilities for magnetic control of chemical and biochemical reactions. Accounts of Chemical Research. 2017; 50(4):877-884

61. Buchachenko AL, Kouznetsov DA, Arkhangelsky SE, Orlova MA, Markarian AA. Spin biochemistry: Magnetic 24Mg-25Mg-26Mg isotope effect in mitochondrial ADP phosphorylation. Cell Biochemistry and Biophysics. 2005; 43(2):243-251

62. Buchachenko AL, Kuznetsov DA, Berdinskii VL. [New mechanisms of biological effects of electromagnetic fields]. Biofizika. 2006; 51(3):545-552

63. Buchachenko AL, Orlov AP, Kuznetsov DA, Breslavskaya NN. Magnetic isotope and magnetic field effects on the DNA synthesis. Nucleic Acids Research. 2013; 41(17):8300-8307

64. Burgess M, Andiappan M, Chalder T. Cognitive behaviour therapy for chronic fatigue syndrome in adults: face to face versus telephone treatment: A randomized controlled trial. Behavioural and Cognitive Psychotherapy. 2012; 40(2):175-191

65. Burke HE. Handbook of magnetic phenomena. New York, NY. Van Nostrand Reinhold. 1986.

66. Butland RJ, Pang J, Gross ER, Woodcock AA, Geddes DM. Two-, six-, and 12-minute walking tests in respiratory disease. British Medical Journal (Clinical Research Ed). 1982; 284(6329):1607-1608

67. Calello M. Two Virginia children diagnosed with polio-like illness AFM. 2018. Available from: https://eu.newsleader.com/story/news/2018/11/26/two-virginia-kids-diagnosed-polio-like-illness-afm-cdc-virginia-department-health/2115535002/ Last accessed: 05/12/2019.

68. Carpenter DO. Human disease resulting from exposure to electromagnetic fields. Reviews on Environmental Health. 2013; 28(4):159-172

69. Carruthers BM, Jain AK, De Meirleir KL, Peterson DL, Klimas NG, Lemer AM et al. Myalgic encephalomyelitis/chronic fatigue syndrome: Clinical working case definition, diagnostic and treatment protocols. Journal of Chronic Fatigue Syndrome. 2003; 11(1):7-115

70. Carruthers BM, Van de Sande MI. Myalgic encephalomyelitis-adult & pediatric: International Consensus Primer for Medical Practitioners. 2012. Available from: http://www.investinme.org/index.shtml

71. Carruthers BM, van de Sande MI, De Meirleir KL, Klimas NG, Broderick G, Mitchell T et al. Myalgic encephalomyelitis: International Consensus Criteria. Journal of Internal Medicine. 2011; 270(4):327-338

72. Casanova C, Celli BR, Barria P, Casas A, Cote C, de Torres JP et al. The 6-min walk distance in healthy subjects: Reference standards from seven countries. European Respiratory Journal. 2011; 37(1):150-156

73. Castro-Marrero J, Saez-Francas N, Santillo D, Alegre J. Treatment and management of chronic fatigue syndrome/myalgic encephalomyelitis: All roads lead to Rome. British Journal of Pharmacology. 2017; 174(5):345-369

74. Castro-Marrero J, Saez-Francas N, Segundo MJ, Calvo N, Faro M, Aliste L et al. Effect of coenzyme Q10 plus nicotinamide adenine dinucleotide supplementation on maximum heart rate after exercise testing in chronic fatigue syndrome - A randomized, controlled, double-blind trial. Clinical Nutrition. 2016; 35(4):826-834

75. Cella M, Chalder T, White PD. Does the heterogeneity of chronic fatigue syndrome moderate the response to cognitive behaviour therapy? An exploratory study. Psychotherapy and Psychosomatics. 2011; 80(6):353-358

76. Cella M, Stahl D, Reme SE, Chalder T. Therapist effects in routine psychotherapy practice: an account from chronic fatigue syndrome. Psychotherapy research: Journal of the Society for Psychotherapy Research. 2011; 21(2):168-178

77. Centers for Disease Control and Prevention. Acute flaccid myelitis. 2019. Available from: https://www.cdc.gov/acute-flaccid-myelitis/cases-in-us.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Facute-flaccid-myelitis%2Fafm-cases.html Last accessed: 04/12/2019.

78. CFS/ME National Outcomes Database Team, SW London and Surrey CFS service NOD local Surrey. Report on Epsom and St Helier CFS/ME service. University of Bristol, 2016.

79. CFS/ME Service for South Yorkshire and North Derbyshire. CFS/ME Service for South Yorkshire and North Derbyshire outcomes up to 2018/19: clincal global improvement scale. 2019.

80. CFS/ME Service for South Yorkshire and North Derbyshire. Feedback after therapy: Summary comparing 2016 (54 replies) and 2018 (47 replies).

81. CFS/ME Working Group. Chief medical officer report of the CFS/ME working group: Annex 3 patient evidence [Unpublished]. 2002.

82. Chalder T. Assessing predictors of outcome and mediators of change in chronic fatigue syndrome after cognitive behaviour therapy. International Journal of Behavioural Medicine. 2010; 17(Suppl 1):228

83. Chalder T, Berelowitz G, Pawlikowska T, Watts L, Wessely S, Wright D et al. Development of a fatigue scale. Journal of Psychosomatic Research. 1993; 37(2):147-153

84. Chalder T, Deary V, Husain K, Walwyn R. Family-focused cognitive behaviour therapy versus psycho-education for chronic fatigue syndrome in 11- to 18-year-olds: A randomized controlled treatment trial. Psychological Medicine. 2010; 40(8):1269-1279

85. Chalder T, Goldsmith KA, White PD, Sharpe M, Pickles AR. Rehabilitative therapies for chronic fatigue syndrome: A secondary mediation analysis of the PACE trial. The Lancet Psychiatry. 2015; 2(2):141-152

86. Chan JSM, Ng S-M, Yuen L-P, Chan CLW. Chapter Five - Qigong exercise for chronic fatigue syndrome. 'In:' Yau S-Y, So K-F, editors. International Review of Neurobiology. 147: Academic Press. 2019. p. 121-153.

87. Chang CM, Warren JL, Engels EA. Chronic fatigue syndrome and subsequent risk of cancer among elderly US adults. Cancer. 2012; 118(23):5929-5936

88. Chaudhuri A, Condon BR, Gow JW, Brennan D, Hadley DM. Proton magnetic resonance spectroscopy of basal ganglia in chronic fatigue syndrome. Neuroreport. 2003; 14(2):225-228

89. Childs K, Krockakova Lerari A, Pattinson P, Smith L, Woodvine K. Parental perspectives of diagnosis and management of ME/CFS in children and young people [Unpublished]. 2019.

90. Christley Y, Hollins Martin CJ, Martin CR. Perinatal perspectives on chronic fatigue syndrome. British Journal of Midwifery. 2012; 20(6):389-393

91. Chu L, Valencia IJ, Garvert DW, Montoya JG. Deconstructing post-exertional malaise in myalgic encephalomyelitis/ chronic fatigue syndrome: A patient-centered, cross-sectional survey. PloS One. 2018; 13(6):e0197811

92. Claypoole KH, Noonan C, Mahurin RK, Goldberg J, Erickson T, Buchwald D. A twin study of cognitive function in chronic fatigue syndrome: The effects of sudden illness onset. Neuropsychology. 2007; 21(4):507-513

93. Cleare AJ, Roberts A, Papadopoulos A, Chalder T, Wessely S. P.6.077 Cognitive behavioural therapy normalises HPA axis dysfunction in chronic fatigue syndrome. European Neuropsychopharmacology. 2004; 14(Suppl 3):S389

94. Cliff JM, King EC, Lee JS, Sepulveda N, Wolf AS, Kingdon C et al. Cellular immune function in myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). Frontiers in Immunology. 2019; 10:796

95. Clinical trial to measure the maximum HR after ReConnect® supplementation vs. Placebo in CFS (ReConnect) [NCT02063126]. 2015. Available from: https://www.clinicaltrials.gov/ct2/show/NCT02063126?recrs=aef&type=Intr&cond=Cfs&draw=7 Last accessed: 29/11/2019.

96. Cockshell SJ, Mathias JL. Cognitive functioning in chronic fatigue syndrome: A meta-analysis. Psychological Medicine. 2010; 40(8):1253-1267

97. Collin SM, Bakken IJ, Nazareth I, Crawley E, White PD. Health care resource use by patients before and after a diagnosis of chronic fatigue syndrome (CFS/ME): A clinical practice research datalink study. BMC Family Practice. 2017; 18(1):60

98. Collin SM, Bakken IJ, Nazareth I, Crawley E, White PD. Trends in the incidence of chronic fatigue syndrome and fibromyalgia in the UK, 2001-2013: A Clinical Practice Research Datalink study. Journal of the Royal Society of Medicine. 2017; 110(6):231-244

99. Collin SM, Crawley E. Specialist treatment of chronic fatigue syndrome/ME: A cohort study among adult patients in England. BMC Health Services Research. 2017; 17(1):488

100. Collin SM, Crawley E, May MT, Sterne JA, Hollingworth W, UK CFS/ME National Outcomes Database. The impact of CFS/ME on employment and productivity in the UK: A cross-sectional study based on the CFS/ME national outcomes database. BMC Health Services Research. 2011; 11:217

101. Collin SM, Heron J, Nikolaus S, Knoop H, Crawley E. Chronic fatigue syndrome (CFS/ME) symptom-based phenotypes and 1-year treatment outcomes in two clinical cohorts of adult patients in the UK and The Netherlands. Journal of Psychosomatic Research. 2018; 104:29-34

102. Collin SM, Nikolaus S, Heron J, Knoop H, White PD, Crawley E. Chronic fatigue syndrome (CFS) symptom-based phenotypes in two clinical cohorts of adult patients in the UK and The Netherlands. Journal of Psychosomatic Research. 2016; 81:14-23

103. Collin SM, Nuevo R, van de Putte EM, Nijhof SL, Crawley E. Chronic fatigue syndrome (CFS) or myalgic encephalomyelitis (ME) is different in children compared to in adults: A study of UK and Dutch clinical cohorts. BMJ Open. 2015; 5(10):e008830

104. Collin SM, Sterne JA, Hollingworth W, May MT, Crawley E. Equity of access to specialist chronic fatigue syndrome (CFS/ME) services in England (2008-2010): A national survey and cross-sectional study. BMJ Open. 2012; 2:e001417

105. Comhaire F. Treating patients suffering from myalgic encephalopathy/chronic fatigue syndrome (ME/CFS) with sodium dichloroacetate: An open-label, proof-of-principle pilot trial. Medical Hypotheses. 2018; 114:45-48

106. Cook DB, Light AR, Light KC, Broderick G, Shields MR, Dougherty RJ et al. Neural consequences of post-exertion malaise in myalgic encephalomyelitis/chronic fatigue syndrome. Brain, Behavior, and Immunity. 2017; 62:87-99

107. Cooper M. North of Tyne CFS/ME service evaluation report: October 2018-January 2019. The New Castle Upon Tyne Hospitals NHS Foundation Trust, 2019.

108. Corsius LAMM, Crijnen BGPJM, Hogeweg AA, Kuijper JSM. Zorg voor beterebehandeling bij ME. Enquête onder ME-patiënten naar hun ervaringen met behandelingen bij ME. 2019. Available from: https://www.me-cvsvereniging.nl/sites/default/files/documenten/Rapport%20Zorg%20voor%20betere%20behandeling.pdf

109. Costa DC, Tannock C, Brostoff J. Brainstem perfusion is impaired in chronic fatigue syndrome. QJM. 1995; 88(11):767-773

110. Crawford J. Internet-based CBT for adolescents with chronic fatigue syndrome. Lancet. 2012; 380(9841):561-562

111. Crawford JS. Effect of a demanding cognitive task on neuropsychological performance in myalgic encephalomyelitis / chronic fatigue syndrome (ME/CFS) and Persian Gulf War illness (GWI). Proceedings of the British Psychological Society. 2010; 18(1)

112. Crawford JS, Reeves A. The patient's voice: An exploration of what aids or hinders patients with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) in the counselling process? Proceedings of the British Psychological Society. 2012; 20(1)

113. Crawley E, Collin SM, White PD, Rimes K, Sterne JA, May MT et al. Treatment outcome in adults with chronic fatigue syndrome: A prospective study in England based on the CFS/ME National Outcomes Database. QJM. 2013; 106(6):555-565

114. Crawley E, Hunt L, Stallard P. Anxiety in children with CFS/ME. European Child and Adolescent Psychiatry. 2009; 18(11):683-689

115. Crawley E, Mills N, Beasant L, Johnson D, Collin SM, Deans Z et al. The feasibility and acceptability of conducting a trial of specialist medical care and the Lightning Process in children with chronic fatigue syndrome: feasibility randomized controlled trial (SMILE study). Trials. 2013; 14:415

116. Crawley E, Sterne JA. Association between school absence and physical function in paediatric chronic fatigue syndrome/myalgic encephalopathy. Archives of Disease in Childhood. 2009; 94(10):752-756

117. Crawley EM, Emond AM, Sterne JA. Unidentified chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) is a major cause of school absence: Surveillance outcomes from school-based clinics. BMJ Open. 2011; 1:e000252

118. Crawley EM, Gaunt DM, Garfield K, Hollingworth W, Sterne JAC, Beasant L et al. Clinical and cost-effectiveness of the Lightning Process in addition to specialist medical care for paediatric chronic fatigue syndrome: Randomised controlled trial. Archives of Disease in Childhood. 2018; 103(2):155-164

119. Crowhurst G. Supporting people with severe myalgic encephalomyelitis. Nursing Standard. 2005; 19(21):38-43

120. Crowhurst G, Crowhurst L. A survey of severe ME patients in Norfolk and Suffolk, November 2007. 2007.

121. Currell S. North of Tyne CFS/ME rehabilitation and management team: Service evaluation 2017/18. The Newcastle Upon Tyne Hospitals NHS Foundation Trust.

122. DARPA. RadioBio: What role does electromagnetic signaling have in biological systems? 2017. Available from: https://www.darpa.mil/news-events/2017-02-07 Last accessed: 04/12/2019.

123. Davenport TE, Lehnen M, Stevens SR, VanNess JM, Stevens J, Snell CR. Chronotropic intolerance: An overlooked determinant of symptoms and activity limitation in myalgic encephalomyelitis/chronic fatigue syndrome? Frontiers in Pediatrics. 2019; 7:82

124. Davenport TE, Stevens SR, Baroni K, Van Ness JM, Snell CR. Reliability and validity of Short Form 36 Version 2 to measure health perceptions in a sub-group of individuals with fatigue. Disability and Rehabilitation. 2011; 33(25-26):2596-2604

125. Davenport TE, Stevens SR, Baroni K, Van Ness M, Snell CR. Diagnostic accuracy of symptoms characterising chronic fatigue syndrome. Disability and Rehabilitation. 2011; 33(19-20):1768-1775

126. Davenport TE, Stevens SR, VanNess JM, Stevens J, Snell CR. Checking our blind spots: Current status of research evidence summaries in ME/CFS. British Journal of Sports Medicine. 2019; 53(19):1198

127. Davenport TE, Stevens SR, VanNess MJ, Snell CR, Little T. Conceptual model for physical therapist management of chronic fatigue syndrome/myalgic encephalomyelitis. Physical Therapy. 2010; 90(4):602-614

128. Davies S, Crawley E. Chronic fatigue syndrome in children aged 11 years old and younger. Archives of Disease in Childhood. 2008; 93(5):419-421

129. De Becker P, McGregor N, De Meirleir K. A definition-based analysis of symptoms in a large cohort of patients with chronic fatigue syndrome. Journal of Internal Medicine. 2001; 250(3):234-240

130. De Becker P, Roeykens J, Reynders M, McGregor N, De Meirleir K. Exercise capacity in chronic fatigue syndrome. Archives of Internal Medicine. 2000; 160(21):3270-3277

131. de Carvalho Leite JC, de LDM, Killett A, Kale S, Nacul L, McArthur M et al. Social support needs for equity in health and social care: a thematic analysis of experiences of people with chronic fatigue syndrome/myalgic encephalomyelitis. International Journal for Equity in Health. 2011; 10:46

132. de Lange FP, Koers A, Kalkman JS, Bleijenberg G, Hagoort P, van der Meer JW et al. Increase in prefrontal cortical volume following cognitive behavioural therapy in patients with chronic fatigue syndrome. Brain. 2008; 131(Pt 8):2172-2180

133. de Vega WC, Herrera S, Vernon SD, McGowan PO. Epigenetic modifications and glucocorticoid sensitivity in myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). BMC Medical Genomics. 2017; 10(1):11

134. Deale A, Chalder T, Marks I, Wessely S. Cognitive behavior therapy for chronic fatigue syndrome: A randomized controlled trial. American Journal of Psychiatry. 1997; 154(3):408-414

135. Deale A, Chalder T, Wessely S. Illness beliefs and treatment outcome in chronic fatigue syndrome. Journal of Psychosomatic Research. 1998; 45(1):77-83

136. Deale A, Husain K, Chalder T, Wessely S. Long-term outcome of cognitive behavior therapy versus relaxation therapy for chronic fatigue syndrome: A 5-year follow-up study. American Journal of Psychiatry. 2001; 158(12):2038-2042

137. Deftereos SN, Vernon SD, Persidis A. Current therapeutic strategies for myalgic encephalomyelitis/chronic fatigue syndrome: Results of an online survey. Fatigue: Biomedicine, Health and Behavior. 2016; 4(1):39-51

138. DeLuca J, Christodoulou C, Diamond BJ, Rosenstein ED, Kramer N, Ricker JH et al. The Nature of Memory Impairment in Chronic Fatigue Syndrome. Rehabilitation Psychology. 2004; 49(1):62-70

139. Devasahayam A, Lawn T, Murphy M, White PD. Alternative diagnoses to chronic fatigue syndrome in referrals to a specialist service: Service evaluation survey. JRSM Short Reports. 2012; 3:4

140. Diao YL, Sun WN, He YQ, Leung SW, Siu YM. Equivalent magnetic vector potential model for low-frequency magnetic exposure assessment. Physics in Medicine and Biology. 2017; 62(19):7905-7922

141. Dobson J. Magnetic properties of biological material. Bioengineering and biophysical aspects of electromagnetic fields. 3rd ed: CRC Press,. 2007.

142. Dougall D, Johnson A, Goldsmith K, Sharpe M, Angus B, Chalder T et al. Adverse events and deterioration reported by participants in the PACE trial of therapies for chronic fatigue syndrome. Journal of Psychosomatic Research. 2014; 77(1):20-26

143. Doukrou M, Hiremath S, Ferin K, Jones S, Begent J, Segal T. G612(P) Characterisation of population, review of service provision, and outcomes for young people with chronic fatigue syndrome in a tertiary care inpatient setting. Archives of Disease in Childhood. 2019; 104(Suppl 2):A247-A247

144. Dowsett EG, Colby J. Long-term sickness absence due to ME/CFS in UK schools: An epidemiological study with medical and educational implications. Journal of Chronic Fatigue Syndrome. 1997; 3(2):29-42

145. Duyn JH, Schenck J. Contributions to magnetic susceptibility of brain tissue. NMR in Biomedicine. 2017; 30(4):1-37

146. Dyda A, Stelzer-Braid S, Adam D, Chughtai AA, MacIntyre CR. The association between acute flaccid myelitis (AFM) and Enterovirus D68 (EV-D68) - what is the evidence for causation? Euro Surveillance. 2018; 23(3):17-00310

147. Effective Health Care Program: Agency for Healthcare Research and Quality (AHRQ). Diagnosis and treatment of myalgic encephalomyelitis/chronic fatigue syndrome. U.S. Department of Health & Human Services, 2014. Available from: https://effectivehealthcare.ahrq.gov/sites/default/files/pdf/chronic-fatigue_research-protocol.pdf

148. Emerge Australia. Health and wellbeing survey 2018. 2018.

149. Emerge Australia. Health and wellbeing survey 2019. 2019. Available from: https://www.emerge.org.au/health-and-wellbeing-survey-report

150. Encephalitis Society. What is encephalitis? 2017. Available from: https://www.encephalitis.info/what-is-encephalitis Last accessed: 29/11/2019.

151. Eroshenko E, Belov A, Mavromichalaki H, Mariatos G, Oleneva V, Plainaki C et al. Cosmic-ray variations during the two greatest bursts of solar activity in the 23rd solar cycle. Solar Physics. 2004; 224(1):345-358

152. Evidence submissions to Health Select Committee Inquiry into aspects of the work of the National Institute for Health and Clinical Excellence (NICE). House of Commons, 2017. Available from: https://publications.parliament.uk/pa/cm200607/cmselect/cmhealth/503/503we01.htm

153. Executive Summary from Forward ME of survey conducted by Prof. Helen Dawes. 2019. Available from: http://www.meresearch.org.uk/wp-content/uploads/2019/04/Amended-Final-Consolidated-Report.pdf

154. Falk Hvidberg M, Brinth LS, Olesen AV, Petersen KD, Ehlers L. The health-related quality of life for patients with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). PloS One. 2015; 10(7):e0132421

155. Faulkner G. In the expectation of recovery: Misleading medical research and welfare reform. The centre for Welfare Reform, 2016. Available from: https://www.centreforwelfarereform.org/uploads/attachment/492/in-the-expectation-of-recovery.pdf

156. Fisher H, Crawley E. Why do young people with CFS/ME feel anxious? A qualitative study. Clinical Child Psychology and Psychiatry. 2013; 18(4):556-573

157. Fisk JD, Ritvo PG, Ross L, Haase DA, Marrie TJ, Schlech WF. Measuring the functional impact of fatigue: Initial validation of the fatigue impact scale. Clinical Infectious Diseases. 1994; 18(Suppl 1):S79-83

158. Flo E, Chalder T. Prevalence and predictors of recovery from chronic fatigue syndrome in a routine clinical practice. Behaviour Research and Therapy. 2014; 63:1-8

159. Fluge O, Mella O, Bruland O, Risa K, Dyrstad SE, Alme K et al. Metabolic profiling indicates impaired pyruvate dehydrogenase function in myalgic encephalopathy/chronic fatigue syndrome. JCI Insight. 2016; 1(21):e89376

160. Fluge O, Rekeland IG, Lien K, Thurmer H, Borchgrevink PC, Schafer C et al. B-Lymphocyte depletion in patients with myalgic encephalomyelitis/chronic fatigue syndrome: A randomized, double-blind, placebo-controlled trial. Annals of Internal Medicine. 2019; 170(9):585-593

161. Fluge O, Risa K, Lunde S, Alme K, Rekeland IG, Sapkota D et al. B-Lymphocyte Depletion in Myalgic Encephalopathy/ Chronic Fatigue Syndrome. An Open-Label Phase II Study with Rituximab Maintenance Treatment. PloS One. 2015; 10(7):e0129898

162. Franklin JD, Atkinson G, Atkinson JM, Batterham AM. Peak oxygen uptake in chronic fatigue syndrome/myalgic encephalomyelitis: A meta-analysis. International Journal of Sports Medicine. 2018; 40(2):77-87

163. Fukuda S, Nojima J, Kajimoto O, Yamaguti K, Nakatomi Y, Kuratsune H et al. Ubiquinol-10 supplementation improves autonomic nervous function and cognitive function in chronic fatigue syndrome. Biofactors. 2016; 42(4):431-440

164. Garner R, Baraniuk JN. Orthostatic intolerance in chronic fatigue syndrome. Journal of Translational Medicine. 2019; 17:185

165. Geraghty K, Hann M, Kurtev S. Myalgic encephalomyelitis/chronic fatigue syndrome patients' reports of symptom changes following cognitive behavioural therapy, graded exercise therapy and pacing treatments: Analysis of a primary survey compared with secondary surveys. Journal of Health Psychology. 2017; 24(10):1318-1333

166. Geraghty K, Jason L, Sunnquist M, Tuller D, Blease C, Adeniji C. The 'cognitive behavioural model' of chronic fatigue syndrome: Critique of a flawed model. Health Psychology Open. 2019; 6(1):1-14

167. Geraghty KJ, Adeniji C. The importance of accurate diagnosis of ME/CFS in children and adolescents: A commentary. Frontiers in Pediatrics. 2019; 6:435

168. Geraghty KJ, Blease C. Cognitive behavioural therapy in the treatment of chronic fatigue syndrome: A narrative review on efficacy and informed consent. Journal of Health Psychology. 2018; 23(1):127-138

169. Geraghty KJ, Blease C. Myalgic encephalomyelitis/chronic fatigue syndrome and the biopsychosocial model: A review of patient harm and distress in the medical encounter Disability and Rehabilitation. 2019; 41(25):3092-3102

170. Geraghty KJ, Esmail A. Chronic fatigue syndrome: Is the biopsychosocial model responsible for patient dissatisfaction and harm? British Journal of General Practice. 2016; 66(649):437-438

171. Ghatineh S, Vink M. FITNET's internet-based cognitive behavioural therapy is ineffective and may impede natural recovery in adolescents with myalgic encephalomyelitis/chronic fatigue syndrome. A review. Behavioral Sciences. 2017; 7(3):11

172. Gielissen MF, Knoop H, Servaes P, Kalkman JS, Huibers MJ, Verhagen S et al. Differences in the experience of fatigue in patients and healthy controls: Patients' descriptions. Health & Quality of Life Outcomes. 2007; 5:36

173. Gieré R. Magnetite in the human body: Biogenic vs. anthropogenic. Proceedings of the National Academy of Sciences. 2016; 113(43):11986-11987

174. Gilder SA, Wack M, Kaub L, Roud SC, Petersen N, Heinsen H et al. Distribution of magnetic remanence carriers in the human brain. Scientific Reports. 2018; 8:11363

175. Gladwell PW, Pheby D, Rodriguez T, Poland F. Use of an online survey to explore positive and negative outcomes of rehabilitation for people with CFS/ME. Disability and Rehabilitation. 2014; 36(5):387-394

176. Goedendorp MM, Knoop H, Schippers GM, Bleijenberg G. The lifestyle of patients with chronic fatigue syndrome and the effect on fatigue and functional impairments. Journal of Human Nutrition & Dietetics. 2009; 22(3):226-231

177. Haig-Ferguson A, Loades M, Whittle C, Read R, Higson-Sweeney N, Beasant L et al. "It's not one size fits all"; the use of videoconferencing for delivering therapy in a Specialist Paediatric Chronic Fatigue Service. Internet Interventions. 2019; 15:43-51

178. Haig-Ferguson A, Tucker P, Eaton N, Hunt L, Crawley E. Memory and attention problems in children with chronic fatigue syndrome or myalgic encephalopathy. Archives of Disease in Childhood. 2009; 94(10):757-762

179. Halapy E, Parlor M. Trends in the Canadian Community Health Survey Data - 2005, 2010, 2014. Quest. 2017; 112(Fall)

180. Harada ND, Chiu V, Stewart AL. Mobility-related function in older adults: Assessment with a 6-minute walk test. Archives of Physical Medicine and Rehabilitation. 1999; 80(7):837-841

181. Haywood KL, Collin SM, Crawley E. Assessing severity of illness and outcomes of treatment in children with chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME): A systematic review of patient-reported outcome measures (PROMs). Child: Care, Health and Development. 2014; 40(6):806-824

182. Haywood KL, Staniszewska S, Chapman S. Quality and acceptability of patient-reported outcome measures used in chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME): A systematic review. Quality of Life Research. 2012; 21(1):35-52

183. Heald A, Barber L, Jones HL, Farman S, Walther A. Service based comparison of group cognitive behavior therapy to waiting list control for chronic fatigue syndrome with regard to symptom reduction and positive psychological dimensions. Medicine (Baltimore). 2019; 98(39):e16720

184. Healthwatch Lancashire. ME/CFS report. 2017. Available from: https://www.healthwatch.co.uk/reports-library/me-cfs-patient-experience-report

185. Healthwatch Trafford. Patient experience report: Tired of explaining: Experiences of services for ME/CFS patients in Trafford and Greater Manchester. 2017. Available from: https://healthwatchtrafford.co.uk/wp-content/uploads/2015/03/Tired-of-explaining-ME-CFS-Report-by-Healthwatch-Trafford.pdf

186. Heins MJ, Knoop H, Bleijenberg G. The role of the therapeutic relationship in cognitive behaviour therapy for chronic fatigue syndrome. Behaviour Research and Therapy. 2013; 51(7):368-376

187. Heins MJ, Knoop H, Burk WJ, Bleijenberg G. The process of cognitive behaviour therapy for chronic fatigue syndrome: which changes in perpetuating cognitions and behaviour are related to a reduction in fatigue? Journal of Psychosomatic Research. 2013; 75(3):235-241

188. Heins MJ, Knoop H, Lobbestael J, Bleijenberg G. Childhood maltreatment and the response to cognitive behavior therapy for chronic fatigue syndrome. Journal of Psychosomatic Research. 2011; 71(6):404-410

189. Heins MJ, Knoop H, Prins JB, Stulemeijer M, van der Meer JW, Bleijenberg G. Possible detrimental effects of cognitive behaviour therapy for chronic fatigue syndrome. Psychotherapy and Psychosomatics. 2010; 79(4):249-256

190. Hives L, Bradley A, Richards J, Sutton C, Selfe J, Basu B et al. Can physical assessment techniques aid diagnosis in people with chronic fatigue syndrome/myalgic encephalomyelitis? A diagnostic accuracy study. BMJ Open. 2017; 7:e017521

191. Hodges LD, Nielsen T, Baken D. Physiological measures in participants with chronic fatigue syndrome, multiple sclerosis and healthy controls following repeated exercise: A pilot study. Clinical Physiology and Functional Imaging. 2018; 38(4):639-644

192. Holtzman CS, Bhatia S, Cotler J, Jason LA. Assessment of post-exertional malaise (PEM) in patients with myalgic encephalomyelitis (ME) and chronic fatigue syndrome (CFS): A patient-driven survey. Diagnostics. 2019; 9(1):1-13

193. Hughes AM, Hirsch CR, Nikolaus S, Chalder T, Knoop H, Moss-Morris R. Cross-cultural study of information processing biases in chronic fatigue syndrome:

Comparison of Dutch and UK chronic fatigue patients. International Journal of Behavioral Medicine. 2018; 25(1):49-54

194. Hughes JL. Illness narrative and chronic fatigue syndrome/myalgic encephalomyelitis: A review. The British Journal of Occupational Therapy. 2002; 65(1):9-14

195. Huibers MJ, Beurskens AJ, Van Schayck CP, Bazelmans E, Metsemakers JF, Knottnerus JA et al. Efficacy of cognitive-behavioural therapy by general practitioners for unexplained fatigue among employees: Randomised controlled trial. British Journal of Psychiatry. 2004; 184:240-246

196. Ickmans K, Meeus M, De Kooning M, Lambrecht L, Pattyn N, Nijs J. Can recovery of peripheral muscle function predict cognitive task performance in chronic fatigue syndrome with and without fibromyalgia? Physical Therapy. 2014; 94(4):511-522

197. ICNIRP Project Group. ICNIRP statement on diagnostic devices using non-ionizing radiation: Existing regulations and potential health risks. Health Physics. 2017; 112(3):305-321

198. Ingman T. A qualitative study investigating how people with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) view recovery [Thesis].

199. Ingman T. A systematic literature review investigating the prognosis and predictors of outcome following treatment for myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS)

200. Ingman T, Ali S, Bhui K, Chalder T. Chronic fatigue syndrome: Comparing outcomes in White British and Black and minority ethnic patients after cognitive-behavioural therapy. British Journal of Psychiatry. 2016; 209:251-256

201. Institute of Medicine. Beyond myalgic encephalomyelitis/chronic fatigue syndrome: Redefining an illness. Washington, DC. The National Academies Press. 2015. Available from: https://dx.doi.org/10.17226/19012

202. ISRCTN. A randomised controlled trial of adaptive pacing, cognitive behaviour therapy, and graded exercise, as supplements to standardised specialist medical care versus standardised specialist medical care alone for patients with the chronic fatigue syndrome/myalgic encephalomyelitis or encephalopathy. 2015. Available from: http://www.isrctn.com/ISRCTN54285094 Last accessed: 11/12/2019.

203. Jackson ML, Bruck D. Sleep abnormalities in chronic fatigue syndrome/myalgic encephalomyelitis: A review. Journal of Clinical Sleep Medicine. 2012; 8(6):719-728

204. Janse A, Bleijenberg G, Knoop H. Prediction of long-term outcome after cognitive behavioral therapy for chronic fatigue syndrome. Journal of Psychosomatic Research. 2019; 121:93-99

205. Janse A, Nikolaus S, Wiborg JF, Heins M, van der Meer JWM, Bleijenberg G et al. Long-term follow-up after cognitive behaviour therapy for chronic fatigue syndrome. Journal of Psychosomatic Research. 2017; 97:45-51

206. Janse A, van Dam A, Pijpers C, Wiborg JF, Bleijenberg G, Tummers M et al. Implementation of stepped care for patients with chronic fatigue syndrome in community-based mental health care: Outcomes at post-treatment and long-term follow-up. Behavioural and Cognitive Psychotherapy. 2019; 47(5):548-558

207. Janse A, Wiborg JF, Bleijenberg G, Tummers M, Knoop H. The efficacy of guided self-instruction for patients with idiopathic chronic fatigue: A randomized controlled trial. Journal of Consulting and Clinical Psychology. 2016; 84(5):377-388

208. Janse A, Worm-Smeitink M, Bleijenberg G, Donders R, Knoop H. Efficacy of web-based cognitive-behavioural therapy for chronic fatigue syndrome: Randomised controlled trial. British Journal of Psychiatry. 2018; 212(2):112-118

209. Janse A, Worm-Smeitink M, Bussel-Lagarde J, Bleijenberg G, Nikolaus S, Knoop H. Testing the efficacy of web-based cognitive behavioural therapy for adult patients with chronic fatigue syndrome (CBIT): Study protocol for a randomized controlled trial. BMC Neurology. 2015; 15:137

210. Jason L, Benton M, Torres-Harding S, Muldowney K. The impact of energy modulation on physical functioning and fatigue severity among patients with ME/CFS. Patient Education and Counseling. 2009; 77(2):237-241

211. Jason LA, Corradi K, Gress S, Williams S, Torres-Harding S. Causes of death among patients with chronic fatigue syndrome. Health Care for Women International. 2006; 27(7):615-626

212. Jason LA, Fennell PA, Taylor RR, Fricano G, Halpert JA. An empirical verification of the Fennell phases of the CFS illness. Journal of Chronic Fatigue Syndrome. 2000; 6(1):47-56

213. Jason LA, Jessen T, Porter N, Boulton A, Gloria-Njoku M, Friedberg F. Examining types of fatigue among individuals with ME/CFS. Disability Studies Quarterly. 2009; 29(3):1-16

214. Jason LA, McManimen SL, Sunnquist M, Holtzman CS. Patient perceptions of post exertional malaise. Fatigue: Biomedicine, Health and Behavior. 2018; 6(2):92-105

215. Jason LA, Taylor SL. Monitoring chronic fatigue syndrome. Journal of Nervous and Mental Disease. 1994; 182(4):243-244

216. Jason LA, Timpo P, Porter N, Herrington J, Brown M, Torres-Harding S et al. Activity logs as a measure of daily activity among patients with chronic fatigue syndrome. Journal of Mental Health. 2009; 18(6):549-556

217. Jason LA, Torres-Harding S, Brown M, Sorenson M, Donalek J, Corradi K et al. Predictors of change following participation in non-pharmacologic interventions for CFS. Japanese Society of Tropical Medicine. 2008; 36(1):22-32

218. Jason LA, Zinn ML, Zinn MA. Myalgic Encephalomyelitis: Symptoms and Biomarkers. Current Neuropharmacology. 2015; 13(5):701-734

219. Jelínek F, Pokorný Jí. Microtubules in biological cells as circular waveguides and resonators. Electro- and Magnetobiology. 2001; 20(1):75-80

220. Jenkins M, Rayman M. Nutrient intake is unrelated to nutrient status in patients with chronic fatigue syndrome. Journal of Nutritional and Environmental Medicine. 2005; 15(4):177-189

221. Jones DE, Hollingsworth KG, Jakovljevic DG, Fattakhova G, Pairman J, Blamire AM et al. Loss of capacity to recover from acidosis on repeat exercise in chronic fatigue syndrome: A case-control study. European Journal of Clinical Investigation. 2012; 42(2):186-194

222. Josev EK, Malpas CB, Seal ML, Scheinberg A, Lubitz L, Rowe K et al. Resting-state functional connectivity, cognition, and fatigue in response to cognitive exertion: a novel study in adolescents with chronic fatigue syndrome. Brain Imaging and Behavior. 2019;

223. Juutilainen J, Herrala M, Luukkonen J, Naarala J, Hore PJ. Magnetocarcinogenesis: Is there a mechanism for carcinogenic effects of weak magnetic fields? Proceedings: Biological Sciences. 2018; 285:20180590

224. Kapitein LC, Hoogenraad CC. Building the neuronal microtubule cytoskeleton. Neuron. 2015; 87(3):492-506

225. Kasevich R. Cellphones radars & health. IEEE Spectrum. 2002; 39(8):15-16

226. Keller BA, Pryor JL, Giloteaux L. Inability of myalgic encephalomyelitis/chronic fatigue syndrome patients to reproduce VO2peak indicates functional impairment. Journal of Translational Medicine. 2014; 12:104

227. Kempke S, Van Den Eede F, Schotte C, Claes S, Van Wambeke P, Van Houdenhove B et al. Prevalence of DSM-IV personality disorders in patients with chronic fatigue syndrome: A controlled study. International Journal of Behavioral Medicine. 2013; 20(2):219-228

228. Kenyon JN, Coe S, Izadi H. A retrospective outcome study of 42 patients with chronic fatigue syndrome, 30 of whom had irritable bowel syndrome. Half were treated with oral approaches, and half were treated with faecal microbiome transplantation. Human Microbiome Journal. 2019; 13:100061

229. Kim JH, Lee JK, Kim HG, Kim KB, Kim HR. Possible effects of radiofrequency electromagnetic field exposure on central nerve system. Biomolecules & Therapeutics. 2019; 27(3):265-275

230. Kindlon T. Change in grey matter volume cannot be assumed to be due to cognitive behavioural therapy. Brain: A Journal of Neurology. 2009; 132(1-2):e119

231. Kindlon T. Do graded activity therapies cause harm in chronic fatigue syndrome? Journal of Health Psychology. 2017; 22(9):1146-1154

232. Kindlon T. Elements of rehabilitative strategies associated with negative outcomes in CFS/ME: The need for further investigations. Disability and Rehabilitation. 2015; 37(5):466-467

233. Kindlon T. Harms of cognitive behaviour therapy designed to increase activity levels in chronic fatigue syndrome: Questions remain. Psychotherapy and Psychosomatics. 2011; 80(2):110-111; author reply 112

234. Kindlon T. Internet-based CBT for adolescents with chronic fatigue syndrome. The Lancet. 2012; 380(9841):561

235. Kindlon T. Objective compliance and outcome measures should be used in trials of exercise interventions for chronic fatigue syndrome. European Journal of Clinical Investigation. 2012; 42(12):1360-1361; author reply 1363-1365

236. Kindlon T. The PACE trial in chronic fatigue syndrome. Lancet. 2011; 377(9780):1833-1835

237. Kindlon T. Reporting of harms associated with graded exercise therapy and cognitive behavioural therapy in myalgic encephalomyelitis/chronic fatigue syndrome. Bulletin of the IACFS/ME. 2011; 19:59-111

238. Kindlon T. Response to: A pilot study of the process of change in a group chronic fatigue syndrome management programme. Bulletin of the IACFS/ME. 2009; 17:84-85

239. Kindlon T. Stratification using biological factors should be performed in more CFS studies. Psychological Medicine. 2010; 40:352

240. Kindlon T, Baldwin A. Response to: Reports of recovery in chronic fatigue syndrome may present less than meets the eye. Evidence-Based Mental Health. 2015; 18(2):e5

241. Kindlon T, Goudsmit EM. Graded exercise for chronic fatigue syndrome: Too soon to dismiss reports of adverse reactions. Journal of Rehabilitation Medicine. 2010; 42(2):184-186

242. Kindlon T, Shepherd C. Treatment of myalgic encephalomyelitis/chronic fatigue syndrome. Annals of Internal Medicine. 2015; 163(11):887-888

243. Kingdon CC, Bowman EW, Curran H, Nacul L, Lacerda EM. Functional status and well-being in people with myalgic encephalomyelitis/chronic fatigue syndrome compared with people with multiple sclerosis and healthy controls. PharmacoEconomics Open. 2018; 2:381-392

244. Knoester M, Helfferich J, Poelman R, Van Leer-Buter C, Brouwer OF, Niesters HGM. Twenty-nine cases of enterovirus-D68-associated acute flaccid myelitis in europe 2016: A case series and epidemiologic overview. Pediatric Infectious Disease Journal. 2019; 38(1):16-21

245. Knoop H, Bleijenberg G, Gielissen MF, van der Meer JW, White PD. Is a full recovery possible after cognitive behavioural therapy for chronic fatigue syndrome? Psychotherapy and Psychosomatics. 2007; 76(3):171-176

246. Knoop H, Prins JB, Stulemeijer M, van der Meer JW, Bleijenberg G. The effect of cognitive behaviour therapy for chronic fatigue syndrome on self-reported cognitive impairments and neuropsychological test performance. Journal of Neurology, Neurosurgery and Psychiatry. 2007; 78(4):434-436

247. Knoop H, Stulemeijer M, de Jong LW, Fiselier TJ, Bleijenberg G. Efficacy of cognitive behavioral therapy for adolescents with chronic fatigue syndrome: long-term follow-up of a randomized, controlled trial. Pediatrics. 2008; 121(3):e619-625

248. Knoop H, Stulemeijer M, Prins JB, van der Meer JW, Bleijenberg G. Is cognitive behaviour therapy for chronic fatigue syndrome also effective for pain symptoms? Behaviour Research and Therapy. 2007; 45(9):2034-2043

249. Knoop H, van der Meer JW, Bleijenberg G. Guided self-instructions for people with chronic fatigue syndrome: Randomised controlled trial. British Journal of Psychiatry. 2008; 193(4):340-341

250. Knudsen AK, Henderson M, Harvey SB, Chalder T. Long-term sickness absence among patients with chronic fatigue syndrome. British Journal of Psychiatry. 2011; 199:430-431

251. Kodama K. Application of broadband alternating current magnetic susceptibility to the characterization of magnetic nanoparticles in natural materials. Journal of Geophysical Research: Solid Earth. 2013; 118(1):1-12

252. Kreyberg S. Myalgic Encephalomyelitis/Postviral fatigue syndrome (G93.3). Basic concepts and guidelines for the diagnosis. 2007.

253. Kreyberg SE. [Caring for seriously ill ME-patients: A small survey]. Norwegian Journal of Nursing Research. 2007; 9(2):16-26

254. Kuehn B. Chronic fatigue care. JAMA. 2018; 320(8):750

255. Lacerda EM, Kingdon CC, Bowman EW, Nacul L. Using a participatory approach to develop and implement the UK ME/CFS Biobank. Fatigue. 2018; 6(1):1-4

256. Lacerda EM, McDermott C, Kingdon CC, Butterworth J, Cliff JM, Nacul L. Hope, disappointment and perseverance: Reflections of people with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and multiple sclerosis participating in biomedical research. A qualitative focus group study. Health Expectations. 2019; 22(3):373-384

257. LaManca JJ, Sisto SA, DeLuca J, Johnson SK, Lange G, Pareja J et al. Influence of exhaustive treadmill exercise on cognitive functioning in chronic fatigue syndrome. American Journal of Medicine. 1998; 105(3 Suppl. 1):59S-65S

258. Lapp CW. Initiating care of a patient with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). Frontiers in Pediatrics. 2019; 6:415

259. Larun L, Odgaard-Jensen J, Brurberg KG, Chalder T, Dybwad M, Moss-Morris RE et al. Exercise therapy for chronic fatigue syndrome (individual patient data). Cochrane Database of Systematic Reviews 2014, Issue 4. Art. No.: CD011040. DOI: http://dx.doi.org/10.1002/14651858.CD011040.

260. Leaman D. Magnetic rocks - Their effect on compass use and navigation in Tasmania. Papers and Proceedings of the Royal Society of Tasmania. 1997; 131:73-75

261. Leary S, Sylvester J, Shorter E, Moreno E. Your experience of ME services. Survey Report by #MEAction UK. 2019. Available from: https://www.meaction.net/wp-content/uploads/2019/10/Your-experience-of-ME-services-Survey-report-by-MEAction-UK.pdf https://www.meaction.net/wp-content/uploads/2019/10/Your-experience-of-ME-services-Survey-report-by-MEAction-UK.pdf

262. Leone SS, Huibers MJ, Kant I, Van Schayck CP, Bleijenberg G, André Knottnerus J. Long-term predictors of outcome in fatigued employees on sick leave: A 4-year follow-up study. Psychological Medicine. 2006; 36(9):1293-1300

263. Lewis I, Pairman J, Spickett G, Newton JL. Clinical characteristics of a novel subgroup of chronic fatigue syndrome patients with postural orthostatic tachycardia syndrome. Journal of Internal Medicine. 2013; 273(5):501-510

264. Lien K, Johansen B, Veierod MB, Haslestad AS, Bohn SK, Melsom MN et al. Abnormal blood lactate accumulation during repeated exercise testing in myalgic encephalomyelitis/chronic fatigue syndrome. Physiological Reports. 2019; 7(11):e14138

265. Light AR, White AT, Hughen RW, Light KC. Moderate exercise increases expression for sensory, adrenergic, and immune genes in chronic fatigue syndrome patients but not in normal subjects. Journal of Pain. 2009; 10(10):1099-1112

266. Lincolnshire Partnership. Lincolnshire Chronic Fatigue Syndrome/ME Service. Lincolnshire Partnership NHS Foundation Trust, 2019.

267. Liu X, Treister R, Lang M, Oaklander AL. IVIg for apparently autoimmune small-fiber polyneuropathy: First analysis of efficacy and safety. Therapeutic Advances in Neurological Disorders. 2018; 11:1-12

268. Lloyd S, Chalder T, Rimes KA. Family-focused cognitive behaviour therapy versus psycho-education for adolescents with chronic fatigue syndrome: Long-term follow-up of an RCT. Behaviour Research and Therapy. 2012; 50(11):719-725

269. Lloyd S, Chalder T, Sallis HM, Rimes KA. Telephone-based guided self-help for adolescents with chronic fatigue syndrome: A non-randomised cohort study. Behaviour Research and Therapy. 2012; 50(5):304-312

270. Loades ME, Read R, Smith L, Higson-Sweeney NT, Laffan A, Stallard P et al. Depression and anxiety in adolescent chronic fatigue syndrome (CFS): A clinical cohort study [Unpublished]. 2019;

271. Loades ME, Rimes KA, Ali S, Chalder T. Depressive symptoms in adolescents with chronic fatigue syndrome (CFS): Are rates higher than in controls and do depressive symptoms affect outcome? Clinical Child Psychology and Psychiatry. 2019; 24(3):580-592

272. Loades ME, Rimes KA, Ali S, Lievesley K, Chalder T. The presence of co-morbid mental health problems in a cohort of adolescents with chronic fatigue syndrome. Clinical Child Psychology and Psychiatry. 2018; 23(3):398-408

273. Loades ME, Sheils EA, Crawley E. Treatment for paediatric chronic fatigue syndrome or myalgic encephalomyelitis (CFS/ME) and comorbid depression: A systematic review. BMJ Open. 2016; 6:e012271

274. Loades ME, Smith L, Higson-Sweeney N, Beasant L, Stallard P, Kessler D et al. Obstacles to recruitment in paediatric studies focusing on mental health in a physical health context: The experiences of clinical gatekeepers in an observational cohort study. BMC Medical Research Methodology. 2019; 19(1):89

275. Loy BD, O'Connor PJ, Dishman RK. Effect of acute exercise on fatigue in people with ME/CFS/SEID: A Meta-analysis. Medicine and Science in Sports and Exercise. 2016; 48(10):2003-2012

276. Lyshevski SE, Tsouri GR. Molecular and biomolecular communication: Waveguides and possible role of microtubules. 2011 11th IEEE International Conference on Nanotechnology. 2011;

277. M.E. Group. Richmond & Kingston local area survey 2014. 2014.

278. M.E. Group. Richmond & Kingston local area survey 2019. 2019.

279. Maes M, Mihaylova I, De Ruyter M. Lower serum zinc in chronic fatigue syndrome (CFS): Relationships to immune dysfunctions and relevance for the oxidative stress status in CFS. Journal of Affective Disorders. 2006; 90(2-3):141-147

280. Maes M, Mihaylova I, Kubera M, Uytterhoeven M, Vrydags N, Bosmans E. Coenzyme Q10 deficiency in myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is related to fatigue, autonomic and neurocognitive symptoms and is another risk factor explaining the early mortality in ME/CFS due to cardiovascular disorder. Neuroendocrinology Letters. 2009; 30(4):470-476

281. Maes M, Twisk FN, Ringel K. Inflammatory and cell-mediated immune biomarkers in myalgic encephalomyelitis/chronic fatigue syndrome and depression: Inflammatory markers are higher in myalgic encephalomyelitis/chronic fatigue syndrome than in depression. Psychotherapy and Psychosomatics. 2012; 81(5):286-295

282. Marshall PS, Forstot M, Callies A, Peterson PK, Schenck CH. Cognitive slowing and working memory difficulties in chronic fatigue syndrome. Psychosomatic Medicine. 1997; 59(1):58-66

283. Marshall PS, Watson D, Steinberg P, Cornblatt B, Peterson PK, Callies A et al. An assessment of cognitive function and mood in chronic fatigue syndrome. Biological Psychiatry. 1996; 39(3):199-206

284. Mathew SJ, Mao X, Keegan KA, Levine SM, Smith EL, Heier LA et al. Ventricular cerebrospinal fluid lactate is increased in chronic fatigue syndrome compared with

generalized anxiety disorder: An in vivo 3.0 T (1)H MRS imaging study. NMR in Biomedicine. 2009; 22(3):251-258

285. May M, Emond A, Crawley E. Phenotypes of chronic fatigue syndrome in children and young people. Archives of Disease in Childhood. 2010; 95(4):245-249

286. McCourt A, Maile E, Gregorowski A, Hargreaves D, Segal T. G599(P) Characteristics of a patient population attending a specialist outpatient service for chronic fatigue syndrome. Archives of Disease in Childhood. 2019; 104(Suppl 2):A242-A242

287. McDermott C, Richards SC, Thomas PW, Montgomery J, Lewith G. A placebo-controlled, double-blind, randomized controlled trial of a natural killer cell stimulant (BioBran MGN-3) in chronic fatigue syndrome. QJM. 2006; 99(7):461-468

288. McGregor NR, Armstrong CW, Lewis DP, Butt HL, Gooley PR. Widespread pain and altered renal function in ME/CFS patients. Fatigue: Biomedicine, Health and Behavior. 2016; 4(3):132-145

289. McGregor NR, Armstrong CW, Lewis DP, Gooley PR. Post-exertional malaise is associated with hypermetabolism, hypoacetylation and purine metabolism deregulation in ME/CFS cases. Diagnostics. 2019; 9(3):70

290. McManimen S, McClellan D, Stoothoff J, Gleason K, Jason LA. Dismissing chronic illness: A qualitative analysis of negative health care experiences. Health Care for Women International. 2019; 40(3):241-258

291. McManimen SL, Devendorf AR, Brown AA, Moore BC, Moore JH, Jason LA. Mortality in patients with myalgic encephalomyelitis and chronic fatigue syndrome. Fatigue. 2016; 4(4):195-207

292. McPhee G, Baldwin A, Kindlon T, Hughes BM. Monitoring treatment harm in myalgic encephalomyelitis/chronic fatigue syndrome: A freedom-of-information study of National Health Service specialist centres in England. Journal of Health Psychology. 2019; https://doi.org/10.1177/1359105319854532

293. ME/cvs Vereniging. Report survey summary 'Zorg voor ME' (Care for ME). 2016. Available from: https://www.me-cvsvereniging.nl/sites/default/files/documenten/Report%20Survey%20Summary%20%27Zorg%20voor%20ME%27%20%28%E2%80%98Care%20for%20ME%E2%80%99%29.pdf

294. Meeus M, Hermans L, Ickmans K, Struyf F, Van Cauwenbergh D, Bronckaerts L et al. Endogenous pain modulation in response to exercise in patients with rheumatoid arthritis, patients with chronic fatigue syndrome and comorbid fibromyalgia, and healthy controls: A double-blind randomized controlled trial. Pain Practice. 2015; 15(2):98-106

295. Melamed KH, Santos M, Oliveira RKF, Urbina MF, Felsenstein D, Opotowsky AR et al. Unexplained exertional intolerance associated with impaired systemic oxygen extraction. European Journal of Applied Physiology. 2019; 119(10):2375-2389

296. Mihelicova M, Siegel Z, Evans M, Brown A, Jason L. Caring for people with severe myalgic encephalomyelitis: An interpretative phenomenological analysis of parents' experiences. Journal of Health Psychology. 2016; 21(12):2824-2837

297. Miller RR, Reid WD, Mattman A, Yamabayashi C, Steiner T, Parker S et al. Submaximal exercise testing with near-infrared spectroscopy in myalgic encephalomyelitis/chronic fatigue syndrome patients compared to healthy controls: A case-control study. Journal of Translational Medicine. 2015; 13:159

298. Millions Missing Canada. Iatrogenic harm: Spring survey results [Unpublished]. 2017.

299. Missen A, Hollingworth W, Eaton N, Crawley E. The financial and psychological impacts on mothers of children with chronic fatigue syndrome (CFS/ME). Child: Care, Health and Development. 2012; 38(4):505-512

300. Moneghetti KJ, Skhiri M, Contrepois K, Kobayashi Y, Maecker H, Davis M et al. Value of circulating cytokine profiling during submaximal exercise testing in myalgic encephalomyelitis/chronic fatigue syndrome. Scientific Reports. 2018; 8:2779

301. Montoya JG, Anderson JN, Adolphs DL, Bateman L, Klimas N, Levine SM et al. KPAX002 as a treatment for myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS): A prospective, randomized trial. International Journal of Clinical and Experimental Medicine. 2018; 11(3):2890-2900

302. Montoya JG, Kogelnik AM, Bhangoo M, Lunn MR, Flamand L, Merrihew LE et al. Randomized clinical trial to evaluate the efficacy and safety of valganciclovir in a subset of patients with chronic fatigue syndrome. Journal of Medical Virology. 2013; 85(12):2101-2109

303. Moore L. Chronic fatigue syndrome: All in the mind? An occupational therapy perspective. British Journal of Occupational Therapy. 2000; 63(4):163-170

304. Moore R, Derry S, Aldington D, Cole P, Wiffen P. Amitriptyline for neuropathic pain in adults. Cochrane Database of Systematic Reviews 2015, Issue 7. Art. No.: CD008242. DOI: 10.1002/14651858.CD008242.pub3.

305. Morens DM, Folkers GK, Fauci AS. Acute flaccid myelitis: Something old and something new. mBio. 2019; 10(2):e00521-00519

306. Morris G, Maes M. Mitochondrial dysfunctions in myalgic encephalomyelitis/chronic fatigue syndrome explained by activated immuno-inflammatory, oxidative and nitrosative stress pathways. Metabolic Brain Disease. 2014; 29:19-36

307. Murdock KW, Wang XS, Shi Q, Cleeland CS, Fagundes CP, Vernon SD. The utility of patient-reported outcome measures among patients with myalgic encephalomyelitis/chronic fatigue syndrome. Quality of Life Research. 2017; 26(4):913-921

308. Myalgic Encephalomyelitis / Chronic Fatigue Syndrome Advisory Committee. Report to the NHMRC Chief Executive Officer. 2019. Available from: https://www.nhmrc.gov.au/about-us/publications/mecfs-advisory-committee-report-nhmrc-chief-executive-officer#block-views-block-file-attachments-content-block-1

309. Nacul L, de Barros B, Kingdon CC, Cliff JM, Clark TG, Mudie K et al. Evidence of clinical pathology abnormalities in people with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) from an analytic cross-sectional study. Diagnostics. 2019; 9(2):1-16

310. Nacul L, Lacerda EM, Kingdon CC, Curran H, Bowman EW. How have selection bias and disease misclassification undermined the validity of myalgic encephalomyelitis/chronic fatigue syndrome studies? Journal of Health Psychology. 2019; 24(12):1765-1769

311. Nacul LC, Lacerda EM, Campion P, Pheby D, Drachler Mde L, Leite JC et al. The functional status and well being of people with myalgic encephalomyelitis/chronic fatigue syndrome and their carers. BMC Public Health. 2011; 11:402

312. Nacul LC, Lacerda EM, Pheby D, Campion P, Molokhia M, Fayyaz S et al. Prevalence of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) in three

regions of England: a repeated cross-sectional study in primary care. BMC Medicine. 2011; 9:91

313. Nacul LC, Mudie K, Kingdon CC, Clark TG, Lacerda EM. Hand grip strength as a clinical biomarker for ME/CFS and disease severity. Frontiers in Neurology. 2018; 9:992

314. Nagy-Szakal D, Barupal DK, Lee B, Che X, Williams BL, Kahn EJR et al. Insights into myalgic encephalomyelitis/chronic fatigue syndrome phenotypes through comprehensive metabolomics. Scientific Reports. 2018; 8:10056

315. Natelson BH, Mao X, Stegner AJ, Lange G, Vu D, Blate M et al. Multimodal and simultaneous assessments of brain and spinal fluid abnormalities in chronic fatigue syndrome and the effects of psychiatric comorbidity. Journal of the Neurological Sciences. 2017; 375:411-416

316. Natelson BH, Vu D, Coplan JD, Mao X, Blate M, Kang G et al. Elevations of ventricular lactate levels occur in both chronic fatigue syndrome and fibromyalgia. Fatigue. 2017; 5(1):15-20

317. National Centers for Environmental Information. Geomagnetism. Available from: https://www.ngdc.noaa.gov/geomag/geomag.shtml Last accessed: 04/12/2019.

318. National Collaborating Centre for Primary Care. Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): Diagnosis and management of chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy) in adults and children. NICE clinical guideline 53. London. Royal College of General Practitioners, 2007. Available from: http://guidance.nice.org.uk/CG53

319. National Institute for Health and Care Excellence. Developing NICE guidelines: the manual [Updated 2018]. London. National Institute for Health and Care Excellence, 2014. Available from: http://www.nice.org.uk/article/PMG20/chapter/1%20Introduction%20and%20overview

320. Naviaux RK, Gordon E. Reply to Roerink et al.: Metabolomics of chronic fatigue syndrome. Proceedings of the National Academy of Sciences. 2017; 114(6):E911

321. Naviaux RK, Naviaux JC, Li K, Bright AT, Alaynick WA, Wang L et al. Metabolic features of chronic fatigue syndrome. Proceedings of the National Academy of Sciences of the United States of America. 2016; 113(37):E5472-5480

322. Newberry F, Hsieh SY, Wileman T, Carding SR. Does the microbiome and virome contribute to myalgic encephalomyelitis/chronic fatigue syndrome? Clinical Science. 2018; 132(5):523-542

323. Newton JL, Mabillard H, Scott A, Hoad A, Spickett G. The Newcastle NHS Chronic Fatigue Syndrome Service: Not all fatigue is the same. Journal of the Royal College of Physicians of Edinburgh. 2010; 40(4):304-307

324. NHS North Bristol. Survey of patients attending NHS specialist CFS/ME Services conducted April-July 2019. North Bristol NHS Trust, 2019.

325. Nijhof SL, Bleijenberg G, Uiterwaal CS, Kimpen JL, van de Putte EM. Effectiveness of internet-based cognitive behavioural treatment for adolescents with chronic fatigue syndrome (FITNET): A randomised controlled trial. Lancet. 2012; 379(9824):1412-1418

326. Nijhof SL, Bleijenberg G, Uiterwaal CS, Kimpen JL, van de Putte EM. Fatigue In Teenagers on the interNET--the FITNET Trial. A randomized clinical trial of web-

based cognitive behavioural therapy for adolescents with chronic fatigue syndrome: Study protocol. BMC Neurology. 2011; 11:23

327. Nijhof SL, Priesterbach LP, Uiterwaal CSPM, Bleijenberg G, Kimpen JLL, Van De Putte EM. Internet-based therapy for adolescents with chronic fatigue syndrome: Long-term follow-up. Pediatrics. 2013; 131(6):e1788-e1795

328. Nijhof SL, Rutten JM, Uiterwaal CS, Bleijenberg G, Kimpen JL, Putte EM. The role of hypocortisolism in chronic fatigue syndrome. Psychoneuroendocrinology. 2014; 42:199-206

329. Norfolk and Suffolk Service. Patient survey report. 2009. Available from: http://nandsme.blogspot.com/p/patient-survey.html

330. Norris T, Hawton K, Hamilton-Shield J, Crawley E. Obesity in adolescents with chronic fatigue syndrome: An observational study. Archives of Disease in Childhood. 2017; 102(1):35-39

331. Ocon AJ, Messer ZR, Medow MS, Stewart JM. Increasing orthostatic stress impairs neurocognitive functioning in chronic fatigue syndrome with postural tachycardia syndrome. Clinical Science. 2012; 122(5):227-238

332. Odoom JK, Adziati I, Quansah E, Attiku K, Ntim NAA, Arthur-Quarm J et al. High serotype diversity of non-polio enteroviruses isolated in Ghana during acute flaccid paralysis surveillance, 2010-2014. Advances in Research. 2018; 16(6):1-9

333. Office for National Statistics. Mentions of postviral fatigue syndrome (benign myalgic encephalomyelitis), deaths registered in England and Wales, 2001 to 2016. 2018. Available from: https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/adhocs/008461mentionsofpostviralfatiguesyndromebenignmyalgicencephalomyelitisdeathsregisteredinenglandandwales2001to2016 Last accessed: 29/11/2019.

334. Ojo-Amaize EA, Conley EJ, Peter JB. Decreased natural killer cell activity is associated with severity of chronic fatigue immune dysfunction syndrome. Clinical Infectious Diseases. 1994; 18(Suppl 1):S157-159

335. Oliver C. University Hospitals of Derby & Burton Foundation Trust: CFS service outcomes 17-18 April. University Hospitals of Derby & Burton Foundation Trust, 2018.

336. Oxford Clinical Allied Technology and Trials Services Unit. Forward-ME Group CBT & GET Survey. 2019.

337. PACE Trial participant dataset. Available from: https://sites.google.com/site/pacefoir/pace-ipd_foia-qmul-2014-f73.xlsx Last accessed: 03/12/2019.

338. Packer TL, Foster DM, Brouwer B. Fatigue and activity patterns of people with chronic fatigue syndrome. Occupational Therapy Journal of Research. 1997; 17(3):186-199

339. Pakpoor J, Goldacre M. Neuroepidemiology: The increasing burden of mortality from neurological diseases. Nature Reviews: Neurology. 2017; 13:518-519

340. Parslow R, Patel A, Beasant L, Haywood K, Johnson D, Crawley E. What matters to children with CFS/ME? A conceptual model as the first stage in developing a PROM. Archives of Disease in Childhood. 2015; 100(12):1141-1147

341. Parslow RM, Anderson N, Byrne D, Shaw A, Haywood KL, Crawley E. Adolescent's descriptions of fatigue, fluctuation and payback in chronic fatigue syndrome/myalgic

encephalopathy (CFS/ME): Interviews with adolescents and parents. BMJ Paediatrics Open. 2018; 2:e000281

342. Parslow RM, Harris S, Broughton J, Alattas A, Crawley E, Haywood K et al. Children's experiences of chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME): A systematic review and meta-ethnography of qualitative studies. BMJ Open. 2017; 7:e012633

343. Parslow RM, Shaw A, Haywood KL, Crawley E. Important factors to consider when treating children with chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME): Perspectives of health professionals from specialist services. BMC Pediatrics. 2017; 17:43

344. Pastula DM, Aliabadi N, Haynes AK, Messacar K, Schreiner T, Maloney J et al. Acute neurologic illness of unknown etiology in children - Colorado, August-September 2014. MMWR: Morbidity and Mortality Weekly Report. 2014; 63(40):901-902

345. Pates A. My life stopped ... voices from action for M.E. 2014 survey: severe M.E. time to deliver report. Action for ME, 2014. Available from: https://www.actionforme.org.uk/uploads/pdfs/my-life-stopped-severe-ME-report.pdf

346. Patient survey results for FDA drug development meeting for ME and CFS, April 25-26, 2013 [Unpublished]. 2013.

347. Patrick Neary J, Roberts AD, Leavins N, Harrison MF, Croll JC, Sexsmith JR. Prefrontal cortex oxygenation during incremental exercise in chronic fatigue syndrome. Clinical Physiology and Functional Imaging. 2008; 28(6):364-372

348. Peci A, Winter A-L, Warshawsky B, Booth TF, Eshaghi A, Li A et al. Epidemiology of Enterovirus D68 in Ontario. PloS One. 2015; 10(11):e0142841

349. Peckerman A, LaManca JJ, Dahl KA, Chemitiganti R, Qureishi B, Natelson BH. Abnormal impedance cardiography predicts symptom severity in chronic fatigue syndrome. American Journal of the Medical Sciences. 2003; 326(2):55-60

350. Pemberton S, Cox D. Perspectives of time and occupation: Experiences of people with chronic fatigue syndrome/myalgic encephalomyelitis. Journal of Occupational Science. 2014; 21(4):488-503

351. Pemberton S, Cox DL. Experiences of daily activity in chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) and their implications for rehabilitation programmes. Disability and Rehabilitation. 2014; 36(21):1790-1797

352. Pemberton S, Dunn N, Bradley J, McKeever V. Survey of patient outcomes and experience for adults and young people accessing a ME/CFS rehabilitation service. 2019.

353. Perrin RN. Chronic fatigue syndrome, a review from the biomechanical perspective. British Osteopathic Journal. 1993; 11:15-23

354. Perrin RN, Edwards J, Hartley P. An evaluation of the effectiveness of osteopathic treatment on symptoms associated with myalgic encephalomyelitis. A preliminary report. Journal of Medical Engineering and Technology. 1998; 22(1):1-13

355. Perrin RN, Richards JD, Pentreath V, Percy DF. Muscle fatigue in chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) and its response to a manual therapeutic approach: A pilot study. International Journal of Osteopathic Medicine. 2011; 14(3):96-105

356. Peterson PK, Schenck CH, Sherman R. Chronic fatigue syndrome in Minnesota. Minnesota Medicine. 1991; 74(5):21-26

357. Peterson PK, Sirr SA, Grammith FC, Schenck CH, Pheley AM, Hu S et al. Effects of mild exercise on cytokines and cerebral blood flow in chronic fatigue syndrome patients. Clinical and Diagnostic Laboratory Immunology. 1994; 1(2):222-226

358. Pheby D, Saffron L. Risk factors for severe ME/CFS. Biology and Medicine. 2009; 1(4):50-74

359. Physios for M.E. An exploratory study of the experiences of M.E patients and physiotherapy [Unpublished].

360. Plascencia-Villa G, Ponce A, Collingwood JF, Arellano-Jiménez MJ, Zhu X, Rogers JT et al. High-resolution analytical imaging and electron holography of magnetite particles in amyloid cores of Alzheimer's disease. Scientific Reports. 2016; 6(1):24873

361. Polli A, Van Oosterwijck J, Meeus M, Lambrecht L, Nijs J, Ickmans K. Exercise-induce hyperalgesia, complement system and elastase activation in myalgic encephalomyelitis/chronic fatigue syndrome - a secondary analysis of experimental comparative studies. Scandinavian Journal of Pain. 2018; 19(1):183-192

362. Polo O, Pesonen P, Tuominen E. Low-dose naltrexone in the treatment of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). Fatigue: Biomedicine, Health & Behavior. 2019; 7(4):207-217

363. Preparing children for starting primary school. 2018. Available from: https://www.thetimes.co.uk/article/preparing-children-for-starting-primary-school-6q6hv8nl3# Last accessed: 05/12/2019.

364. Prins J, Bleijenberg G, Rouweler EK, van der Meer J. Effect of psychiatric disorders on outcome of cognitive-behavioural therapy for chronic fatigue syndrome. British Journal of Psychiatry. 2005; 187:184-185

365. Prins JB, Bleijenberg G, Bazelmans E, Elving LD, de Boo TM, Severens JL et al. Cognitive behaviour therapy for chronic fatigue syndrome: A multicentre randomised controlled trial. Lancet. 2001; 357(9259):841-847

366. Prokhorov BE, Förster M, Stolle C, Lesur V, Namgalagze AA, Holschneider M. The ionospheric current system and its contribution to the Earth's magnetic field. Geophysical Research Abstracts. 2016; 18

367. Puri BK, Gunatilake KD, Fernando KA, Gurusinghe AI, Agour M, Treasaden IH. Increased tenderness in the left third intercostal space in adult patients with myalgic encephalomyelitis: A controlled study. Journal of International Medical Research. 2011; 39(1):212-214

368. Quarmby L, Rimes KA, Deale A, Wessely S, Chalder T. Cognitive-behaviour therapy for chronic fatigue syndrome: Comparison of outcomes within and outside the confines of a randomised controlled trial. Behaviour Research and Therapy. 2007; 45(6):1085-1094

369. Raine R, Carter S, Sensky T, Black N. General practitioners' perceptions of chronic fatigue syndrome and beliefs about its management, compared with irritable bowel syndrome: Qualitative study. BMJ. 2004; 328(7452):1354-1357

370. Rand Corporation. 36-Item Short Form Survey Instrument (SF-36). Available from: https://www.rand.org/health-care/surveys_tools/mos/36-item-short-form/survey-instrument.html Last accessed: 03/12/2019.

371. Rawlins M. De Testimonio: On the evidence for decisions about the use of therapeutic interventions. Clinical Medicine (London, England). 2008; 8(6):579-588

372. Reactive oxygen species in biology and human health. Ahmad SI. 1st ed. Boca Raton. CRC Press. 2016.

373. Regland B, Forsmark S, Halaouate L, Matousek M, Peilot B, Zachrisson O et al. Response to vitamin B12 and folic acid in myalgic encephalomyelitis and fibromyalgia. PloS One. 2015; 10(4):e0124648

374. Reynolds GK, Lewis DP, Richardson AM, Lidbury BA. Comorbidity of postural orthostatic tachycardia syndrome and chronic fatigue syndrome in an Australian cohort. Journal of Internal Medicine. 2014; 275(4):409-417

375. Richardson J. Myalgic enchephalomyelitis: guidelines for doctors. Journal of Chronic Fatigue Syndrome. 2002; 10(1):65-80

376. Rimes KA, Papadopoulos AS, Cleare AJ, Chalder T. Cortisol output in adolescents with chronic fatigue syndrome: Pilot study on the comparison with healthy adolescents and change after cognitive behavioural guided self-help treatment. Journal of Psychosomatic Research. 2014; 77(5):409-414

377. Roberts AD, Papadopoulos AS, Wessely S, Chalder T, Cleare AJ. Salivary cortisol output before and after cognitive behavioural therapy for chronic fatigue syndrome. Journal of Affective Disorders. 2009; 115(1-2):280-286

378. Roberts D. Chronic fatigue syndrome and quality of life. Patient Related Outcome Measures. 2018; 9:253-262

379. Roberts E, Wessely S, Chalder T, Chang CK, Hotopf M. Mortality of people with chronic fatigue syndrome: A retrospective cohort study in England and Wales from the South London and Maudsley NHS Foundation Trust Biomedical Research Centre (SLaM BRC) Clinical Record Interactive Search (CRIS) Register. Lancet. 2016; 387(10028):1638-1643

380. Roe A. North of Tyne CFS/ME rehabilitation and management team: Service evaluation 2016.

381. Roerink ME, Bredie SJH, Heijnen M, Dinarello CA, Knoop H, Van der Meer JWM. Cytokine inhibition in patients with chronic fatigue syndrome: A randomized trial. Annals of Internal Medicine. 2017; 166(8):557-564

382. Roerink ME, Knoop H, Bredie SJ, Heijnen M, Joosten LA, Netea MG et al. Cytokine inhibition in chronic fatigue syndrome patients: Study protocol for a randomized controlled trial. Trials. 2015; 16:439

383. Roerink ME, Knoop H, Bronkhorst EM, Mouthaan HA, Hawinkels LJAC, Joosten LAB et al. Cytokine signatures in chronic fatigue syndrome patients: A case control study and the effect of anakinra treatment. Journal of Translational Medicine. 2017; 15:267

384. Roma M, Marden CL, Flaherty MAK, Jasion SE, Cranston EM, Rowe PC. Impaired health-related quality of life in adolescent myalgic encephalomyelitis/chronic fatigue syndrome: The impact of core symptoms. Frontiers in Pediatrics. 2019; 7:26

385. Roor JJ, Knoop H, Dandachi-FitzGerald B, Peters MJV, Bleijenberg G, Ponds R. Feedback on underperformance in patients with Chronic Fatigue Syndrome: The impact on subsequent neuropsychological test performance Applied Neuropsychology. 2020; 27(2):188-196

386. Ross SD, Estok RP, Frame D, Stone LR, Ludensky V, Levine CB. Disability and chronic fatigue syndrome: a focus on function. Archives of Internal Medicine. 2004; 164(10):1098-1107

387. Rowe KS. Long term follow up of young people with chronic fatigue syndrome attending a pediatric outpatient service. Frontiers in Pediatrics. 2019; 7:21

388. Rowe PC, Underhill RA, Friedman KJ, Gurwitt A, Medow MS, Schwartz MS et al. Myalgic encephalomyelitis/chronic fatigue syndrome diagnosis and management in young people: A primer. Frontiers in Pediatrics. 2017; 5:121

389. Ruggieri V, Paz MI, Peretti MG, Rugilo C, Bologna R, Freire C et al. Enterovirus D68 infection in a cluster of children with acute flaccid myelitis, Buenos Aires, Argentina, 2016. European Journal of Paediatric Neurology. 2017; 21(6):884-890

390. Santini SJ, Cordone V, Falone S, Mijit M, Tatone C, Amicarelli F et al. Role of mitochondria in the oxidative stress induced by electromagnetic fields: Focus on reproductive systems. Oxidative Medicine and Cellular Longevity. 2018; 2018:5076271

391. Šarić A, Buell AK, Meisl G, Michaels TCT, Dobson CM, Linse S et al. Physical determinants of the self-replication of protein fibrils. Nature Physics. 2016; 12:874-880

392. Scheeres K, Knoop H, Meer v, Bleijenberg G. Clinical assessment of the physical activity pattern of chronic fatigue syndrome patients: A validation of three methods. Health & Quality of Life Outcomes. 2009; 7:29

393. Scheeres K, Wensing M, Bleijenberg G, Severens JL. Implementing cognitive behavior therapy for chronic fatigue syndrome in mental health care: A costs and outcomes analysis. BMC Health Services Research. 2008; 8(175)

394. Scheeres K, Wensing M, Knoop H, Bleijenberg G. Implementing cognitive behavioral therapy for chronic fatigue syndrome in a mental health center: A benchmarking evaluation. Journal of Consulting and Clinical Psychology. 2008; 76(1):163-171

395. Scheeres K, Wensing M, Mes C, Bleijenberg G. The impact of informational interventions about cognitive behavioral therapy for chronic fatigue syndrome on GPs referral behavior. Patient Education and Counseling. 2007; 68(1):29-32

396. Schmaling KB, Patterson TL. The association of major life events with chronic fatigue. Journal of Psychosomatic Research. 2019; 125:109810

397. Schweitzer R, Kelly B, Foran A, Terry D, Whiting J. Quality of life in chronic fatigue syndrome. Social Science and Medicine. 1995; 41(10):1367-1372

398. Service related research project: a service evaluation of an eight-week lifestyle management programme run by a chronic fatigue syndrome.

399. Service related research project: executive summary. A service evaluation of a lifestyle management group programme at a chronic fatigue syndrome service. 2015.

400. Severens JL, Prins JB, van der Wilt GJ, van der Meer JW, Bleijenberg G. Cost-effectiveness of cognitive behaviour therapy for patients with chronic fatigue syndrome. QJM. 2004; 97(3):153-161

401. Shakespeare T, Watson N, Alghaib OA. Blaming the victim, all over again: Waddell and Aylward's biopsychosocial (BPS) model of disability. Critical Social Policy. 2017; 37(1):22-41

402. Shan ZY, Finegan K, Bhuta S, Ireland T, Staines DR, Marshall-Gradisnik SM et al. Brain function characteristics of chronic fatigue syndrome: A task fMRI study. NeuroImage: Clinical. 2018; 19:279-286

403. Sharpe M, Goldsmith KA, Johnson AL, Chalder T, Walker J, White PD. Rehabilitative treatments for chronic fatigue syndrome: Long-term follow-up from the PACE trial. The Lancet Psychiatry. 2015; 2(12):1067-1074

404. Sharpe MC, Archard LC, Banatvala JE, Borysiewicz LK, Clare AW, David A et al. A report--chronic fatigue syndrome: Guidelines for research. Journal of the Royal Society of Medicine. 1991; 84(2):118-121

405. Shukla SK, Cook D, Meyer J, Vernon SD, Le T, Clevidence D et al. Changes in gut and plasma microbiome following exercise challenge in myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). PloS One. 2015; 10(12):e0145453

406. Shungu DC, Weiduschat N, Murrough JW, Mao X, Pillemer S, Dyke JP et al. Increased ventricular lactate in chronic fatigue syndrome. III. Relationships to cortical glutathione and clinical symptoms implicate oxidative stress in disorder pathophysiology. NMR in Biomedicine. 2012; 25(9):1073-1087

407. Smith ME, Haney E, McDonagh M, Pappas M, Daeges M, Wasson N et al. Treatment of myalgic encephalomyelitis/chronic fatigue syndrome: A systematic review for a national institutes of health pathways to prevention workshop. Annals of Internal Medicine. 2015; 162(12):841-850

408. Smith MEB, Nelson HD, Haney E, Pappas M, Daeges M, Wasson N et al. Diagnosis and treatment of myalgic encephalomyelitis/chronic fatigue syndrome. Evidence Report/Technology Assessment 2014; (219):1-433

409. Smith SN, Crawley E. Is there effective behavioural treatment for children with chronic fatigue syndrome/myalgic encephalomyelitis? Archives of Disease in Childhood. 2013; 98(7):561-563

410. Snell CR, Stevens SR, Davenport TE, Van Ness JM. Discriminative validity of metabolic and workload measurements for identifying people with chronic fatigue syndrome. Physical Therapy. 2013; 93(11):1484-1492

411. Snounou R, Woods N, Henry L, Adams JA. Focus group evaluation of an eight-week group condition management programme for myalgic encephalomyelitis/ chronic fatigue syndrome (ME/CFS).

412. Solomon-Moore E, Jago R, Beasant L, Brigden A, Crawley E. Physical activity patterns among children and adolescents with mild-to-moderate chronic fatigue syndrome/myalgic encephalomyelitis. BMJ Paediatrics Open. 2019; 3:e000425

413. Stahl D, Rimes KA, Chalder T. Mechanisms of change underlying the efficacy of cognitive behaviour therapy for chronic fatigue syndrome in a specialist clinic: A mediation analysis. Psychological Medicine. 2014; 44(6):1331-1344

414. Staud R, Boissoneault J, Craggs JG, Lai S, Robinson ME. Task related cerebral blood flow changes of patients with chronic fatigue syndrome: An arterial spin labeling study. Fatigue. 2018; 6(2):63-79

415. Staud R, Kizer T, Robinson ME. Muscle injections with lidocaine improve resting fatigue and pain in patients with chronic fatigue syndrome. Journal of Pain Research. 2017; 10:1477-1486

416. Steffen TM, Hacker TA, Mollinger L. Age- and gender-related test performance in community-dwelling elderly people: Six-Minute Walk Test, Berg Balance Scale, Timed Up & Go Test, and gait speeds. Physical Therapy. 2002; 82(2):128-137

417. Stevelink SAM, Fear NT, Hotopf M, Chalder T. Factors associated with work status in chronic fatigue syndrome. Occupational Medicine. 2019; 69(6):453-458

418. Stevens S, Snell C, Stevens J, Keller B, VanNess JM. Cardiopulmonary exercise test methodology for assessing exertion intolerance in myalgic encephalomyelitis/chronic fatigue syndrome. Frontiers in Pediatrics. 2018; 6:242

419. Stevens SR, Davenport TE. Functional outcomes of anaerobic rehabilitation in a patient with chronic fatigue syndrome: Case report with 1-year follow up. Bulletin of the IACFS/ME. 2010; 18(3):93-98

420. Stoll SVE, Crawley E, Richards V, Lal N, Brigden A, Loades ME. What treatments work for anxiety in children with chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME)? Systematic review. BMJ Open. 2017; 7(9):e015481

421. Stordeur S, Thiry N, Eyssen M. Chronisch Vermoeidheidssyndroom: Diagnose, behandeling en zorgorganisatie. Brussel. Federaal Kenniscentrum voor de Gezondheidszorg (KCE), 2008. Available from: https://kce.fgov.be/sites/default/files/atoms/files/d20081027358.pdf

422. Strassheim VJ, Sunnquist M, Jason LA, Newton JL. Defining the prevalence and symptom burden of those with self-reported severe chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME): A two-phase community pilot study in the North East of England. BMJ Open. 2018; 8:e020775

423. Strawbridge R, Sartor ML, Scott F, Cleare AJ. Inflammatory proteins are altered in chronic fatigue syndrome-A systematic review and meta-analysis. Neuroscience and Biobehavioral Reviews. 2019; 107:69-83

424. Strayer DR, Carter WA, Stouch BC, Stevens SR, Bateman L, Cimoch PJ et al. A double-blind, placebo-controlled, randomized, clinical trial of the TLR-3 agonist rintatolimod in severe cases of chronic fatigue syndrome. PloS One. 2012; 7(3):e31334

425. Strbak O, Kopcansky P, Frollo I. Biogenic magnetite in humans and new magnetic resonance hazard questions. Mesurament Science Review. 2011; 11(3):85-91

426. Stulemeijer M, de Jong LW, Fiselier TJ, Hoogveld SW, Bleijenberg G. Cognitive behaviour therapy for adolescents with chronic fatigue syndrome: Randomised controlled trial. BMJ. 2005; 330(7481):14

427. Sumathipala A, Siribaddana S, Abeysingha MR, De Silva P, Dewey M, Prince M et al. Cognitive-behavioural therapy v. structured care for medically unexplained symptoms: Randomised controlled trial. British Journal of Psychiatry. 2008; 193(1):51-59

428. Sunnquist M, Jason LA. A reexamination of the cognitive behavioral model of chronic fatigue syndrome. Journal of Clinical Psychology. 2018; 74(7):1234-1245

429. Sutton and St Helier Hospitals. Chronic Fatigue Service Sutton and St Helier Hospitals Audit: Group programme satisfaction questionnaires. October 2006-May 2007.

430. Suvorov IM, Sushentsova TI, Posokhin VV, Chekodanova NV, Popova VI, Kormushina VV. [Microwave radiation as a factor in altering the health of the population]. Meditsina Truda i Promyshlennaia Ekologiia. 1998; (11):29-30

431. Swinscow TDV. Correlation and regression. Statistics at square one. 9th ed. 1997.

432. Taylor AP. Environmental magnetite in the human brain. 2016. Available from: https://www.the-scientist.com/daily-news/environmental-magnetite-in-the-human-brain-32901 Last accessed: 04/12/2019.

433. Taylor D. Clinical outcome evaluation for the Leeds and York CFS/ME Service 18/19 [Unpublished]. 2019.

434. Taylor RR. Quality of life and symptom severity for individuals with chronic fatigue syndrome: Findings from a randomized clinical trial. American Journal of Occupational Therapy. 2004; 58(1):35-43

435. Teitelbaum JE, Bird B, Greenfield RM, Weiss A, Muenz L, Gould L. Effective treatment of chronic fatigue syndrome and fibromyalgia - A randomized, double-blind, placebo-controlled, intent-to-treat study. Journal of Chronic Fatigue Syndrome. 2001; 8(2):3-28

436. Terzi M, Ozberk B, Deniz OG, Kaplan S. The role of electromagnetic fields in neurological disorders. Journal of Chemical Neuroanatomy. 2016; 75(Pt B):77-84

437. The 25% ME Group. Analysis report. 2010. Available from: www.25megroup.org/download/1819/?v=3069

438. The 25% ME Group. Exercise & ensuring patient safety [Unpublished]. 2014.

439. The 25% ME Group. Follow up survey on people with M.E., 2001. Available from: https://25megroup.org/factsheets-and-leaflets

440. The 25% ME Group. Input to consultation on draft scope for the Guideline Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: Diagnosis and management (in development). 2018.

441. The 25% ME Group. Input to consultation on NG74 ‘Intermediate care including reablement'. 2017.

442. The 25% ME Group. M.E. family/household members survey questionnaire results. 2001. Available from: https://25megroup.org/download/1819/?v=1830

443. The 25% ME Group. M.E. generic members survey questionnaire results [unpublished]. 2002.

444. The 25% ME Group. M.E. questionnaire results. 2000.

445. The 25% ME Group. Our newsletter. 2019. Available from: https://25megroup.org/our-newsletter Last accessed: 11/12/2019.

446. The 25% ME Group. Severe myalgic encephalomyelitis: Understanding and Remembrance Day (8th August) [pamphlet].

447. The 25% ME Group. Severely affected ME (myalgic encephalomyelitis) analysis report on questionnaire issued January 2004. 2004.

448. The Consortium of Multiple Sclerosis Centers Health Services Research Subcommittee. Multiple Sclerosis Quality of Life Inventory: A user's manual 1997. Available from: https://www.nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Brochures/MSQLI_-A-User-s-Manual.pdf

449. The GK, Bleijenberg G, Buitelaar JK, van der Meer JW. The effect of ondansetron, a 5-HT3 receptor antagonist, in chronic fatigue syndrome: A randomized controlled trial. Journal of Clinical Psychiatry. 2010; 71(5):528-533

450. The GK, Bleijenberg G, van der Meer JW. The effect of acclydine in chronic fatigue syndrome: A randomized controlled trial. PLoS Clinical Trials. 2007; 2(5):e19

451. The ME Association. Managing my M.E. What people with ME/CFS and their carers want from the UK's health and social services. The results of the ME Association's major survey of illness management requirements. Buckinghamshire The ME Association, 2010.

452. The ME Association. ME/CFS illness management survey results: No decisions about me without me. Part 1. 2015. Available from: https://www.meassociation.org.uk/wp-content/uploads/2015-ME-Association-Illness-Management-Report-No-decisions-about-me-without-me-30.05.15.pdf

453. The Neurological Alliance, Quality Health. The National Neurology Patient Experience Survey 2018/2019: Technical report. 2019. Available from: https://www.neural.org.uk/wp-content/uploads/2019/07/Neuro-Patience-Techincal-Report.pdf

454. Thomas M, Smith A. An investigation into the cognitive deficits associated with chronic fatigue syndrome. Open Neurology Journal. 2009; 3:13-23

455. Tiersky LA, DeLuca J, Hill N, Dhar SK, Johnson SK, Lange G et al. Longitudinal assessment of neuropsychological functioning, psychiatric status, functional disability and employment status in chronic fatigue syndrome. Applied Neuropsychology. 2001; 8(1):41-50

456. Tillett A, Glass S, Reeve A, Burt A, Fisher M. Provision of health and education services in school children with chronic fatigue syndrome. Ambulatory Child Health. 2000; 6(2):83-89

457. Timbol CR, Baraniuk JN. Chronic fatigue syndrome in the emergency department. Open Access Emergency Medicine. 2019; 11:15-28

458. Togo F, Lange G, Natelson BH, Quigley KS. Attention network test: Assessment of cognitive function in chronic fatigue syndrome. Journal of Neuropsychology. 2015; 9(1):1-9

459. Trabal J, Leyes P, Fernandez-Sola J, Forga M, Fernandez-Huerta J. Patterns of food avoidance in chronic fatigue syndrome: Is there a case for dietary recommendations? Nutrición Hospitalaria. 2012; 27(2):659-662

460. Tummers M, Knoop H, Bleijenberg G. Effectiveness of stepped care for chronic fatigue syndrome: A randomized noninferiority trial. Journal of Consulting and Clinical Psychology. 2010; 78(5):724-731

461. Tummers M, Knoop H, van Dam A, Bleijenberg G. Implementing a minimal intervention for chronic fatigue syndrome in a mental health centre: A randomized controlled trial. Psychological Medicine. 2012; 42(10):2205-2215

462. Tummers M, Knoop H, van Dam A, Bleijenberg G. Moderators of the treatment response to guided self-instruction for chronic fatigue syndrome. Journal of Psychosomatic Research. 2013; 74(5):373-377

463. Twisk F. Dutch Health Council Advisory report on myalgic encephalomyelitis and chronic fatigue syndrome: Taking the wrong turn. Diagnostics. 2018; 8(2):34

464. Twisk F. Studies and surveys implicate potential iatrogenic harm of cognitive behavioral therapy and graded exercise therapy for myalgic encephalomyelitis and chronic fatigue syndrome patients. Research on Chronic Diseases. 2017; 1(2):13-14

465. Twisk F, Geraghty K. Deviant cellular and physiological responses to exercise in myalgic encephalomyelitis and chronic fatigue syndrome. Jacobs Journal of Physiology. 2015; 1(2):1-6

466. Twisk FN. Accurate diagnosis of myalgic encephalomyelitis and chronic fatigue syndrome based upon objective test methods for characteristic symptoms. World Journal of Methodology. 2015; 5(2):68-87

467. Twisk FNM. A definition of recovery in myalgic encephalomyelitis and chronic fatigue syndrome should be based upon objective measures. Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation. 2014; 23(9)

468. van Campen C, Rowe PC, Visser FC. Blood volume status in ME/CFS correlates with the presence or absence of orthostatic symptoms: Preliminary results. Frontiers in Pediatrics. 2018; 6:352

469. van Campen CM, Riepma K, Visser FC. Open trial of vitamin B12 nasal drops in adults with myalgic encephalomyelitis/chronic fatigue syndrome: Comparison of responders and non-responders. Frontiers in Pharmacology. 2019; 10:1102

470. Van Campen CMC, Visser FC. The abnormal cardiac index and stroke volume index changes during a normal tilt table test in ME/CFS patients compared to healthy volunteers, are not related to deconditioning. Journal of Thrombosis and Circulation. 2018:107

471. Van Den Eede F, Moorkens G, Hulstijn W, Maas Y, Schrijvers D, Stevens SR et al. Psychomotor function and response inhibition in chronic fatigue syndrome. Psychiatry Research. 2011; 186(2-3):367-372

472. van der Schaaf ME, De Lange FP, Schmits IC, Geurts DEM, Roelofs K, van der Meer JWM et al. Prefrontal structure varies as a function of pain symptoms in chronic fatigue syndrome. Biological Psychiatry. 2017; 81(4):358-365

473. van Der Schaaf ME, Schmits IC, Roerink M, Geurts DE, Toni I, Roelofs K et al. Investigating neural mechanisms of change of cognitive behavioural therapy for chronic fatigue syndrome: A randomized controlled trial. BMC Psychiatry. 2015; 15:144

474. van der Werf SP, de Vree B, Alberts M, van der Meer JW, Bleijenberg G, Netherlands Fatigue Research Group Nijmegen. Natural course and predicting self-reported improvement in patients with chronic fatigue syndrome with a relatively short illness duration. Journal of Psychosomatic Research. 2002; 53(3):749-753

475. Van Konynenburg R, Nayhan N. Application of Yasko Protocol to the treatment of chronic fatigue syndrome Boston. 2010.

476. van Kuppeveld FJ, de Jong AS, Lanke KH, Verhaegh GW, Melchers WJ, Swanink CM et al. Prevalence of xenotropic murine leukaemia virus-related virus in patients with chronic fatigue syndrome in the Netherlands: Retrospective analysis of samples from an established cohort. BMJ. 2010; 340:c1018

477. VanNess JM, Snell CR, Stevens SR. Diminished cardiopulmonary capacity during post-exertional malaise. Journal of Chronic Fatigue Syndrome. 2007; 14(2):77-85

478. VanNess JM, Stevens SR, Bateman L, Stiles TL, Snell CR. Postexertional malaise in women with chronic fatigue syndrome. Journal of Women's Health. 2010; 19(2):239-244

479. Velleman S, Collin SM, Beasant L, Crawley E. Psychological wellbeing and quality-of-life among siblings of paediatric CFS/ME patients: A mixed-methods study. Clinical Child Psychology and Psychiatry. 2016; 21(4):618-633

480. Vercoulen JH, Swanink CM, Fennis JF, Galama JM, van der Meer JW, Bleijenberg G. Prognosis in chronic fatigue syndrome: A prospective study on the natural course. Journal of Neurology, Neurosurgery and Psychiatry. 1996; 60(5):489-494

481. Vercoulen JHMM, Swanink CMA, Zitman FG, Vreden SGS, Hoofs MPE, Fennis JFM et al. Randomised, double-blind, placebo-controlled study of fluoxetine in chronic fatigue syndrome. Lancet. 1996; 347(9005):858-861

482. Vermeulen RC, Kurk RM, Visser FC, Sluiter W, Scholte HR. Patients with chronic fatigue syndrome performed worse than controls in a controlled repeated exercise study despite a normal oxidative phosphorylation capacity. Journal of Translational Medicine. 2010; 8:93

483. Vermeulen RC, Vermeulen van Eck IW. Decreased oxygen extraction during cardiopulmonary exercise test in patients with chronic fatigue syndrome. Journal of Translational Medicine. 2014; 12:20

484. Vernon D, Stockport ME Group Members. Survey. 2004.

485. Verspaandonk J, Coenders M, Bleijenberg G, Lobbestael J, Knoop H. The role of the partner and relationship satisfaction on treatment outcome in patients with chronic fatigue syndrome. Psychological Medicine. 2015; 45(11):2345-2352

486. Vink M. Assessment of individual pace trial data: In myalgic encephalomyelitis/chronic fatigue syndrome, cognitive behavioral and graded exercise therapy are ineffective, do not lead to actual recovery and negative outcomes may be higher than reported. Journal of Neurology and Neurobiology. 2017; 3(1):1-10

487. Vink M, Vink-Niese A. Cognitive behavioural therapy for myalgic encephalomyelitis/chronic fatigue syndrome is not effective. Re-analysis of a Cochrane review. Health Psychology Open. 2019; 6(1):1-23

488. Vink M, Vink-Niese A. Graded exercise therapy for myalgic encephalomyelitis/chronic fatigue syndrome is not effective and unsafe. Re-analysis of a Cochrane review. Health Psychology Open. 2018; 5(2):1-12

489. Vink M, Vink-Niese A. Multidisciplinary rehabilitation treatment is not effective for myalgic encephalomyelitis/chronic fatigue syndrome: A review of the FatiGo trial. Health Psychology Open. 2018; 5(2):1-8

490. Vink M, Vink-Niese F. Work rehabilitation and medical retirement for myalgic encephalomyelitis/chronic fatigue syndrome patients. A review and appraisal of diagnostic strategies. Diagnostics. 2019; 9(4):1-33

491. Wallis A, Ball M, Butt H, Lewis DP, McKechnie S, Paull P et al. Open-label pilot for treatment targeting gut dysbiosis in myalgic encephalomyelitis/chronic fatigue syndrome: Neuropsychological symptoms and sex comparisons. Journal of Translational Medicine. 2018; 16:24

492. Wallis A, Butt H, Ball M, Lewis DP, Bruck D. Support for the microgenderome: Associations in a human clinical population. Scientific Reports. 2016; 6:19171

493. Wang H, Liu X, Lv B, Yang F, Hong Y. Reliable multi-label learning via conformal predictor and random forest for syndrome differentiation of chronic fatigue in traditional Chinese medicine. PloS One. 2014; 9(6):e99565

494. Wang H, Zhang X. Magnetic fields and reactive oxygen species. International Journal of Molecular Sciences. 2017; 18(10):2175

495. Watt T, Oberfoell S, Balise R, Lunn MR, Kar AK, Merrihew L et al. Response to valganciclovir in chronic fatigue syndrome patients with human herpesvirus 6 and Epstein-Barr virus IgG antibody titers. Journal of Medical Virology. 2012; 84(12):1967-1974

496. Wearden AJ, Dowrick C, Chew-Graham C, Bentall RP, Morriss RK, Peters S et al. Nurse led, home based self help treatment for patients in primary care with chronic fatigue syndrome: Randomised controlled trial. BMJ. 2010; 340:c1777

497. Wearden AJ, Emsley R. Mediators of the effects on fatigue of pragmatic rehabilitation for chronic fatigue syndrome. Journal of Consulting and Clinical Psychology. 2013; 81(5):831-838

498. Wearden AJ, Riste L, Dowrick C, Chew-Graham C, Bentall RP, Morriss RK et al. Fatigue Intervention by Nurses Evaluation--the FINE Trial. A randomised controlled trial of nurse led self-help treatment for patients in primary care with chronic fatigue syndrome: study protocol. BMC Medicine. 2006; 4:9

499. Weatherburn GC, Goldsmith Lister A, Findley LJ. The feasibility of reviewing chronic fatigue syndrome clients at a distance: a teleconference pilot study. Journal of Chronic Fatigue Syndrome. 2007; 14(1):23-32

500. Webb CM, Collin SM, Deave T, Haig-Ferguson A, Spatz A, Crawley E. What stops children with a chronic illness accessing health care: A mixed methods study in children with chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME). BMC Health Services Research. 2011; 11:308

501. Werbach MR. Nutritional strategies for treating chronic fatigue syndrome. Alternative Medicine Review. 2000; 5(2):93-108

502. White PD, Goldsmith K, Johnson AL, Chalder T, Sharpe M. Recovery from chronic fatigue syndrome after treatments given in the PACE trial. Psychological Medicine. 2013; 43(10):2227-2235

503. White PD, Goldsmith KA, Johnson AL, Potts L, Walwyn R, DeCesare JC et al. Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): A randomised trial. Lancet. 2011; 377(9768):823-836

504. White PD, Sharpe MC, Chalder T, DeCesare JC, Walwyn R, Pace Trial Group. Protocol for the PACE trial: A randomised controlled trial of adaptive pacing, cognitive behaviour therapy, and graded exercise, as supplements to standardised specialist medical care versus standardised specialist medical care alone for patients with the chronic fatigue syndrome/myalgic encephalomyelitis or encephalopathy. BMC Neurology. 2007; 7:6

505. Whitehead L. The measurement of fatigue in chronic illness: A systematic review of unidimensional and multidimensional fatigue measures. Journal of Pain and Symptom Management. 2009; 37(1):107-128

506. Whitehead L, Campion P. Can general practitioners manage chronic fatigue syndrome? A controlled trial. Journal of Chronic Fatigue Syndrome. 2002; 10(1):55-64

507. Wiborg JF, Knoop H, Prins JB, Bleijenberg G. Does a decrease in avoidance behavior and focusing on fatigue mediate the effect of cognitive behavior therapy for chronic fatigue syndrome? Journal of Psychosomatic Research. 2011; 70(4):306-310

508. Wiborg JF, Knoop H, Stulemeijer M, Prins JB, Bleijenberg G. How does cognitive behaviour therapy reduce fatigue in patients with chronic fatigue syndrome? The role of physical activity. Psychological Medicine. 2010:1-7

509. Wiborg JF, van Bussel J, van Dijk A, Bleijenberg G, Knoop H. Randomised controlled trial of cognitive behaviour therapy delivered in groups of patients with chronic fatigue syndrome. Psychotherapy and Psychosomatics. 2015; 84(6):368-376

510. Wiborg JF, Wensing M, Tummers M, Knoop H, Bleijenberg G. Implementing evidence-based practice for patients with chronic fatigue syndrome. Clinical Psychology & Psychotherapy. 2014; 21(2):108-114

511. Wilshire C, Kindlon T, Matthees A, McGrath S. Can patients with chronic fatigue syndrome really recover after graded exercise or cognitive behavioural therapy? A critical commentary and preliminary re-analysis of the PACE trial. Fatigue: Biomedicine, Health and Behavior. 2017; 5(1):43-56

512. Wilshire C, Kindlon T, McGrath S. PACE trial claims of recovery are not justified by the data: A rejoinder to Sharpe, Chalder, Johnson, Goldsmith and White. Fatigue: Biomedicine, Health and Behavior. 2017; 5(1):62-67

513. Wilshire CE, Kindlon T. Response: Sharpe, Goldsmith and Chalder fail to restore confidence in the PACE trial findings. BMC Psychology. 2019; 7(1):19

514. Wilshire CE, Kindlon T, Courtney R, Matthees A, Tuller D, Geraghty K et al. Rethinking the treatment of chronic fatigue syndrome-a reanalysis and evaluation of findings from a recent major trial of graded exercise and CBT. BMC Psychology. 2018; 6(1):6

515. Worm-Smeitink M, Gielissen M, Bloot L, van Laarhoven HWM, van Engelen BGM, van Riel P et al. The assessment of fatigue: Psychometric qualities and norms for the Checklist individual strength. Journal of Psychosomatic Research. 2017; 98:40-46

516. Worm-Smeitink M, Janse A, van Dam A, Evers A, van der Vaart R, Wensing M et al. Internet-based cognitive behavioral therapy in stepped care for chronic fatigue syndrome: Randomized noninferiority trial. Journal of Medical Internet Research. 2019; 21(3):e11276

517. Worm-Smeitink M, Nikolaus S, Goldsmith K, Wiborg J, Ali S, Knoop H et al. Cognitive behaviour therapy for chronic fatigue syndrome: Differences in treatment outcome between a tertiary treatment centre in the United Kingdom and the Netherlands. Journal of Psychosomatic Research. 2016; 87:43-49

518. Zablotskii V, Lunov O, Kubinova S, Polyakova T, Sykova E, Dejneka A. Effects of high-gradient magnetic fields on living cell machinery. Journal of Physics D: Applied Physics. 2016; 49(49):493003

519. Zablotskii V, Polyakova T, Dejneka A. Cells in the non-uniform magnetic world: How cells respond to high-gradient magnetic fields. Bioessays. 2018; 40(8):1800017

520. Zhi W-J, Wang L-F, Hu X-J. Recent advances in the effects of microwave radiation on brains. Military Medical Research. 2017; 4:29

521. Zielinski MR, Systrom DM, Rose NR. Fatigue, sleep, and autoimmune and related disorders. Frontiers in Immunology. 2019; 10:1827