



DEBATE PACK

Number CDP 2018-0155, 18 June 2018

Myalgic Encephalomyelitis treatment and research

This pack has been prepared ahead of the debate to be held in Westminster Hall on Thursday 21 June 2018 at 1.30pm on Myalgic Encephalomyelitis treatment and research. The subject for the debate has been selected by the Backbench Business Committee and the debate will be opened by Carol Monaghan MP.

By Dr Sarah Barber
Nikki Sutherland
Dr Rachael Harker

Contents

1. Summary	2
1.1 Background	2
1.2 Treatment	3
Services for CFS/ME	4
Clinical guidelines	5
1.3 Research	7
Government funding for CFS/ME research	8
2. News items	10
3. Press releases	12
4. Parliamentary material	26
Debate	26
PQs	26
5. Useful links and further reading	38

The House of Commons Library prepares a briefing in hard copy and/or online for most non-legislative debates in the Chamber and Westminster Hall other than half-hour debates. Debate Packs are produced quickly after the announcement of parliamentary business. They are intended to provide a summary or overview of the issue being debated and identify relevant briefings and useful documents, including press and parliamentary material. More detailed briefing can be prepared for Members on request to the Library.

1. Summary

A debate on Myalgic Encephalomyelitis: Treatment and Research will take place in Westminster Hall on 21 June 2018. The debate will be led by Carol Monaghan MP.

There has been recent debate on a number of issues relating to treatment and research for Myalgic Encephalomyelitis (ME). These have included calls for improved awareness of this condition and greater provision of services and specialist care. Following a recent review, clinical guidelines on the diagnosis and management of this condition are currently being updated.

Both the type and funding of research undertaken into this condition is also an issue that has been raised recently. Charities and campaigners report that funding is significantly less than for conditions with a similar prevalence and disease burden.¹

1.1 Background

Myalgic Encephalomyelitis (ME), also referred to as Chronic Fatigue Syndrome (CFS/ME) is a long-term neurological condition. Estimates on number of people affected in the UK vary between 190,000² to 260,000.³

The most common symptom is persistent fatigue that is not relieved by rest or sleep. A briefing prepared by a number of CFS/ME organisations prior to the Westminster Hall debate describes the fatigue that is associated with CFS/ME and other symptoms individuals may experience:

People with ME experience severe, persistent fatigue associated with post-exertional malaise (PEM), their systems' inability to recover after expending even small amounts of energy, leading to a flare-up in symptoms. PEM means that simple mental or physical activities can leave people with ME debilitated, experiencing a range of symptoms that are not significantly relieved by resting. PEM is the hallmark symptom of ME, other symptoms can include muscle and joint pain, cognitive difficulties, noise and light sensitivities and digestive problems.⁴

The presentation of CFS/ME can be variable with mild through to very severe symptoms. The effects of CFS/ME can affect an individual's life in a number of ways. Severe fatigue can make it very difficult to undertake many normal everyday activities and some people will have to adapt their lifestyles. Some people cannot maintain employment, and

¹ ME Association, Action for M.E., ME Trust and #ME action, [Parliamentary briefing for Carol Monaghan MP's debate on Myalgic Encephalomyelitis Treatment and research](#), 12 June 2018

² NICE, [NICE to begin review of its guidance on the diagnosis and treatment of CFS/ME](#), September 2017

³ 2020health and Optimum Health Clinic Foundation, [Counting the cost: chronic fatigue syndrome/myalgic encephalomyelitis](#), September 2017

⁴ ME Association, Action for M.E., ME Trust and #ME action, [Parliamentary briefing for Carol Monaghan MP's debate on Myalgic Encephalomyelitis Treatment and research](#), 12 June 2018

children may not be able to attend school which can result in their education being affected. CFS/ME can also affect people's emotional and mental health.

Individuals with severe ME can be significantly affected, may be housebound, spend extended periods in bed and require support from carers.

A 2017 report from the thinktank 2020health and the Optimum Health Clinic Foundation reported that the cost of CFS/ME to the UK economy was at least £3.3 billion in 2014/15.⁵

More information about the symptoms and effects of CFS/ME is provided in the following sources:

- NHS Choices, [Chronic fatigue syndrome \(CFS/ME\)](#), May 2017
- ME Association, [What is ME? Symptoms, testing, and assessment](#), 2017
- Action on ME, [Newly diagnosed with M.E./CFS](#), 2016 and [Living with M.E](#)

1.2 Treatment

The [cause of CFS/ME](#) is unknown, but a number of causes have been suggested. These include that a viral infection could trigger the condition or that it may be related to problems with the immune system, a hormonal imbalance or genetic factors.⁶ There is no cure for this condition, treatment is primarily focused on addressing the symptoms.

The NHS Choices website states that there is "*no single way of managing CFS/ME that works for everyone, but there are a number of treatment options.*"⁷

There are a number of treatment options that may be offered in treating CFS/ME, including:

- Cognitive Behavioural Therapy (CBT)- a talking therapy that aims to help individuals manage CFS/ME;
- Graded Exercise Therapy (GET)- a structured exercise programme that aims to increase an individual's physical activity;
- Activity management- a technique that involves setting individual goals and gradually increasing activity levels;
- Medications which may treat certain symptoms (such as pain relief medicines for muscle pain and headaches, and anti-depressants which may be used in patients who are having problems sleeping); and

⁵ 2020health and Optimum Health Clinic Foundation, [Counting the cost: chronic fatigue syndrome/myalgic encephalomyelitis](#), September 2017

⁶ NHS Choices, [Chronic fatigue syndrome \(CFS/ME\)](#), 2017

⁷ NHS Choices, [Chronic fatigue syndrome \(CFS/ME\)](#), 2017

- Lifestyle changes- these can include changes to diet and sleep practices.⁸

There has been debate on a number of issues relating to treatment for CFS/ME. This has included calls for improved awareness, provision of services and specialist care. Concerns have also been expressed about the clinical guidelines for CFS/ME and recommended treatments. The National Institute for Health and Care Excellence (NICE) has recently started a review and update of its NICE guidance on CFS/ME.

Services for CFS/ME

A briefing prepared by a group of CFS/ME organisations for the debate on 21 June has said that "*many people with ME do not have access to appropriate medical care, whether in a primary or secondary setting.*" It states that many patients are wrongly diagnosed as having 'medically unexplained symptoms' and there is a lack of specialist in-patient services for individuals with ME/CFS. It calls for timely diagnosis of the condition and access to services, improved funding for services for CFS/ME, a defined referral pathway and the development of services for those individuals who are severely affected.⁹

[A November 2017 Lords Parliamentary question](#) response highlighted the responsibilities of Clinical commissioning groups in providing services to meet the needs of the local population:

Clinical commissioning groups (CCG) are responsible for commissioning many healthcare services to meet the needs and requirements of their local population, including those for people with chronic fatigue syndrome/myalgic encephalomyelitis. In doing so, CCGs commission services that reflect the needs of local people and that support improvements in health and healthcare outcomes.

The National Institute for Health and Clinical Excellence (NICE) guidance set outs best practice for clinicians on the diagnosis, treatment care and support of people with myalgic encephalomyelitis and supports commissioners to plan services for local populations.

On 20 September 2017, NICE announced plans to undertake a full review of the guidance.

A copy of the [guidance](#) is attached.¹⁰

For more information on the commissioning of NHS services, please see this 2017 Library briefing paper, [The structure of the NHS in England](#).

Another issue raised by stakeholders is a need for greater awareness amongst healthcare professionals of CFS/ME. The provision of education and training to raise awareness of CFS/ME in healthcare professionals was raised in response to a June 2018 Parliamentary Question:

⁸ NHS Choices, [Chronic fatigue syndrome \(CFS/ME\): Treatment](#), 2017

⁹ ME Association, Action for M.E., ME Trust and #ME action, [Parliamentary briefing for Carol Monaghan MP's debate on Myalgic Encephalomyelitis Treatment and research](#), 12 June 2018

¹⁰ [HL Written question - HL2531 Chronic Fatigue Syndrome](#), November 2017

[...] Education and training is also an important feature in building the awareness of clinical professionals. In terms of education and training, the General Medical Council sets out the knowledge, skills and behaviours that new United Kingdom medical graduates must be able to demonstrate and Royal Medical Colleges, such as the Royal College of General Practitioners (RCGP), set the standards for postgraduate medical education in general practice. General practice is where most patients with CFS/ME are likely to be managed, and the condition is identified as a key area of clinical knowledge in the RCGP Applied Knowledge Test (AKT) content guide. The AKT is a summative assessment of the knowledge base that underpins general practice in the United Kingdom within the context of the National Health Service and is a key part of GPs' qualifying exams. In addition, the RCGP offers a free online e-learning course for clinicians which covers the diagnosis treatment and care of patients with CFS/ME.

Once fully qualified, clinicians are responsible for ensuring their own clinical knowledge remains up-to-date and for identifying learning needs as part of their continuing professional development. This activity should include taking account of new research and developments in guidance, such as that produced by NICE.¹¹

Clinical guidelines

The National Institute for Health and Care Excellence (NICE) provides evidence-based information for the NHS on the effectiveness and cost-effectiveness of healthcare interventions. It publishes mandatory technology appraisal guidance stipulating clinical interventions (mainly medicines) which must be funded by NHS commissioners, as well as advisory clinical guidelines and public health guidance.

In 2007, NICE produced the best practice clinical guideline, [Chronic Fatigue Syndrome/Myalgic Encephalomyelitis \(or encephalopathy\): Diagnosis and management](#). The guideline sets out best practice on the diagnosis, treatment care and support of children and adults with CFS/ME and advises local NHS commissioners and clinicians on the delivery of services.

In 2017, NICE conducted a review of these guideline. It initially decided that it did not think that new evidence would lead to a change in the guidelines. However, a strong response to the consultation on this decision highlighted broader issues in relation to the guideline, and NICE announced in September 2017 that it would fully update them. The Chief Executive of NICE, Sir Andrew Dillon said that the "strong message from stakeholders was that the continuing debate about the causes of this condition and the best approach to treatment argued for a review of the current guideline."¹²

Concerns raised both in the consultation, and prior to this, included that:

- Changes to diagnostic criteria should be considered;
- severe ME is not well covered in the guideline;

¹¹ [HC Written question – 148978, Chronic fatigue Syndrome](#), 11 June 2018

¹² NICE, [NICE to begin review of its guidance on the diagnosis and treatment of CFS/ME](#), September 2017

- there has been variability in the adoption of the NICE guidance; and
- new evidence on treatment approaches should be considered.¹³

Concerns have been raised about the use of evidence in the NICE guideline from clinical trials such as the PACE trial.¹⁴ This trial reported that Graded-Exercise Therapy and Cognitive Behavioural Therapy could “safely be added to standard medical care to moderately improve outcomes for chronic fatigue syndrome.” There have been a number of criticisms of the trial, and how it was conducted,¹⁵ and reanalyses of the trial data have reported that the benefits of the treatments in the trial were modest and were not long term.^{16,17} The PACE trial authors have defended the results of the trial¹⁸ and have responded to criticisms in medical journals¹⁹ and on the PACE trial website.²⁰

In response to a Westminster Hall debate about the PACE trial in February 2018, the Minister for Care, Caroline Dineage, welcomed the NICE update of the guidelines, which will examine concerns relating to the PACE trial:

Clearly, the controversy around the trial is problematic for researchers, but it is most of all distressing for patients with CFS/ME, who deserve the most appropriate treatment from the NHS and to have confidence in the treatment that is being provided. That is why we welcome the NICE decision to undertake a full review of the guidance, which will examine the concerns around the PACE trial and any implications for its current recommendations. NICE develops its guidance independently to support NHS organisations and clinicians to deliver services in line with the best available evidence. It welcomes the input of stakeholders and more than 10 CFS/ME charities and organisations are already registered to support the guideline development process. All other parties who are interested can comment on the draft scope and draft guidelines at the

¹³ NICE, [Surveillance report 2017 – Chronic fatigue syndrome/myalgic encephalomyelitis \(or encephalopathy\): diagnosis and management \(2007\) NICE guideline CG53](#), September 2017

¹⁴ [Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome \(PACE\): a randomised trial](#) White, PD et al. *The Lancet*, Volume 377, Issue 9768, 823 - 836

¹⁵ Examples include [‘PACE-Gate’: When clinical trial evidence meets open data access](#), Keith J Geraghty *Journal of Health Psychology* Vol 22, Issue 9, pp. 1106 - 1112 and Jonathon Edwards, [PACE team response shows a disregard for the principles of science](#) *Journal of Health Psychology* Vol 22, Issue 9, pp. 1155 - 1158

¹⁶ Wilshire 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, Volume 6, Number 1, Page 1

¹⁷ Wise Jacqui, [Reanalysis of PACE trial reignites row over chronic fatigue treatment](#) *BMJ* 2016; 354 :i5230

¹⁸ Science Media Centre, [expert reaction to reanalysis of the PACE trial for chronic fatigue syndrome \(CFS\) treatments](#), 22 March 2018

¹⁹ Examples include [Response to the editorial by Dr Geraghty](#) Peter D White et al, *Journal of Health Psychology* Vol 22, Issue 9, pp. 1113 – 1117, January 2017 and Wise Jacqui and White, P., Chalder, T., & Sharpe, M. (2015). [The planning, implementation and publication of a complex intervention trial for chronic fatigue syndrome: The PACE trial](#). *BIPsych Bulletin*, 39(1), 24-27. doi:10.1192/pb.bp.113.045005

²⁰ QMUL, [PACE trial, FAQ](#) [accessed 19 June 2018]

appropriate time during the development process. Final guidance is expected in October 2020.²¹

More detailed information about the NICE guideline review and the consultation is provided in the NICE document, [Surveillance report 2017: Chronic fatigue syndrome/myalgic encephalomyelitis \(or encephalopathy\): diagnosis and management \(2007\) NICE guideline CG53](#).

In February 2018, NICE reported on the next steps of the guideline update, including that a scoping workshop had been held with stakeholders:

Professor Mark Baker, director of the NICE centre for guidelines, said: “We wanted to get the views and insights of as many people as possible who are affected, either directly or indirectly, by ME/CFS to make sure we understand the issues that are important to them.

“The clear message from the workshop was the need to ensure the new guideline properly addresses and resolves the continuing debate about the best approach to treating people with this condition. It also confirmed our intention to ensure robust representation of people with ME/CFS, or their carers, on the independent committee that will develop the guideline.

“Therefore, following the scoping workshop we’re holding in May, we will recruit a guideline committee which will include 4 people with the condition or their carers, rather than the usual 2. Additionally, we will include a lay member on the recruitment panel for the chair of the guideline committee.”²²

The expected publication date of the updated guidelines is October 2020.²³

1.3 Research

Patients and CFS/ME organisations are calling for increased funding for biomedical research to improve knowledge of the potential causes and effects of CFS/ME. They report that this condition has received far less funding for research than other conditions with similar prevalence and disease burden and that this funding has tended to be for psychological and behavioural studies rather than biomedical research.²⁴

Carol Monaghan MP explained the call for more biomedical research funding for CFS/ME in an article on the Politics Home website:

To develop effective treatments, we need a more realistic approach to biomedical research. A recent study by researchers at Columbia University found that there were specific patterns in immune biomarkers in people with ME, and some patients have reported improvements in their condition as a result of courses of

²¹ [HC Deb 20 February 2018, c36WH](#)

²² NICE, [NICE announces next steps in updating its guideline on ME/CFS](#), February 2018

²³ NICE, [Myalgic encephalomyelitis \(or encephalopathy\)/chronic fatigue syndrome: diagnosis and management](#)

²⁴ ME Association, Action for M.E., ME Trust and #ME action, [Parliamentary briefing for Carol Monaghan MP’s debate on Myalgic Encephalomyelitis Treatment and research](#), 12 June 2018

antiviral drugs. But how can we genuinely consider that we are able to provide treatments for a condition that we as yet do not understand?

Since the start of the year, I have been pressing the government for significantly increased funding for biomedical investigation. Recent parliamentary questions reveal that the average research spend per person living with ME is around £1 per year, much of which is funded, not by government, but by ME charities. Compared to the economic cost of lost days at work, unemployment, and disability benefits, this is simply unacceptable. However, because of the nature of the condition, those with ME are often unable to campaign. One group's name, "Millions Missing", is an accurate description of the uphill battle faced while attempting to bring about change from a sick bed.²⁵

Government funding for CFS/ME research

The Government currently funds health related research through two main routes, the National Institute for Health Research (NIHR) and the UK Research Councils (mainly through the Medical Research Council – MRC). Broadly, the NIHR is responsible for allocating research funding to NHS organisations (typically NHS Trusts), whilst the MRC provides research grants and career awards to scientists in UK universities and hospitals.

Figures on research expenditure for specific conditions are not easily obtainable. Research Council annual accounts detail funding allocations by the institution that receives them rather than the research purpose. Meanwhile, individual NHS organisations' programme budgets do not break down their expenditure in the way required to identify CFS/ME research funding.

However, some information on funding for Chronic Fatigue Syndrome/Myalgic Encephalitis (CFS/ME) is available from PQ responses. The table below gives details of NIHR funding for biomedical research into CFS/ME, as well as total research in the area from 2014/15 to 2016/17.

NIHR FUNDING FOR CFS/ME RESEARCH			
	Biomedical research	All CFS/ME research	% biomedical
2014-15	£280,442	£426,055	66%
2015-16	£295,626	£475,676	62%
2016-17	£130,958	£554,785	24%

Sources:

[PQ 147821, 4 June 2018](#)

[PQ 145356, 22 May 2018](#)

Information is also available on funding for biomedical research into CFS/ME by the NIHR Clinical Research Network (CRN) (separate from the

²⁵ Carol Monaghan, [We must change perception of the debilitating disease ME, Politics Home](#), 18 June 2018

funding set out above). This organisation provides the infrastructure to allow clinical research funded by charities, research funders and life-sciences industry to be undertaken throughout the National Health Service. The level of funding for biomedical research into CFS/ME from 2014-15 to 2016-17 is shown in the table below. Expenditure from the CRN Coordinating centre is also shown. Details of overall NIHR CRN CFS/ME research funding are not available.

NIHR CRN FUNDING FOR BIOMEDICAL CFS/ME RESEARCH		
	CRN funding	Coordinating expenditure
2014-15	£134,769	£17,485
2015-16	£125,176	£17,796
2016-17	£82,866	£7,821

[Source: PQ 145356, 22 May 2018](#)

Finally, details of MRC expenditure research into CFS/ME are shown below. Separate figures for biomedical research are not available.

MRC SPENDING CFS/ME RESEARCH	
2014-15	£652,044
2015-16	£287,234
2016-17	£286,197

[Source: PQ 145356, 22 May 2018](#)

The Government have set out recently what action is being taken to encourage more research in this area:

The Department National Institute for Health Research (NIHR) recognises that chronic fatigue syndrome (CFS), also known as myalgic encephalomyelitis (ME), is a debilitating condition. The NIHR is speaking with the United Kingdom's CFS/ME Research Collaborative and patient representatives about how best we can support a joined up approach to high quality research into this complex disorder.

The NIHR welcomes funding applications for research into any aspect of human health, including CFS/ME; it is not usual practice to ring-fence funds for particular topics or conditions. Applications are subject to peer review and judged in open competition, with awards being made on the basis of the importance of the topic to patients and health and care services, value for money and scientific quality.²⁶

²⁶ HC [Written question – 143805, Chronic Fatigue Syndrome](#), 22 May 2018

2. News items

The Conversation

What causes chronic fatigue? What we know, don't know and suspect

24 May 2018

<https://theconversation.com/what-causes-chronic-fatigue-what-we-know-dont-know-and-suspect-94395>

BBC News Online

Chronic fatigue syndrome treatment 'should be withdrawn'

8 May 2018

<https://www.bbc.co.uk/news/newsbeat-44004882>

BBC News Online

Chronic fatigue trial results 'not robust', new study says

22 March 2018

<https://www.bbc.co.uk/news/health-43490335>

Scotsman

New funding to support research into causes, diagnosis and treatment of Myalgic Encephalomyelitis (ME)

22 February 2018

<https://www.scotsman.com/news/new-funding-to-support-research-into-causes-diagnosis-and-treatment-of-myalgic-encephalomyelitis-me-1-4694899>

Independent

Time for Unrest: Why patients with ME are demanding justice

7 January 2018

https://www.independent.co.uk/news/long_reads/why-patients-me-demanding-justice-millions-missing-chronic-fatigue-illness-disease-a8133616.html

Nature

A reboot for chronic fatigue syndrome research

3 January 2018

<https://www.nature.com/articles/d41586-017-08965-0>

Independent

Finally, recognition for chronic fatigue syndrome

A major shift is underway as far as how to approach treatment of a condition once met with scepticism

5 December 2017

<https://www.independent.co.uk/life-style/health-and-families/new-recognition-for-chronic-fatigue-a8081751.html>

Telegraph

Could this documentary change the way we perceive chronic fatigue syndrome?

24 October 2017

<https://www.telegraph.co.uk/health-fitness/body/could-documentary-change-way-perceive-chronic-fatigue-syndrome/>

3. Press releases

#MEActionUK

UK MPS Secure Westminster Hall Debate on ME

6 June 2018

Mark your calendars! A 3-hour [Westminster Hall](#) debate on Myalgic Encephalomyelitis (ME) treatment and research has been scheduled for Thursday, 21st June, 1:30-4:30 p.m.

The fight for a larger debate on ME has had cross party support with Carol Monaghan MP securing the debate, along with the support of five other MPs.

#MEAction UK and three other ME charities – ME Association, Action for M.E., and the ME Trust – came together to prepare a [parliamentary briefing](#) on Myalgic Encephalomyelitis. The partnership originally formed after these charities expressed interest in getting involved in the “Time for Unrest” campaign following the parliamentary screening of the documentary, [Unrest](#).

Together, these charities had worked to secure the first Westminster Hall debate on the PACE trial last February, and to apply for a larger House of Commons debate that has resulted in this Westminster Hall debate on 21st of June.

Take Action! We have tools that make it easier than ever to urge your MP to attend the Westminster Hall debate to learn about ME treatment and research.

[Contact Your MP](#)

Carol Monaghan had [applied](#) for a full debate in the House of Commons. Her application to the BackBench Business Committee was supported by five other cross party MPs. The fact that Carol’s application was successful is great news, and there is still a chance that a full Chamber debate might be granted in the autumn.

Supporting MPs include: Nicky Morgan MP (Cons), Stephen Pound (Lab), Alex Chalk (Cons), Ben Lake (Plaid) and Kerry McCarthy (Lab).

We need your help to keep the momentum going. Help us hire a full-time, on-the-ground #MEAction team member in the UK to support more work like this by donating to our [UK crowdfunding campaign](#) today.

#MEactionUK**How Much Does the UK Dept. of Health Spend on ME?****31 May 2018**

MP Carol Monaghan (Glasgow North West) had asked the UK Secretary of State for Health and Social Care how much it plans to allocate to *biomedical* research for Myalgic Encephalomyelitis in the *current* financial year?

In quotations below is the [response](#) from the Minister of State at the Department of Health and Social Care, Caroline Dinéage. Her response only references past spending, and does not indicate whether or not the spending is for biomedical research. *Editor's notes are in Italics.*

Her answer is confusing but the take-away appears that an annual £507, 842 pounds is being spent on ME research. *However*, that figure includes contributions from charities and £286,197 of that funding is most likely being spent on psycho-social research – *not* biomedical research. In other words, it's not clear that any money is being spent on biomedical research by the Department of Health and Social Care.

Dinéage's response about funding for ME:

In the period in question, the major National Institute for Health Research (NIHR) funding for biomedical research was through its Biomedical Research Centres and Units. These support research funded by the NIHR itself and also research funded by other public, charity and industry research funders. The level of funding for biomedical research into chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) for each financial year can be found in the table below. The funding for this research came from a combination of funders.

The first table includes funding from charities so it's not clear if anything came from the NIHR or MRC.

Financial Year£

2014-15	280,442
2015-16	295,626
2016-17	130,958

The NIHR Clinical Research Network (CRN) provides the infrastructure that allows high-quality clinical research funded by charities, research funders and life-sciences industry to be undertaken throughout the National Health Service. The level of funding for biomedical research into CFS/ME for each financial year can be found in the table below. The funding for this research came from a combination of the NIHR, the Medical Research Council (MRC) and medical research charities. Expenditure from the CRN coordinating centre itself is also outlined below:

The second table simply says that NIHR spends a bit of money co-ordinating the money spent by others on research.

Financial Year	CRN funding for research, £	Coordinating expenditure, £
2014-15	134,769	17,485
2015-16	125,176	17,796
2016-17	82,866	7,821

The MRC spend on research directly relating to CFS/ME can be found in the following table. Research into CFS/ME is a continuing priority for the MRC.

The third table is, mostly likely, psycho-social research funded by the MRC.

Financial Year	£
2014-15	652,044
2015-16	287,234
2016-17	286,197

The NIHR and the MRC welcomes funding applications for research into any aspect of human health, including biomedical research into CFS/ME. It is not usual practice to ring-fence funds for particular topics or conditions. Applications are subject to peer review and judged in open competition, with awards being made on the basis of the importance of the topic to patients and health and care services, value for money and scientific quality. On this basis, it is not possible to say how much funding is planned in the current financial year.

The NIHR recognises that CFS/ME is a debilitating condition and is speaking with the United Kingdom CFS/ME Research Collaborative and patient representatives about how best we can support a joined up approach to high quality research into this complex disorder.

Action for M.E.

Action for M.E. attending NICE guideline meeting

May 25, 2018

Action for M.E. will be representing people affected by M.E. at a workshop held by the National Institute of Health and Care Excellence (NICE) today to inform their development of an [updated guideline on M.E.](#)

Clare Ogden, Head of Communications and Engagement, will be attending the workshop which gives stakeholders the chance to discuss a draft scope for the guideline with NICE, prior to a formal consultation on the scope.

The scope will outline the broad topics that will be considered throughout the NICE guideline review process, providing the framework for what would be a valid contribution to the guideline. It does not contain any information on what recommendations NICE will make.

The consultation on the scope is scheduled to take place between 21 June and 19 July 2018. We will be asking people with M.E., and their families and carers, for their comments before and during this consultation period to inform our response. Once the consultation is over, a final scope will be published and NICE will begin the development of the guideline. A draft of the guideline is expected in April 2020.

Action for M.E. will continue to provide updates on the progress of the NICE guideline review, as well as opportunities for people with M.E. to share their thoughts and experiences to ensure their voices are heard.

Action for M.E.

M.E. highlighted at the 71st World Health Assembly

23 May 2018

The need for accelerated biomedical research, and training and education for health professionals has been highlighted at the first-ever World Health Assembly side event focused on M.E.

Taking place last night in Geneva and held by the International Alliance for M.E. (IAFME), led by Action for M.E. and hosted by the Union for International Cancer Control (UICC), the aim of the event was to raise awareness and understanding of M.E. among international policy-makers, and to build connections with other public health organisations and individuals who support the IAFME's goal of achieving a global public health response to M.E.

Those attending were visibly shocked by a short screening from Jen Brea's award-winning documentary *Unrest*, showing the devastating impact of M.E. on people across the world. Afterwards, panel members Sonya Chowdhury, Prof Chris Ponting, Greg Perry and M.E. patient Steven offered their view on the challenges facing people affected by M.E., and those that support them, and the steps that must be taken to address these.

It is not OK that people with M.E. are being told there is nothing wrong with them, whether that's one person, 100 people, or 35 million people – which is the latest estimated number of people with M.E., using data from a new research due to be published,

said Sonya Chowdhury, Chief Executive, Action for M.E.

The universal health coverage championed by the World Health Organisation must include coverage for every single person. They must not turn their backs on one person with M.E., let alone 35 million.

Steven, who lives on the French-Swiss border, described the difficulties he faced in getting a diagnosis, and we also heard, via video, from Dr Nina Muirhead, a UK surgeon living with M.E.

It is true of most hospital doctors that they do not know about, or understand, M.E./CFS,

she said.

This was the case for me before I got ill in 2016.

You can watch Nina's video on the [IAFME Facebook page](#).

Turning to the urgent need for accelerated biomedical research, Prof Chris Ponting, University of Edinburgh, suggested four key areas of focus: a large-scale genome-wide association study that will help us understand the genetics of M.E.; cheap, longitudinal, population-scale immune system surveys; molecular and physiological measurements of people with M.E. following exercise; and taking action to ensure that case-control studies use more appropriate control cohorts with individuals with sedentary lives. He was also emphatic about the need to bring more new and established scientists into the field.

Our final speaker was Greg Perry, Assistant Director General, International Federation of Pharmaceutical Manufacturers and Associations.

I am struck by the fact that M.E. has been around for a long time, but there has still not been any real progress ,

he said.

I do think that the World Health Organisation is a hub of innovate thinking, so there are great opportunities here to focus on this neglected disease.

During a lively discussion, moderated by Alexandra Heumber, Head of International Advocacy and Coordinator of the IAFME, based in Geneva, the panel heard from people directly affected by M.E., and from those working within global health policy. They reinforced the need for global leadership from the World Health Organisation in setting-up a framework, at global level, that guides and supports policy-makers and health professionals whose decisions impact the lives of those with M.E.

We are hugely grateful to Dr Cary Adams, Chief Executive, UICC, for hosting this event, and for everyone who contributed, particularly those affected by M.E.

ME Association

People with M.E. 'measurably more disabled' than people with Multiple Sclerosis

16 March 2018

A misunderstood disease wrongly labelled make-believe by some GPs is more devastating to sufferers than multiple sclerosis, a new scientific study has found.

People with M.E. were 'measurably more disabled' than those with MS.

More than 250,000 people in the UK have M.E. (myalgic encephalomyelitis), which manifests as unrelenting fatigue and profound pain.

The condition, also known as Chronic Fatigue Syndrome, has no known cure and is made worse by exertion.

Sufferers are often confined to their beds, unable to walk, and need help even to shower – an action that could then lay them low for hours, days, weeks or longer.

But, despite the illness being recognised as a neurological condition by the World Health Organisation, patients are often branded hysterical, hypochondriac or even lazy.

Many M.E. sufferers report having to give up employment and tell of a struggle to obtain benefits.

Now a study shows that people with M.E. can be more disabled than those who suffer from multiple sclerosis, a similar but recognised illness that affects more than 100,000 in the UK.

The paper, '[Functional Status and Well-Being in People with Myalgic Encephalomyelitis](#)', was published in *Pharmacoeconomics* – Open.

The study used anonymised clinical data that was collected from people with M.E. and MS who have donated blood samples to the UK [ME/CFS Biobank](#) in London, and also assessed how their illnesses affect areas such as employment and income.

Scientists found that the people with M.E. were 'measurably more disabled' than those with MS, work fewer hours and have lower incomes.

The report states:

People with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) continue to struggle to have their condition recognised as disabling in the face of public and professional prejudice and discrimination.

Researchers said that their findings should encourage the health community to:

- Recognise the disabling effects of ME/CFS;
- Advocate for the needs of people with ME/CFS;
- And to investigate strategies to address the cost of the disease
- to both individuals and society. It has been previously estimated that the cost of ME/CFS to the UK economy is more than £3bn per year.

The report concludes:

More people with ME than people with MS lost their jobs after becoming ill, and the income of people with ME decreased markedly more than for people with MS.

Unemployment costs are borne by both the individual and society. The prevalence of ME/CFS [...] and the economic cost of the illness to society should be powerful motivators for policy makers to encourage better funding of research to discover the cause of, and establish effective treatments for, this disease.

ME Biobank coordinator and paper lead author, Caroline Kingdon said:

It is impossible to visit people severely affected by ME/CFS in their homes or to meet those more moderately affected, as I have had the privilege of doing, without recognising the injustice inherent in a system that often fails to recognise the existence of the disease or the disability it causes.

I hope that this paper will help to validate the experiences of people with ME/CFS. Few other diseases are so stigmatised.

While some people with M.E. do improve over the course of time, it is only a small minority that return to full health. And the disease is indiscriminate, affecting both sexes, all ages and all races.

Dr Charles Shepherd, Hon. Medical Advisor to the ME Association, said:

For people with ME/CFS, this is a very important piece of research involving clinical data collected by the ME Biobank.

It not only validates the very severe level of disability that ME/CFS can cause.

The findings can also be used to help support claims for sickness and disability benefits, which are often refused, as well as providing firm evidence of disability for those who require modifications to help them to continue in employment or education.

The Biobank, which contains extensive and anonymised clinical data on people with ME, MS, and healthy control, is funded by donations to the ME Association's [Ramsey Research Fund](#). Participants have donated blood samples and answered questions about themselves for research purposes.

For more information on M.E., visit the [ME Association website](#). For press enquiries, contact 07598032845.

Notes:

The UK ME/CFS Biobank was launched in 2011, and it is led and managed by the [CureME](#) research team at the London School of Hygiene & Tropical Medicine.

The physical Biobank is located at the Royal Free Hospital – where it forms part of the University College London Biobank.

From the very beginning, the ME Association [Ramsay Research Fund](#) has provided significant finance for this charity-backed project, and because we see real value in this initiative, we will continue to support it as a major investor.

This is the only such project in the UK aimed at the study of ME/CFS and the supply of samples to outside researchers. It has successfully obtained more than 30,000 aliquot samples from people with very carefully defined ME/CFS.

Some of the participants with ME/CFS are being followed up for another 3 years with funding from a grant from the US National Institutes of Health.

The full research study can be read [here](#).

ME Association

The CFS/ME Research Collaborative (CMRC) Announces Major Change in Policy and New Deputy Chair

7 March 2018

The CMRC refocuses its research strategy, welcomes individuals with M.E. onto its executive, and Professor Chris Ponting replaces Professor Esther Crawley as Deputy Chair.

A new, ambitious, scientific strategy has been developed by the UK CFS/ME Research Collaborative (CMRC), of which Action for M.E. and the ME Association are Executive Board members.

The Executive Board of the CMRC has decided that, while there is a broader need for research across all disciplines, there has continued to be a distinct lack of biomedical CFS/ME research, so it will now adopt this as its core focus.

Several individuals affected by M.E., originally members of the Patient Advisory Group for the MEGA^[1] research project, have agreed to form a CMRC Patient Reference Group, as full members of the CMRC Executive Board.

With their support, the CMRC is seeking to:

- Build on the momentum created by the [Institute of Medicine in the US](#) by securing a high-level report on the illness and research in the UK, and use this to seek greater investment from policy and decision-makers
- Secure a [James Lind Alliance Priority Setting Partnership](#) to shape the research priorities for the field, which will have patients views at its heart
- Establish a CFS/ME Platform, like that of the [Dementias UK Platform](#), to expedite and consolidate biomedical CFS/ME research.

We have laid some important foundations

says Prof Stephen Holgate, CMRC Chair.

But this is not enough. We need action from the highest level and the CMRC is committed to working with others to drive this.

Most importantly, we need to see results now, not in another five years.

I look forward to updating members at our 2018 conference in Bristol on Wednesday 19 and Thursday 20 September.

Professor Chris Ponting appointed

After completing a five-year term of office as Deputy Chair, Professor Esther Crawley (Bristol University) will be standing down from this position and, due to a change in her role at the university, from the Board itself.

Prof Stephen Holgate stated,

We are immensely grateful to the hard work and commitment that Esther has provided to the CMRC and wish her the very best in her new role at Bristol University.

Professor [Chris Ponting](#) (Section Head, Biomedical Genomics, Chair of Medical Bioinformatics MRC/University of Edinburgh) has been elected by the Board to replace Professor Crawley.

New members Dr Joanna Elson (Newcastle University), Professor Colin Smith (Brighton University), [Dr Neil Harrison](#) (Sussex University) and Professor Patrick Chinnery (Cambridge University) have joined the Executive Board.

You can see the full executive board membership listed in the [CMRC section](#) of our website.

New mission

The Executive Board also took a fresh look at CMRC's Charter and terms of reference, with a focus on how the Board and CMRC members will work together and with others. The new mission statement is reproduced below:

CMRC Purpose

To promote the discovery of the biological mechanisms that underpin CFS/ME, which, together with clinical observation, will drive the development of targeted new treatments for this highly underserved patient population.

CMRC Objectives

- To design, implement and analyse the outcome of a cross-stakeholder, comprehensive, national research strategy for CFS/ME and experimental medicine.
- To create an open cross-sector platform for effective knowledge-exchange and data sharing both nationally and internationally, to optimise research, raise awareness of the disease, and influence policymakers and investors.

CMRC Values

- We are an intellectually generous community sharing data, best practice and technologies.
- We are a creative community harnessing new ideas, new technologies and new ways of working.
- We are a collaborative community inviting all stakeholders to join our programmes and shape our activity.
- We are an enabling community, facilitating the leverage of further resources for CFS/ME research.

You can also read the CMRC's new purpose, objectives and values, which replace its previous Charter, [here](#).

Achievements

Since its inception five years ago, the CMRC has successfully brought together significant numbers of researchers from across the UK and internationally with charities, mainstream funders and patients.

With an aim to drive interest and funding in CFS/ME research, the CMRC has held four successful conferences, initiated and supported new collaborations, worked with mainstream funders and secured interest from pharma/industry, and brought researchers in from outside of the field as well as partners from charities covering overlapping illnesses.

More information:

1. The above changes are reflected in the [CMRC executive meeting minutes](#) from February.
2. All the latest information is now reflected in the [CMRC section](#) of our website.
3. Details about the Autumn CMRC Research Conference in Bristol will be available soon.

[\[1\] ME/CFS Epidemiology and Genomics Alliance](#)

Scottish Government**£90,000 for Ph.D studentship**

22 February 2018

New funding will support research into the causes, diagnosis and treatment of Myalgic Encephalomyelitis (ME).

Funding of £90,000 will be provided for a Scottish university to host a new Ph.D studentship focussed on improving understanding of ME – a condition characterised by long-term fatigue and other symptoms that can make it more difficult for a person to carry on their daily life.

The studentship, jointly funded by Scottish Government and Action for ME, is in response to calls from ME organisations for increased research into the condition.

Health Secretary Shona Robison said:

We want people living with ME to access the best possible care and support, and have listened closely to their views on how we can ensure that.

That is why we are funding this new post – to support the development of new and effective approaches to diagnosis and treatment of the condition.

We are committed to working with partners such as Action for ME to both increase our understanding of ME, and improve the support available for those living with it.

Sonya Chowdhury, Action for M.E. Chief Executive, said:

This devastating neurological condition steals the lives of 20,000 men, women and children in Scotland, one in four of whom are so severely ill that they remain hidden from view in darkened rooms, unable to bear even gentle hugs.

Only by working collaboratively can we address the urgent needs of these vulnerable patients, including the need to advance biomedical research. We are delighted to work with the Chief Scientist Office in encouraging early-career scientists to move this field forward.

Background

Action for ME has previously received £300,000 from the Scottish Government's Transforming Self-Management Fund, for the Inform ME Scotland project. This project will develop a peer-mentoring, self-management support network – to build confidence and reduce isolation in people affected by M.E.

M.E. is a chronic, fluctuating, neurological condition, often diagnosed within the NHS as chronic fatigue syndrome (CFS) or M.E./CFS. It affects 20,000 people in Scotland. People with M.E. score lower overall on health-related quality of life tests than most other chronic conditions and one-in-four people with M.E. are house- and/or bed-bound, unable to manage even basic self-care.

National Institute for Health and Care Excellence

NICE announces next steps in updating its guideline on ME/CFS

15 February 2018

A workshop last month with stakeholders marked the formal start of NICE's collaborative work to update its 2010 guideline on the diagnosis and management of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS).

The workshop was held so that stakeholders, including patient groups for people with ME/CFS and their carers, could help NICE identify at an early stage the issues they consider most important for the development of the new guideline.

Over 45 people attended the workshop, representing 37 different organisations supporting people with ME/CFS.

NICE has also confirmed the next steps in the development of the new guideline, starting with a further workshop with stakeholder organisations on 25 May to discuss the scope of the guideline.

Stakeholders will then have the opportunity to comment on the draft scope between 21 June and 19 July. This will coincide with recruitment to the independent guideline committee, which will also begin on 21 June with adverts posted on the [NICE website](#).

Professor Mark Baker, director of the NICE centre for guidelines, said:

We wanted to get the views and insights of as many people as possible who are affected, either directly or indirectly, by ME/CFS

to make sure we understand the issues that are important to them.

The clear message from the workshop was the need to ensure the new guideline properly addresses and resolves the continuing debate about the best approach to treating people with this condition. It also confirmed our intention to ensure robust representation of people with ME/CFS, or their carers, on the independent committee that will develop the guideline.

Therefore, following the scoping workshop we're holding in May, we will recruit a guideline committee which will include 4 people with the condition or their carers, rather than the usual 2. Additionally, we will include a lay member on the recruitment panel for the chair of the guideline committee.

Once recruited, the committee will review a wide range of evidence and develop recommendations, based on the agreed scope of the guideline.

ME/CFS is a relatively common condition affecting around 190,000 people in the UK. It comprises a range of symptoms that includes fatigue, headaches, sleep disturbances, difficulty concentrating and muscle pain.

It can cause prolonged illness and disability and although some people have relatively mild symptoms and can still manage daily activities with additional rest, others have a more serious form of the illness that severely affects their everyday lives and can leave them housebound. The pattern of a person's symptoms, and their severity, can vary from day to day, or even in the same day.

Further details about the development of the new NICE ME/CFS guideline, including the timeline and information about how to get involved, either by sharing your views and experiences of ME/CFS, or by becoming a member of the guideline committee, are available on the [NICE website](#) or by emailing CFSME@nice.org.uk

Our [public involvement](#) team is also on hand to advise members of the public and patient groups who wish to be involved in this work.

2020 Health

The Optimum Health Clinic Foundation Press Release

28th September 2017

Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis (CFS/ME) costs the UK economy £3.3 billion a year

Today, the Optimum Health Clinic (OHC), a charity specialising in the research into CFS/ME, launches in conjunction with the think tank 2020health, ground-breaking research assessing the costs of CFS/ME to the UK economy. This study entitled "CFS/ME: counting the cost" is the first study to assess both the direct and indirect cost of this illness.

This illness costs the UK economy at least £3.3 billion each year.

David Butcher, chairman of the OHC said:

For too long there has been too much argument about CFS/ME which has not translated into effective treatments for sufferers. The cost of this illness to our country shows that the time has come for a comprehensive research strategy into the bio medical causes of and effective treatments for this appalling illness. We commissioned this research into the cost of CFS/ME to the economy because we want to improve awareness of this poorly understood illness in order to argue for greater funding of research

Julia Manning, Founder Director of 2020health, the health think tank who carried out this research, said:

2020health was very keen to undertake this research because we are acutely aware that there is a lack of understanding about CFS/ME in both the NHS and society, and that the economic implications of the condition were unknown. We are especially pleased to have shone a spotlight on the previously underestimated costs of CFS/ME to society, as this should provide a real incentive for more support and research into this illness.

CFS/ME devastates the lives of sufferers, their families and their carers and destroyed lives deserve attention.

The only way we will put an end to the needless waste of lives and money is to develop a better understanding of this illness and finding more effective treatments, and the only way we will achieve that is by funding research into both bio medical causes and treatments,

said David Butcher.

National Institute for Health and Care Excellence

NICE to begin review of its guidance on the diagnosis and treatment of CFS/ME

20 September 2017

NICE is to begin a review of its 2010 guideline on the diagnosis and management of chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) following a recent public consultation with patient and professional groups.

Sir Andrew Dillon, NICE chief executive, said:

The strong message from stakeholders was that the continuing debate about the causes of this condition and the best approach to treatment argued for a review of the current guideline.

We will now recruit a guideline committee which will include people with the condition and their carers, the healthcare professionals who treat them and the organisations which commission that treatment. As with all the guidance we produce, we will also ensure that stakeholders have the opportunity to provide evidence and insights throughout the development of the guideline.

CFS/ME is a relatively common condition affecting around 190,000 people in the UK. It comprises a range of symptoms that includes

tiredness, headaches, sleep disturbances, difficulties concentrating and muscle pain.

It can cause prolonged illness and disability and although some people have relatively mild symptoms and can still manage daily activities with additional rest, others have a serious illness that severely affects their everyday lives and may be housebound. The pattern of a person's symptoms, and their severity, can vary from day to day, or even in the same day.

Further details about the review, including a scope outlining what it will cover and information about recruitment to the guideline committee, will be published on the [NICE website](#) as they become available.

4. Parliamentary material

Debate

Commons debate - [PACE Trial: People with ME](#)

Motion that this House has considered the PACE trial and its effect on people with ME.

HC Deb 20 February 2018 | Vol 636 cc27-37WH

PQs

[Chronic Fatigue Syndrome](#)

Asked by: Osamor, Kate

To ask the Secretary of State for Health and Social Care, what steps his Department is taking to raise awareness of myalgic encephalomyelitis among the public and medical practitioners.

Answering member: Steve Brine | Department: Department of Health and Social Care

There is information on chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) for both healthcare professionals and the general public via the NHS Choices website. Further information is also provided in the National Institute for Health and Care Excellence (NICE) clinical guideline on CFS/ME, which is provided in formats suitable for both professionals and the public. Both the NHS Choices and NICE guidance can be found at the following links:

www.nhs.uk/conditions/chronic-fatigue-syndrome-cfs/

www.nice.org.uk/guidance/cg53

Education and training is also an important feature in building the awareness of clinical professionals. In terms of education and training, the General Medical Council sets out the knowledge, skills and behaviours that new United Kingdom medical graduates must be able to demonstrate and Royal Medical Colleges, such as the Royal College of General Practitioners (RCGP), set the standards for postgraduate medical education in general practice. General practice is where most patients with CFS/ME are likely to be managed, and the condition is identified as a key area of clinical knowledge in the RCGP Applied Knowledge Test (AKT) content guide. The AKT is a summative assessment of the knowledge base that underpins general practice in the United Kingdom within the context of the National Health Service and is a key part of GPs' qualifying exams. In addition, the RCGP offers a free online e-learning course for clinicians which covers the diagnosis treatment and care of patients with CFS/ME.

Once fully qualified, clinicians are responsible for ensuring their own clinical knowledge remains up-to-date and for identifying learning needs as part of their continuing professional development. This activity should include taking account of new research and developments in guidance, such as that produced by NICE.

HC Deb 11 June 2018 | PQ 148978

[Mental Health Services](#)

Asked by: The Countess of Mar

To ask Her Majesty's Government, further to the Written Answer by Lord O'Shaughnessy on 15 May (HL7468), upon what scientific evidence the promotion of cognitive behaviour therapy and graded exercise therapy in the Improving Access to Psychological Therapies programme is based; and what assessment they have made of recovery rates for patients with myalgic encephalomyelitis or chronic fatigue syndrome from pilot programmes of such therapies.

Answering member: Lord O'Shaughnessy | Department: Department of Health and Social Care

The inclusion of these therapies is based on National Institute for Health and Care Excellence (NICE) guidance. NICE is the independent expert body responsible for developing robust, evidence based guidance for the National Health Service. In 2007, NICE published a guideline on the management of chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) in adults and children that sets out best practice on the treatment and support of patients. The guidance recommended cognitive behavioural therapy (CBT) and graded exercise therapy (GET) as appropriate treatments for mild to moderate CFS/ME, in line with the best available evidence from eight randomised controlled trials. A copy of the guidance, [Chronic fatigue syndrome/myalgic encephalomyelitis \(or encephalopathy\): diagnosis and management](#), is attached.

Information concerning the assessment of recovery rates for patients with CFS/ME accessing CBT or GET through Improving Access to Psychological Therapies services is not available.

HL Deb 05 June 2018 | PQ HL8135

[Chronic Fatigue Syndrome](#)

Asked by: Monaghan, Carol

To ask the Secretary of State for Health and Social Care, how much funding from the public purse was allocated to biomedical research into myalgic encephalomyelitis in 2010-2011.

To ask the Secretary of State for Health and Social Care, how much funding from the public purse was allocated to biomedical research into myalgic encephalomyelitis in 2011-2012.

To ask the Secretary of State for Health and Social Care, how much funding from the public purse was allocated to biomedical research into myalgic encephalomyelitis in 2012-2013.

To ask the Secretary of State for Health and Social Care, how much funding from the public purse was allocated to biomedical research into myalgic encephalomyelitis in 2013-2014.

Answering member: Caroline Dinenage | Department: Department of Health and Social Care

In the period in question, the major National Institute for Health Research funding for biomedical research was through its Biomedical Research Centres (BRCs) and Units. These support research funded by the NIHR itself and also research funded by other public, charity and industry research funders. Prior to the financial year 2104-15, the way data was collected does not allow us to directly report the level of funding for biomedical research into chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME). Three BRCs were supporting biomedical research into CFS/ME during this time period.

The NIHR Clinical Research Network (CRN) provides the infrastructure that allows high-quality clinical research funded by charities, research funders and life-sciences industry to be delivered throughout the National Health Service. The level of funding for biomedical research into CFS/ME for each financial year supported by the CRN can be found in the following table. The funding for this research came from a combination of the Medical Research Council (MRC) and medical research charities. Expenditure from the CRN itself is also outlined below:

Financial Year	Research funding £	CRN expenditure £
2010-11	0	0
2011-12	43,467	5,217
2012-13	114,349	13,616
2013-14	171,860	21,353

The MRC spend on research directly relating to CFS/ME can be found in the following table. The MRC does not classify research in the area by type and is therefore not able to include a further breakdown by type of project. Research into CFS/ME is a continuing priority for the MRC.

Financial Year	£
2010-11	0
2011-12	0
2012-13	504,194
2013-14	601,509

The NIHR and the MRC welcome funding applications for research into any aspect of human health, including biomedical research into CFS/ME. It is not usual practice to ring-fence funds for particular topics or conditions. Applications are subject to peer review and judged in open competition, with awards being made on the basis of the importance of the topic to patients and health and care services, value for money and scientific quality.

The NIHR recognises that CFS/ME is a debilitating condition and is speaking with the United Kingdom CFS/ME Research Collaborative and patient representatives about how best we can support a joined up approach to high quality research into this complex disorder.

HC Deb 24 May 2018 | PQ 146299; PQ 146298; PQ 146297; PQ 146296

[Chronic Fatigue Syndrome](#)

Asked by: Monaghan, Carol

To ask the Secretary of State for Health and Social Care, how much funding from the public purse he plans to allocate to biomedical research into Myalgic Encephalomyelitis in the current financial year.

To ask the Secretary of State for Health and Social Care, how much funding from the public purse was allocated to biomedical research into Myalgic Encephalomyelitis 2016-2017.

To ask the Secretary of State for Health and Social Care, how much funding from the public purse was allocated to biomedical research into Myalgic Encephalomyelitis 2015-2016.

To ask the Secretary of State for Health and Social Care, how much funding from the public purse was allocated to biomedical research into Myalgic Encephalomyelitis 2014-2015.

Answering member: Caroline Dinenage | Department: Department of Health and Social Care

In the period in question, the major National Institute for Health Research (NIHR) funding for biomedical research was through its Biomedical Research Centres and Units. These support research funded by the NIHR itself and also research funded by other public, charity and industry research funders. The level of funding for biomedical research into chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) for each financial year can be found in the table below. The funding for this research came from a combination of funders.

Financial Year	£
2014-15	280,442
2015-16	295,626
2016-17	130,958

The NIHR Clinical Research Network (CRN) provides the infrastructure that allows high-quality clinical research funded by charities, research funders and life-sciences industry to be undertaken throughout the National Health Service. The level of funding for biomedical research into CFS/ME for each financial year can be found in the table below. The funding for this research came from a combination of the NIHR, the Medical Research Council (MRC) and medical research charities. Expenditure from the CRN coordinating centre itself is also outlined below:

Financial Year	CRN funding for research, £	Coordinating expenditure, £
2014-15	134,769	17,485
2015-16	125,176	17,796
2016-17	82,866	7,821

The MRC spend on research directly relating to CFS/ME can be found in the following table. Research into CFS/ME is a continuing priority for the MRC.

Financial Year	£
2014-15	652,044
2015-16	287,234
2016-17	286,197

The NIHR and the MRC welcomes funding applications for research into any aspect of human health, including biomedical research into CFS/ME. It is not usual practice to ring-fence funds for particular topics or conditions. Applications are subject to peer review and judged in open competition, with awards being made on the basis of the importance of the topic to patients and health and care services, value for money and scientific quality. On this basis, it is not possible to say how much funding is planned in the current financial year.

The NIHR recognises that CFS/ME is a debilitating condition and is speaking with the United Kingdom CFS/ME Research Collaborative and patient representatives about how best we can support a joined up approach to high quality research into this complex disorder.

HC Deb 22 May 2018 | PQ 145357; PQ 145356; PQ 145355; PQ 145354

[Chronic Fatigue Syndrome](#)

Asked by: Chalk, Alex

To ask the Secretary of State for Health and Social Care, what steps his Department is taking to stimulate and facilitate high-quality research into chronic fatigue syndrome.

Answering member: Caroline Dinénage | Department: Department of Health and Social Care

The Department National Institute for Health Research (NIHR) recognises that chronic fatigue syndrome (CFS), also known as myalgic encephalomyelitis (ME), is a debilitating condition. The NIHR is speaking with the United Kingdom's CFS/ME Research Collaborative and patient representatives about how best we can support a joined up approach to high quality research into this complex disorder.

The NIHR welcomes funding applications for research into any aspect of human health, including CFS/ME; it is not usual practice to ring-fence funds for particular topics or conditions. Applications are subject to peer review and judged in open competition, with awards being made on the basis of the importance of the topic to patients and health and care services, value for money and scientific quality.

HC Deb 22 May 2018 | PQ 143805

[Chronic Fatigue Syndrome: Medical Treatments](#)

Asked by: The Countess of Mar

To ask Her Majesty's Government why the NHS Choices website includes an article on the Lightning Process when this treatment is not available on the NHS.

Answering member: Lord O'Shaughnessy | Department: Department of Health and Social Care

In addition to providing an overview of the symptoms, diagnosis and treatment of a wide range of conditions, NHS Choices also seeks to provide a balanced view of emerging, new or controversial treatments that are reported in the press, to help the public understand the facts of the story. In September 2017 the 'Behind the headlines' section of the NHS Choices website included a piece on the Lightning Process for treating chronic fatigue syndrome, following national press coverage which reported the findings of trial of this treatment.

HL Deb 08 May 2018 | PQ HL7246

[Chronic Fatigue Syndrome](#)

Asked by: Sobel, Alex

To ask the Secretary of State for Health and Social Care, what plans he has to raise (a) awareness of and (b) accessibility to support for people suffering from myalgic encephalomyelitis.

Answering member: Steve Brine | Department: Department of Health and Social Care

Information is available for the general public via the NHS Choices website on myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome (ME/CFS).

Clinical commissioning groups (CCGs) are responsible for commissioning many healthcare services to meet the needs and requirements of their local population including those for people with ME/CFS. In doing so, CCGs will commission services that reflect the needs of local people and that support improvements in health and healthcare outcomes.

The National Institute for Health and Care Excellence's (NICE) clinical guidance on ME/CFS sets out best practice for treatment, care and support. On 20 September 2017, NICE announced its decision to undertake a full update of this guideline, following a review of the latest available evidence on the diagnosis and management of CFS/ME and a public consultation. More information can be found at the following links:

www.nice.org.uk/guidance/cg53

www.nice.org.uk/news/article/nice-to-begin-review-of-its-guidance-on-the-diagnosis-and-treatment-of-cfs-me

HL Deb 23 April 2018 | PQ 135844

[Chronic Fatigue Syndrome](#)

Asked by: Sheerman, Mr Barry

To ask the Secretary of State for Health and Social Care, if he will take steps to improve free of charge information sharing between GPs and (a) clinical commissioning groups and (b) health trusts on which of their patients have ME.

Answering member: Jackie Doyle-Price | Department: Department of Health and Social Care

The commissioning of services for people with Myalgic Encephalomyelitis is a matter for local clinical commissioning groups. General practitioner (GP) Practices are required to keep adequate records of the attendance and treatment of all their patients.

Summary Care Records enable healthcare professionals working in different care settings to access an electronic summary of key information from a patient's GP record. Currently, Summary Care Records are widely used across National Health Service urgent and emergency care. However, the Summary Care Record may also be used in planned care to provide up to date clinical information.

HC Deb 29 March 2018 | PQ 133604

[Chronic Fatigue Syndrome](#)

Asked by: Sheerman, Mr Barry

To ask the Secretary of State for Health and Social Care, what steps his Department is taking to improve the medical records held by GPs on the number of patients GPs have seen who have been diagnosed with ME/Chronic Fatigue Syndrome.

Answering member: Steve Brine | Department: Department of Health and Social Care

Under the terms of their contract with NHS England, general practitioner practices are required to keep adequate records of the attendance and treatment of all their patients, including those who have been diagnosed with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome.

HC Deb 15 March 2018 | PQ 131695

[Chronic Fatigue Syndrome](#)

Asked by: Blomfield, Paul

To ask the Secretary of State for Health and Social Care, what assessment has been made of the potential merits of removing cognitive behavioural therapy and graded exercise therapy as treatments for ME from the current NICE guidelines.

Answering member: Steve Brine | Department: Department of Health and Social Care

The National Institute for Health and Care Excellence (NICE) is an independent body and develops its guidance based on a thorough assessment of the available evidence and in consultation with stakeholders. The Department is a stakeholder in the development of NICE's guidance, but has no direct influence over its recommendations. Its revised guidance on the diagnosis and management of chronic fatigue syndrome/myalgic encephalomyelitis is due for publication in October 2020. Registered stakeholders are encouraged to respond to consultations. However, the guideline is also clear that there is no one form of treatment to suit every patient. Treatment approaches will not be appropriate for all patients and the needs and preferences of patients should be taken into account.

HC Deb 28 February 2018 | PQ 128537

[Chronic Fatigue Syndrome](#)

Asked by: Day, Martyn

To ask the Secretary of State for Health, what steps his Department is taking as a result of the latest evidence on the diagnosis and treatment of Chronic Fatigue Syndrome.

Answering member: Steve Brine | Department of Health and Social Care

The National Institute for Health and Care Excellence (NICE) is the independent expert body responsible for developing robust, evidence based guidance for the National Health Service to support it in designing services that are in line with the best available evidence.

The NICE guideline Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): Diagnosis and management of CFS/ME in adults

and children sets out best practice for clinicians on the diagnosis, treatment, care and support of people with the condition and assists commissioners in planning services for local populations. The full guideline can be found at the following link:

www.nice.org.uk/guidance/cg53

NICE routinely reviews its guidance to ensure it reflects the latest available evidence. On 20 September 2017, NICE announced its decision to undertake a full update of the CFS/ME guidance. More information on this decision can be found at the following link:

www.nice.org.uk/guidance/cg53/resources/surveillance-report-2017-chronic-fatigue-syndromemyalgic-encephalomyelitis-or-encephalopathy-diagnosis-and-management-2007-nice-guideline-cg53-pdf-5964455783941

HC Deb 12 January 2018 | PQ 120854

[Chronic Fatigue Syndrome: Research](#)

Asked by: Drew, Dr David

To ask the Secretary of State for Health, what recent research his Department has commissioned on the diagnosis and treatment of ME.

Answering member: Jackie Doyle-Price | Department: Department of Health

The Department, through the National Institute for Health Research, has recently commissioned one project on the treatment of symptoms of Myalgic Encephalomyelitis (ME). Professor Esther Crawley, of the University of Bristol, was awarded funding for research entitled, 'Investigating the effectiveness and cost effectiveness of using FITNET to treat paediatric CFS/ME in the UK'. This project began in May 2016. Full details of the research can be found at:

<https://www.journalslibrary.nihr.ac.uk/programmes/hta/14192109/#/summary-of-research>

HC Deb 22 December 2017 | PQ 120493

[Chronic Fatigue Syndrome](#)

Asked by: The Countess of Mar

To ask Her Majesty's Government when the Chronic Fatigue Syndrome/Myalgic Encephalomyelitis National Outcomes Database ceased to exist; and why the data included in that database is no longer collected.

Answering member: Lord O'Shaughnessy | Department: Department of Health

The chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) National Outcome Database was developed by three NHS Clinical Network Co-ordinating Centres in 2006 and managed by Bristol

University. Its development was part of a wider initiative to establish services for CFS/ME in the National Health Service at the time. Neither the Department nor NHS England has oversight of it, or responsibility for it.

HL Deb 01 December 2017 | PQ HL3499

[Chronic Fatigue Syndrome](#)

Asked by: The Countess of Mar

To ask Her Majesty's Government, further to the Written Answers of Lord O'Shaughnessy on 19 July 2017 (HL684 and HL685), and in the light of two recent studies on chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) services, Specialist treatment of chronic fatigue syndrome/ME (Bristol University, July 2017), and Spotlight on specialist services; UK healthcare for people with ME (Action for ME July 2017), what assessment they have made of the findings that (1) fewer than half the commissioning bodies commission specialist services for people with ME/CFS, (2) fewer than a third of patients seen report improvements, and (3) there are no domiciliary or in-patient services for the severely ill and housebound; and whether they intend to conduct an examination of ME/CFS provision nationwide.

Answering member: Lord O'Shaughnessy | Department: Department of Health

Clinical commissioning groups (CCG) are responsible for commissioning many healthcare services to meet the needs and requirements of their local population, including those for people with chronic fatigue syndrome/myalgic encephalomyelitis. In doing so, CCGs commission services that reflect the needs of local people and that support improvements in health and healthcare outcomes.

The National Institute for Health and Clinical Excellence (NICE) guidance set outs best practice for clinicians on the diagnosis, treatment care and support of people with myalgic encephalomyelitis and supports commissioners to to plan services for local populations.

On 20 September 2017, NICE announced plans to undertake a full review of the guidance.

A copy of the [guidance](#) is attached.

HL Deb 02 November 2017 | PQ HL2531

[Myalgic Encephalomyelitis and Chronic Fatigue Syndrome](#)

Asked by: Field, Frank

To ask the Secretary of State for Health, what assessment he has made of the effect of cognitive behavioural therapy and graded exercise therapy treatment administered by the NHS on the health and wellbeing of people suffering with (a) myalgic encephalomyelitis and (b) chronic fatigue syndrome.

Answering member: Steve Brine | Department: Department of Health

No assessment he has made of the effect of cognitive behavioural therapy (CBT) and graded exercise therapy (GET) treatment offered by the National Health Service for patients with chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME).

The National Institute for Health and Care Excellence (NICE) guideline on CFS/ME, published in 2007 and routinely reviewed thereafter, recommends treatments such as CBT and GET approaches be considered. On 20 September 2017, NICE announced its decision to undertake a full update of this guideline, following a review of the latest available evidence on the diagnosis and management of CFS/ME and a public consultation. More information on this decision can be found at the following link:

www.nice.org.uk/guidance/cg53/resources/surveillance-report-2017-chronic-fatigue-syndromemyalgic-encephalomyelitis-or-encephalopathy-diagnosis-and-management-2007-nice-guideline-cg53-pdf-5964455783941

HC Deb 12 October 2017 | PQ 106121

[Chronic Fatigue Syndrome](#)

Asked by: Kawczynski, Daniel

To ask the Secretary of State for Health, how much funding is provided each year for research into myalgic encephalomyelitis.

Answering member: Jackie Doyle-Price | Department: Department of Health

The Department's National Institute for Health Research (NIHR) welcomes funding applications for research into any aspect of human health, including myalgic encephalomyelitis (ME); it is not usual practice to ring-fence funds for particular topics or conditions. Applications are subject to peer review and judged in open competition, with awards being made on the basis of the importance of the topic to patients and health and care services, value for money and scientific quality. In all disease areas, the amount of NIHR funding depends on the volume and quality of scientific activity. Currently, the NIHR is funding one project on ME; a large randomised controlled trial of an internet-based cognitive behavioural therapy for children aged 11-17 years. It is being led by Professor Esther Crawley at Bristol University and is funded for £994,430. It began in May 2016 and further information on this, and all NIHR funded projects, can be found at:

<https://www.journalslibrary.nihr.ac.uk/programmes/hta/14192109/#/summary-of-research>

HC Deb 12 September 2017 | PQ 7182

[Chronic Fatigue Syndrome](#)

Asked by: The Countess of Mar

Her Majesty's Government whether they have any plans to set up an independent review of ME/CFS services which includes an epidemiological study to establish the true incidence of ME/CFS in the population and the impact of the shortage of doctors trained in this specialism; and, if not, why not.

**Answering member: Lord O'Shaughnessy | Department:
Department of Health**

There are no plans to set up an independent review of chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) services. Services for patients with CFS/ME are supported by independent, evidence-based guidance produced by the National Institute for Health and Care Excellence on the diagnosis, treatment and support of patients with the condition. Commissioners should deliver services that meet the needs of local populations. Assessments of service need for CFS/ME may be supported by the available population prevalence estimates as required.

HL Deb 19 July 2017 | PQ HL685

5. Useful links and further reading

ME Association, Action for M.E., ME Trust and #ME action, *Parliamentary briefing for Carol Monaghan MP's debate on Myalgic Encephalomyelitis Treatment and research*, 12 June 2018

<https://www.meaction.net/2018/06/read-the-new-parliamentary-briefing/>

NHS Choices *Chronic fatigue syndrome (CFS/ME)*

<https://www.nhs.uk/conditions/chronic-fatigue-syndrome-cfs/>

ME Association

<http://www.meassociation.org.uk/>

Forward-ME

<http://www.forward-me.org.uk/>

Action for ME

<https://www.actionforme.org.uk/>

ME Association *M.E. Research Conference Report: London 1st June 2018 13th Invest in ME Research (IIMER) Conference*

<http://www.meassociation.org.uk/wp-content/uploads/Dr-Shepherd-IIMER-Conference-Report-2018-13.06.18.pdf>

Cochrane evidence review *Exercise as treatment for patients with chronic fatigue syndrome* 25 April 2017

http://www.cochrane.org/CD003200/DEPRESSN_exercise-treatment-patients-chronic-fatigue-syndrome

Royal College of Psychiatrists Mental Health and Growing Up Factsheet *Chronic Fatigue Syndrome (CFS) - helping your child to get better: information for parents, carers and anyone who works with young people*

<https://www.rcpsych.ac.uk/healthadvice/parentsandyoungpeople/parentscarers/chronicfatiguesyndrome.aspx>

National Academies of Science, Engineering and Medicine *Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness* 10 February 2015

<http://www.nationalacademies.org/hmd/Reports/2015/ME-CFS.aspx>

2020 Health The Optimum Health Clinic Foundation *Counting the Cost: CFS/ME* 28 September 2017

<http://www.2020health.org/2020health/Publications/Publications-2017/OHC.html>

About the Library

The House of Commons Library research service provides MPs and their staff with the impartial briefing and evidence base they need to do their work in scrutinising Government, proposing legislation, and supporting constituents.

As well as providing MPs with a confidential service we publish open briefing papers, which are available on the Parliament website.

Every effort is made to ensure that the information contained in these publically available research briefings is correct at the time of publication. Readers should be aware however that briefings are not necessarily updated or otherwise amended to reflect subsequent changes.

If you have any comments on our briefings please email papers@parliament.uk. Authors are available to discuss the content of this briefing only with Members and their staff.

If you have any general questions about the work of the House of Commons you can email hcinfo@parliament.uk.

Disclaimer

This information is provided to Members of Parliament in support of their parliamentary duties. It is a general briefing only and should not be relied on as a substitute for specific advice. The House of Commons or the author(s) shall not be liable for any errors or omissions, or for any loss or damage of any kind arising from its use, and may remove, vary or amend any information at any time without prior notice.

The House of Commons accepts no responsibility for any references or links to, or the content of, information maintained by third parties. This information is provided subject to the [conditions of the Open Parliament Licence](#).