Source: UK House of Commons

Date: September 4, 2025

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https://questions-statements.parliament.uk/written-questions/detail/2025-08-29/72042

https://questions-statements.parliament.uk/written-questions/detail/2025-08-29/72045

Ref: http://www.me-net.combidom.com/meweb/web1.4.htm#westminster

[Written Answers]

Chronic Fatigue Syndrome: Research

Tom Morrison

To ask the Secretary of State for Health and Social Care, whether his Department plans to establish a research hub to (a) coordinate research and (b) support early-career researchers working on ME and Chronic Fatigue Syndrome.

To ask the Secretary of State for Health and Social Care, how much funding his Department has allocated for Myalgic encephalomyelitis research in each of the last five years.

Ashley Dalton

The Department funds research through the National Institute for Health and Care Research (NIHR). Between the 2019/20 and 2023/24 financial years the NIHR committed approximately 3.7 million pounds to research projects and programmes on myalgic encephalomyelitis, also known as chronic fatigue syndrome (ME/CFS). The NIHR, alongside other Government research funders, remains committed to funding high-quality research to understand the causes, consequences, and treatment for ME/CFS.

Together with the Medical Research Council (MRC), which is part of UK Research and Innovation, we are actively exploring next steps in ME/CFS research, as outlined in the ME/CFS final delivery plan. This includes a

new funding opportunity for a development award focussed on evaluating repurposed pharmaceutical inventions for post-acute infection syndromes and associated conditions, including ME/CFS. This funding opportunity is one component of our approach to improve the evidence around the diagnosis, management, and treatment of post-acute infection conditions, including ME/CFS. We are also planning an NIHR and MRC hosted showcase event for post-acute infection conditions research, including ME/CFS and long COVID, later this year to stimulate further research in this field.

The NIHR welcomes funding applications for research into any aspect of human health and care, including post-acute infection conditions such as ME/CFS, and research funding is available. These 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. Welcoming applications on ME/CFS and other post-acute infection conditions to all NIHR programmes enables maximum flexibility both in terms of the amount of research funding a particular area can be awarded, and the type of research which can be funded. Establishing a research hub for ME/CFS would not provide the same level of flexibility. The NIHR Academy offers extensive support for early-career researchers through various fellowships, training awards, and mentoring structures. For instance, through the INSIGHT Programme, they work with universities to fund research masters studentships and attract students into research. Through Academic Clinical Fellowships, for doctors and dentists, and Predoctoral Academic Fellowships, for other health professionals, the NIHR Academy supports healthcare practitioners in integrating research with clinical practice.

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Source: UK House of Commons

Date: September 5, 2025

URL:

https://questions-statements.parliament.uk/written-questions/detail/2025-07-22/70262

Ref: http://www.me-net.combidom.com/meweb/web1.4.htm#westminster

Ref:

https://questions-statements.parliament.uk/written-questions/detail/2025-08-29/72976

https://questions-statements.parliament.uk/written-questions/detail/2025-08-29/72978

[Written Answers]

Chronic Fatigue Syndrome: Health Services

Cameron Thomas

To ask the Secretary of State for Health and Social Care, what assessment he has made of the potential merits of increasing funding for new (a) services and (b) research to support people with (i) myalgic encephalomyelitis and (ii) chronic fatigue syndrome.

Ashley Dalton

NHS England is responsible for allocating funding to integrated care boards, which in turn are responsible for commissioning specialist myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) services that meet the needs of their population, subject to local prioritisation and funding.

On 22 July 2025, we published the final ME/CFS delivery plan, which is available at the following link:

https://www.gov.uk/government/publications/mecfs-the-final-delivery-plan(opens in a new tab)

Within the plan there is an action for the Department and NHS England to explore whether a specialised service should be prescribed for very severe ME/CFS.

The Government funds research through the National Institute for Health and Care Research (NIHR) and the Medical Research Council (MRC). We have assessed the ME/CFS research portfolio funded through NIHR and MRC and acknowledge that this is an under-funded area. The level of funding

awarded is directly related to the number and quality of applications received and we have historically received a small number of applications for funding in this area. Between 2019/20 and 2023/24, the NIHR committed approximately 3.7 million pound to research projects and programmes on ME/CFS. In the same period, the MRC committed approximately 2.9 million pounds to research into ME/CFS.

Together with the MRC, we are actively exploring next steps for research in ME/CFS. In the final delivery plan for ME/CFS, we have outlined the research actions and additional support that we will offer to the research community to increase the volume and quality of applications. This includes a new funding opportunity for a development award focussed on evaluating repurposed pharmaceutical inventions for post-acute infection syndromes and associated conditions, including ME/CFS.

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Source: UK House of Commons

Date: September 8, 2025

URL:

https://questions-statements.parliament.uk/written-questions/detail/2025-08-29/72977

Ref: http://www.me-net.combidom.com/meweb/web1.4.htm#westminster

[Written Answers]
Chronic Fatigue Syndrome
----Bobby Dean

To ask the Secretary of State for Health and Social Care, what steps his Department is taking to ensure that referrals for ME/CFS are not rejected solely on the basis of a long covid diagnosis being mentioned in GP notes.

Ashley Dalton

We published the Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) Final Delivery Plan on 22 July 2025. The plan focuses on boosting research, improving attitudes and education, and bettering the lives of people with this debilitating disease.

Within the ME/CFS Final Delivery Plan's actions, NHS England will co-design resources, including a template specification for systems to improve services for mild and moderate ME/CFS. Additionally, the Department of Health and Social Care, with NHS England, will explore whether a specialised service should be prescribed by the Secretary of State for Health and Social Care for very severe ME/CFS.

The template specification for mild and moderate ME/CFS will be developed nationally through engagement with stakeholders, drawing on local expertise and models, and existing evidence.

In order to improve awareness and understanding of ME/CFS amongst healthcare professionals, the Department is working with NHS England to develop an e-learning programme on ME/CFS, with the aim of supporting staff to be able to provide better care and improve patient outcomes.

Commissioning of post-viral services is the responsibility of local integrated care boards (ICBs) and the output of the above engagement aims to support ICBs with their local commissioning decisions based on their local population needs.

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Source: UK House of Commons

Date: September 8, 2025

URL:

https://questions-statements.parliament.uk/written-questions/detail/2025-08-29/70927

https://questions-statements.parliament.uk/written-questions/detail/2025-08-29/70928

Ref: http://www.me-net.combidom.com/meweb/web1.4.htm#westminster

[Written Answers]

Chronic Fatigue Syndrome: Research

Jo Platt

To ask the Secretary of State for Health and Social Care, how much funding his Department plans to allocate for research on ME and Chronic Fatigue Syndrome in the next (a) year and (b) five years.

To ask the Secretary of State for Health and Social Care, what steps his Department is taking to (a) encourage research on and (b) support the development of (i) strategic partnerships and (ii) research infrastructure for ME and Chronic Fatigue Syndrome.

Ashley Dalton

The Department funds research through the National Institute for Health and Care Research (NIHR). The NIHR welcomes funding applications for research into any aspect of human health and care, including post-acute infection condition such as myalgic encephalomyelitis, also known as chronic fatigue syndrome (ME/CFS), for which research funding is available. These 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, rather than designating an amount of funding for a particular condition. Welcoming applications on ME/CFS and other post-acute infection conditions to all NIHR programmes enables maximum flexibility both in terms of the amount of research funding a particular area can be awarded, and the type of research which can be funded.

The NIHR Academy offers extensive support for early-career researchers through various fellowships, training awards, and mentoring structures. For instance, through the INSIGHT Programme, they work with universities to fund research masters studentships and to attract students into research. Through Academic Clinical Fellowships, for doctors and

dentists, and Predoctoral Academic Fellowships, for other health professionals, the NIHR Academy supports healthcare practitioners in integrating research with clinical practice.

Together with the Medical Research Council (MRC), which is part of UK Research and Innovation, we are actively exploring next steps in ME/CFS research, as outlined in the ME/CFS final delivery plan. This includes a new funding opportunity for a development award focussed on evaluating repurposed pharmaceutical inventions for post-acute infection syndromes and associated conditions, including ME/CFS. This funding opportunity is one component of our approach to improve evidence around the diagnosis, management, and treatment of post-acute infection conditions, including ME/CFS. We are also planning an NIHR and MRC hosted showcase event for post-acute infection conditions research, including for ME/CFS and long COVID, later this year to stimulate further research in this field.

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Date: September 9, 2025

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https://questions-statements.parliament.uk/written-questions/detail/2025-08-29/72044

https://questions-statements.parliament.uk/written-questions/detail/2025-08-29/73036

Ref: http://www.me-net.combidom.com/meweb/web1.4.htm#westminster

[Written Answers]

Chronic Fatigue Syndrome

Tom Morrison

To ask the Secretary of State for Health and Social Care, whether his Department has made a recent estimate of the potential impact of Myalgic encephalomyelitis on the economy.

Anna Gelderd

To ask the Secretary of State for Health and Social Care, whether his Department plans to allocate (a) new and (b) ring-fenced funding to support the implementation of the Final Delivery Plan for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, published in July 2025.

Ashley Dalton

We recognise the negative impact that myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) has on patients and their loved ones, and also the cost to health and care services and the wider economy through, for example, loss of work and an increased benefits bill. We, therefore, recently published the ME/CFS final delivery plan, which focuses on boosting research, improving attitudes and education, and bettering the lives of people with this debilitating disease.

There are currently no plans to allocate new or ring-fenced funding specifically to support the implementation of the ME/CFS final delivery plan. However, we continue to commission research on ME/CFS services across the United Kingdom, focussing on the most severely affected. The plan includes increased funding for research, awarded through the National Institute for Health and Care Research, into how existing medicines can be used for post-viral conditions, including ME/CFS. Additionally, there are always opportunities for researchers to bid for and secure research funding for ME/CFS through our open research funding calls.

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Source: UK House of Commons

Date: September 8, 2025

URL: https://edm.parliament.uk/early-day-motion/64248

Ref: http://www.me-net.combidom.com/meweb/web1.4.htm#westminster

[Early Day Motion]

Final delivery plan on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)

Tom Morrison

That this House welcomes the publication by the Department of Health and Social Care of the Final Delivery Plan on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), and recognises the work of officials and the ME community in shaping the plan; notes with concern, that the plan falls short of delivering the meaningful change urgently needed by people with ME/CFS; further notes the absence of a strategic approach to ME research, including the omission of proposals for a dedicated ME research hub; expresses concern that much of the new funding cited, such as for the PRIME (Patients, Researchers and Industry for Myalgic Encephalomyelitis) project, was already secured through existing competitive processes; highlights the lack of sufficient accountability for implementing services and updating medical education in line with the NICE Guidelines on ME; regrets the limited attention given to severe ME and the absence of guarantees on specialist care provision; and calls on the Government to ensure robust accountability for its implementation, and provide the resources necessary to improve care, support and outcomes for people living with ME/CFS.

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Source: UK House of Commons Date: September 10, 2025

URL:

https://questions-statements.parliament.uk/written-questions/detail/2025-09-01/73858

Ref: http://www.me-net.combidom.com/meweb/web1.4.htm#westminster

[Written Answers]

Chronic Fatigue Syndrome: Health Services

Mary Glindon

To ask the Secretary of State for Health and Social Care, pursuant to the Answer of 10 July 2025 to Question 62460 on Chronic Fatigue Syndrome: Health Services, whether a date has been set for the showcase event for post-acute infection conditions.

Ashley Dalton

A provisional date of 6 November 2025 has been set for the showcase event for post-acute infection conditions. The event looks to encourage researchers to join the myalgic encephalomyelitis, also known as chronic fatigue syndrome (ME/CFS), and long COVID research field, to enable new collaborations across specialties and disciplines to stimulate further vital research.

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Source: UK House of Commons Date: September 12, 2025

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https://questions-statements.parliament.uk/written-questions/detail/2025-08-29/70926

Ref: http://www.me-net.combidom.com/meweb/web1.4.htm#westminster

[Written Answers]
Chronic Fatigue Syndrome: Research

Jo Platt

To ask the Secretary of State for Science, Innovation and Technology, if he will hold discussions with the Secretary of State fo Health and Social Care on the potential merits of funding a research hub to (a) coordinate research and (b) support early-career researchers working on ME and Chronic Fatigue Syndrome.

Kanishka Narayan

UK Research and Innovation (UKRI) and the National Institute for Health and Care Research (NIHR) work closely together to coordinate research into Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). Extensive support is provided to early-career researchers through the NIHR Academy and NIHR Infrastructure.

ME/CFS is a priority area for UKRI's Medical Research Council (MRC) and it has committed over 4,460,000 pounds to ME/CFS research since 2020. NIHR has also committed approximately 3.7 million pounds to this area across the 2019/20-2023/24 financial years.

MRC recently awarded funding to PRIME, a 800,000 pounds partnership to build new research infrastructure for ME/CFS research. PRIME will establish new research collaborations, bringing together researchers and private sector partners, to investigate the genetics, biomarkers and disease mechanisms of ME/CFS.

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Source: Liberal Democrat Voice Date: September 20, 2025

URL:

https://www.libdemvoice.org/john-milne-mp-and-cross-party-parliamentarians-write-to-wes-streeting-with-concerns-about-the-mecfs-strategy-78332.html

Ref: Read more in The Voice about ME/CFS, https://www.libdemvoice.org/tag/me-cfs

Ref: http://www.me-net.combidom.com/meweb/web1.4.htm#westminster

John Milne MP and cross party parliamentarians write to Wes Streeting with concerns about the ME/CFS strategy

In a joint letter to Health Secretary Wes Streeting under a title 'Concerns regarding ME/CFS Strategy in the Final Delivery Plan', John Milne MP has questioned 'the absence of strategic approach to biomedical research into Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) as part of the Final Delivery Plan'.

John is lead signatory, joined by MP Jo Platt, All-Party Parliamentary Group on ME chair, plus his co-MPs and Huse of Lords members who are Champions for Action for ME.

Here is the text of the letter:

Dear Wes

Concerns regarding ME/CFS Strategy in the Final Delivery Plan

As Members of Parliament and Champions for Action for ME, we are writing to express our collective concern about the absence of strategic approach to biomedical research into Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) as part of the Final Delivery Plan – ME/CFS are debilitating and affect an estimated 1.3 million people in the UK.

Despite its scale and impact, ME remains severely underfunded and poorly understood. There are currently no diagnostic tests of effective treatments. Research activity is limited, fragmented, and lacks the coordination necessary to deliver meaningful progress. This is particularly troubling given the availability of valuable research assets such s the UK Biobank and DecodeME, and the clear overlap with the growing phenomenon of Long Covid. Evidence suggests that up to half of the people with Long Covid are experiencing symptoms that closely mirror those of ME.

The UK is rightly recognised for its world-leading life sciences sector and yet this strength has not been directed towards solving ME, which continues to leave millions without answers or hope. In 2017, ME was estimated to cost the UK economy 3.3 billion pounds a year. Adjusted for

inflation and revised prevalence estimates, that figure is now thought to exceed 20 billion pounds annually, largely due to lost productivity and the pressures placed on carers and the health system.

We believe there is now a clear case for a national, coordinated approach to ME and post-Infectious disease research. A dedicated hub would help unlock scientific breakthroughs, attract long-term investment and ensure that parents, clinicians and researchers are working together to build a future with effective diagnosis

Will you agree to meet with Action for ME to discuss these concerns and explore how the Department can support a more strategic response?

Yours sincerely,
John Milne MP
Member of Parliament for Horsham

Graeme Downie MP

Member of Parliament for Dunfermline and Dollar

Monica Harding MP

Member of Parliament for Esher and Walton

Max Wilkinson MP
Member of Parliament for Cheltenham

Steve Race MP Member of Parliament for Exeter

Wendy Chamberlain MP
Member of Parliament for North East Fife

Alison Hume MP Member of Parliament for Scarborough and Whitby

John McDonnell MP Member of Parliament for Hayes and Harlington

Tessa Munt MP Member of Parliament for Wells Baroness Scott of Needham Market Member of the House of Lords

The Rt Hon, The Lord Bethell Member of the House of Lords

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