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Date: April 8, 2024

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<https://questions-statements.parliament.uk/written-questions/detail/2024-03-25/hl3584>

<https://questions-statements.parliament.uk/written-questions/detail/2024-03-25/hl3585>

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

[Written Answers]

Chronic Fatigue Syndrome: Research  
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Lord Hunt

To ask His Majesty's Government what progress they have made on the funding of biomedical research into myalgic encephalomyelitis (ME) since the then Parliamentary Under Secretary of State for Health and Social Care stated on 24 January 2019 that 'there have not been good enough research proposals in the ME space, partly because of the stigma ... and partly because of the division in the medical community'.

To ask His Majesty's Government how much research funding the National Institute for Health and Care Research and the Medical Research Council have invested in biomedical studies of the causes and treatment of myalgic encephalomyelitis (ME) and non-biomedical studies of ME since 2019.

Lord Markham

The Department funds research through the National Institute for Health and Care Research (NIHR). Since 2019, the NIHR has awarded 1.9 million pounds for research into myalgic encephalomyelitis (ME), also known as chronic fatigue syndrome. The Medical Research Council (MRC), part of UK Research and Innovation (UKRI), has invested 3.6 million pounds since 2019.

This funding includes the NIHR and UKRI co-funded DecodeME study, a 3.2 million pounds study into the genetic underpinning of ME. The study will analyse samples from 25,000 people with ME, to search for genetic differences that may indicate underlying causes or an increased risk of developing the condition. This study aims to increase our understanding of the disease, and therefore contribute to the research base on diagnostic tests and targeted treatments for ME.

In 2020, the NIHR, the Chief Scientist Office in Scotland, and the MRC also funded the James Lind Alliance Priority Setting Partnership for ME, facilitated by the charity Action for ME. The report sets out the top 10 research priorities for ME. These recommendations have been co-produced through a process led by a steering group of people living with ME, carers, and clinicians.

In the interim delivery plan on ME, the Department recognised that there has been a relatively low amount of biomedical research funded on ME, compared with disease burden. The NIHR and MRC welcome applications for further biomedical research into ME. 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. In all disease areas, the amount of funding depends on the volume and quality of scientific activity.

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Source: UK House of Lords

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[Written Answers]

Chronic Fatigue Syndrome: Health Services

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Lord Hunt of Kings Heath

To ask His Majesty's Government what assessment they have made of the extent to which the 2021 NICE guidance for myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) has been implemented (1) in general, and (2) in relation to the training health and social care professionals on how to employ the new recommendations, (a) establishing a UK-wide network of hospital-based ME/CFS specialist services, (b) making all NHS services accessible and capable of providing personalised ongoing care and support to those with ME/CFS, and (c) ensuring social care provision for ME/CFS is monitored and regularly reviewed.

Lord Markham

No formal assessment has been made of the extent to which the 2021 National Institute for Health and Care Excellence (NICE) guidance for myalgic encephalomyelitis (ME), also known as chronic fatigue syndrome (CFS), has been implemented.

NHS England does not centrally commission services for ME. Services to support people living with ME are commissioned by integrated care boards (ICBs) to meet the needs of their local population, and are not reviewed or assessed by NHS England centrally. In October 2023, the British Association of Clinicians in ME published their ME/CFS National Services

Survey 2023. This survey provides insight on the services being delivered for adults, and children and young people, living with ME. A copy of the survey is attached.

In relation to the training of health and social care professionals, it is the duty of clinicians to keep themselves apprised of best practice, in particular guidance issued by the NICE. The Department is working with NHS England to develop an e-learning course on ME for healthcare professionals, with the aim of supporting staff to be able to provide better care and improve patient outcomes. This has involved feedback and input from the ME Research Collaborative (MERC) Patient Advisory Group. The Medical Schools Council will promote the NHS England e-learning package on ME to all United Kingdom medical schools, and encourage medical schools to provide undergraduates with direct patient experience of ME.

The Department published My full reality: an interim delivery plan for ME/CFS in August 2023, which sets out a number of actions to improve the experiences and outcomes for people living with the condition, including better education of professionals and improvements to service provision. More information about the interim plan is available on the GOV.UK website, in an online only format.

Alongside the publication of the interim delivery plan, we ran a public consultation to build a picture of how well the plan meets the needs of the ME community, and to understand if there are any gaps where further action may be necessary. The Department is currently analysing over 3,000 responses to the consultation on the interim delivery plan on ME, and will publish a final delivery plan later this year.

In relation to the monitoring of social care provision for individuals with ME, the Department has made a landmark shift in how we hold local authorities to account for their adult social care duties, through a new Care Quality Commission (CQC) assessment. The CQC will examine how well local authorities deliver their Care Act duties, increasing transparency and accountability and, most importantly, driving improved outcomes for people, including those with ME, who draw on care and support. The CQC completed five pilot assessments and is now rolling out assessment to all local authorities.

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[Written Answers]

Chronic Fatigue Syndrome: Health Services  
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Cat Smith

To ask the Secretary of State for Health and Social Care, what steps her Department is taking to ensure hospitals follow the NICE guidelines on Myalgic encephalomyelitis or chronic fatigue syndrome.

To ask the Secretary of State for Health and Social Care, what steps her Department is taking to ensure hospitals develop treatment pathways for Myalgic encephalomyelitis or chronic fatigue syndrome patients at risk of starvation.

Andrew Stephenson

It is the duty of clinicians to keep themselves appraised of best practice, in particular guidance issued by the National Institute for Health and Care Excellence (NICE). The Department is working with NHS England to develop an e-learning course on myalgic encephalomyelitis (ME), also known as chronic fatigue syndrome, for healthcare professionals, with the aim of supporting staff in providing better care and improving patient outcomes. This has involved feedback and input from the ME Research Collaborative Patient Advisory Group. The Medical Schools Council will promote the NHS England e-learning package on ME to all United Kingdom medical schools, and encourage medical schools to provide undergraduates with direct patient experience of ME. The NICE's guidance NG206 states that people with ME should undertake a dietetic assessment by a dietitian with a special interest in ME, if they are losing weight and at risk of malnutrition.

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<https://questions-statements.parliament.uk/written-questions/detail/2024-04-22/22956>

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

[Written Answers]

[No title]  
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Seema Malhotra

To ask the Secretary of State for Health and Social Care, whether her Department is taking steps to increase inpatient provision for patients with myalgic encephalomyelitis.

To ask the Secretary of State for Health and Social Care, with reference to section 1.17 of the National Institute for Health and Care Excellence (NICE) guidelines entitled Myalgic encephalomyelitis (or encephalopathy) chronic fatigue syndrome: diagnosis and management, published on 29 October 2021, what steps her Department is taking to help ensure that hospital staff are aware of NICE guidelines for caring patients with very severe myalgic encephalomyelitis.

To ask the Secretary of State for Health and Social Care, pursuant to the Answer of 11 March 2024 to Question 16630 on Chronic Fatigue Syndrome, when she plans to publish the final myalgic encephalomyelitis delivery plan.

Andrew Stephenson

The National Institute for Health and Care Excellence's (NICE) guideline, Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management, published in October 2021, outlines the expectations for inpatient care for patients with myalgic encephalomyelitis (ME), also known as chronic fatigue syndrome. The guidance states that where possible, patients with ME should be provided with a single room, and that factors such as the level of lighting and sound should be taken into consideration, and necessary adjustments made.

It is the duty of clinicians to keep themselves appraised of best practice, in particular guidance issued by the NICE. Whilst guidelines are not mandatory, clinicians and commissioners are expected to take them fully into account when designing services that meet the needs of their local population. The NICE promotes its guidance via its website, newsletters, and other media.

The Department is working with NHS England to develop an e-learning course on ME for healthcare professionals, with the aim of supporting staff in providing better care and improving patient outcomes. The Medical Schools Council will promote the NHS England e-learning package on ME to all United Kingdom medical schools, and encourage medical schools to provide undergraduates with direct patient experience of ME.

We have finished consulting on My Full Reality, the cross-Government interim delivery plan on ME, which seeks to improve the experiences and outcomes of people living with this condition. We are in the process of analysing the results of the consultation. The views and experiences gathered through this consultation will be used to build a picture of how well the interim delivery plan identifies and meets the needs of the

ME community, and to highlight any significant gaps where further action may be necessary. We will publish a summary of the consultation responses, which will inform the final delivery plan being published later this year, in due course.

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