Source: UK House of Commons
Date: July 25, 2024
URL:
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Ref: http://www.me-net.combidom.com/meweb/web1.4.htm#westminster

[Written Answers]

Chronic Fatigue Syndrome: Health Services

Sonia Kumar

To ask the Secretary of State for Health and Social Care, what steps his Department is taking to improve (a) diagnosis, (b) treatment and (c) awareness of Myalgic Encephalomyelitis (ME) in the NHS.

Andrew Gwynne

The Department, through the National Institute for Health and Care Research (NIHR), provides funding for research projects which aim to understand the underlying causes of myalgic encephalomyelitis, also known as chronic fatigue syndrome (ME/CFS), and find new treatments for the condition. For example, the NIHR, together with the Medical Research Council, have funded the world's largest genome-wide association study of ME/CFS. This 3.2 million pounds study, termed DecodeME, will analyse samples from 25,000 people with ME/CFS to search for genetic differences that may indicate underlying causes or an increased risk of developing the condition. By helping us to understand ME/CFS better, this research has the potential to lead to new treatments for the condition.

Integrated care boards (ICBs) are responsible for commissioning specialist ME/CFS services that meet the needs of their population, subject to local prioritisation and funding. The process of commissioning services should take into account best practice guidance such as the National Institute for Health and Care Excellence's (NICE) guidance on ME/CFS diagnosis and management, published in October 2021.

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 to meet the needs of their local population. The NICE promotes its guidance via its website, newsletters, and other media.

In October 2023, the British Association of Clinicians in ME/CFS published the ME/CFS National Services Survey. This report provides insight into the services being delivered for adults, children, and young people with ME/CFS.

The Department has been working with NHS England to develop an e-learning course on ME/CFS for healthcare professionals, to support staff to be able to provide better care and improve patient outcomes. This has involved feedback and input from patients. The Medical Schools Council will promote the NHS England e-learning package on ME/CFS to all United Kingdom medical schools, and encourage medical schools to provide undergraduates with direct patient experience of ME/CFS. A decision on next steps on ME/CFS at the national level will be taken in the coming weeks.

Source: UK House of Commons
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[Written Answers]

Chronic Fatigue Syndrome: Health Services

Dr Rupa Huq

To ask the Secretary of State for Health and Social Care, what steps he plans to take to improve support for people with myalgic encephalomyelitis.

Andrew Gwynne

Integrated care boards (ICBs) are responsible for commissioning specialist myalgic encephalomyelitis, also known as chronic fatigue syndrome (ME/CFS), services that meet the needs of their population, subject to local prioritisation and funding. The process of commissioning services should take into account best practice guidance, such as the National Institute for Health and Care Excellence's (NICE) guidance on ME/CFS diagnosis and management, published in October 2021.

The Department funds research into ME/CFS through the National Institute for Health and Care Research (NIHR). The NIHR, together with the Medical Research Council, is funding the world's largest genome-wide association study of ME/CFS. This 3.2 million pounds study, termed DecodeME, will analyse samples from 25,000 people with ME/CFS to search for genetic differences that may indicate underlying causes or an increased risk of developing the condition. A decision on the next steps for ME/CFS at the national level will be taken in the coming weeks.

Source: UK House of Lords
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Ref: http://www.me-net.combidom.com/meweb/web1.4.htm#westminster

[Written Answers]

Chronic Fatigue Syndrome: Health Services

Baroness Scott of Needham Market

To ask His Majesty's Government, further to the Written Statement by the Secretary of State for Health and Social Care on 12 May 2022 (HCWS23), what plans are in plans to publish the cross-Government delivery plan for myalgic encephalomyelitis/chronic fatigue syndrome.

Baroness Merron

A consultation was run in 2023 on the interim delivery plan for myalgic encephalomyelitis, also known as chronic fatigue syndrome (ME/CFS). In the World ME Day Westminster Hall debate in May 2024, the current Parliamentary Under-Secretary of State for Public Health and Prevention pushed for the publication of a response to the consultation. It is now a priority for the Department, and it is our intention to publish a response in the coming months. The consultation responses, along with continued close engagement with stakeholders, will inform the development of the Final Delivery Plan, which we aim to publish in the winter of 2024/25.

No specific assessment has been made of the proportion of the research budget allocated for ME/CFS or long COVID. Over the last five years, the Department, through the National Institute for Health and Care Research (NIHR), has allocated 6.64 million pounds of funding to support 10 research projects, including the 3.2 million pounds DecodeME study, co-funded with the Medical Research Council. Over the same period, the NIHR and UK Research and Innovation have awarded over 50 million pounds for long COVID research. The NIHR remains committed to funding high-quality research to better understand the causes and health impacts of ME/CFS and long COVID, and to identify and evaluate new treatments and interventions.

It is not usual practice for the NIHR to ring-fence funds for particular topics or conditions. The NIHR welcomes funding applications for research into any aspect of human health, including ME/CFS and long COVID. 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.
