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Date: March 8, 2024

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<https://questions-statements.parliament.uk/written-questions/detail/2024-03-04/16631>

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

[Written Answers]

Chronic Fatigue Syndrome: Research

Mrs Sharon Hodgson

To ask the Secretary of State for Health and Social Care, what steps her Department is taking to fund research to (a) tackle the causes of and (b) treat Myalgic Encephalomyelitis.

Andrew Stephenson

The Department commissions research through the National Institute for Health and Care Research (NIHR). The NIHR welcomes funding applications for research into any aspect of human health, including on the causes and treatment of myalgic encephalomyelitis (ME).

In the last five years, the NIHR has allocated approximately 3.44 million pounds to support nine research projects on ME and chronic fatigue syndrome. The NIHR is also co-funding, with the Medical Research Council, a 3.2 million pounds study called DecodeME, which is the world's largest genetic study of the disease.

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<https://questions-statements.parliament.uk/written-questions/detail/2024-03-04/16657>

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[Written Answers]

Chronic Fatigue Syndrome: Diagnosis

Mrs Sharon Hodgson

To ask the Secretary of State for Health and Social Care, what steps she has taken to ensure that the SNOMED CT classification system used by GPs in primary care is (a) adequate and (b) used consistently for diagnosing myalgic encephalomyelitis.

Andrew Stephenson

The Systematized Nomenclature of Medicine - Clinical Terms (SNOMED CT) is the structured clinical vocabulary for use in an electronic health record. It is a contractual requirement for all National Health Service healthcare providers in England to use SNOMED CT for capturing clinical terms, including diagnoses, within electronic patient record systems.

Within SNOMED CT, all content for myalgic encephalomyelitis and chronic fatigue syndrome is contained within a single overarching code, with linked codes for mild, moderate, and severe forms. These can be used by all NHS healthcare providers, including general practitioners.

Updates to the United Kingdom's edition of SNOMED CT are made by NHS England, with any user being able to submit requests for new or changed concepts and codes, via a central portal.

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<https://questions-statements.parliament.uk/written-questions/detail/2024-03-04/16632>

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[Written Answers]

Chronic Fatigue Syndrome: Long Covid

Mrs Sharon Hodgson

To ask the Secretary of State for Health and Social Care, what research the National Institute for Health and Care Research is undertaking on the potential link between Myalgic Encephalomyelitis and long covid.

Andrew Stephenson

The Government has invested more than 50 million pounds into 22 research projects for long COVID, through the National Institute for Health and Care Research (NIHR) and UK Research and Innovation.

In the last five years, the NIHR has allocated approximately 3.44 million pounds to support nine research projects on myalgic encephalomyelitis (ME) and chronic fatigue syndrome. The NIHR is also co-funding, with the Medical Research Council, a 3.2 million pounds study called DecodeME, which is the world's largest genetic study of the disease.

The Department commissions research through the NIHR. It is not currently specifically funding research on potential links between ME and long COVID, but it welcomes funding applications for research into any aspect of human health.

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<https://questions-statements.parliament.uk/written-questions/detail/2024-03-04/16633>

<https://questions-statements.parliament.uk/written-questions/detail/2024-03-04/16634>

<https://questions-statements.parliament.uk/written-questions/detail/2024-03-04/16635>

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

[Written Answers]

Chronic Illnesses: Research

Mrs Sharon Hodgson

To ask the Secretary of State for Science, Innovation and Technology, what research the Medical Research Council is funding on the (a) causes and (b) treatment of Myalgic Encephalomyelitis.

To ask the Secretary of State for Science, Innovation and Technology, what steps her Department is taking to support research into (a) understanding, (b) treating and (c) curing Myalgic Encephalomyelitis.

To ask the Secretary of State for Science, Innovation and Technology, how the Government plans to allocate funding for research into (a) myalgic encephalomyelitis and (b) other post-viral diseases.

Andrew Griffith

Medical Research Council (MRC) has invested in research into Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) for many years, awarding 6.6m pound in this area since 2012. This includes through DecodeME, the world's largest ME/CSF study, via strategic co-funding with the National Institute of Health and Care Research, which aims to find genetic factors to better understand ME/CFS disease pathways and unlock future treatment pathways.

We continue to encourage high-quality proposals across our funding opportunities, maintaining an open highlight notice to encourage ME/CFS research. MRC also co-funded the ME/CFS Priority Setting Partnership to identify research priorities for ME/CFS, led by people with ME/CFS, their carers and clinicians, and facilitated by Action for M.E.

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<https://questions-statements.parliament.uk/written-questions/detail/2024-03-04/16630>

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[Written Answers]

Chronic Fatigue Syndrome

Mrs Sharon Hodgson

To ask the Secretary of State for Health and Social Care, what progress her Department has made on the final delivery plan for ME/CFS.

Andrew Stephenson

We have been consulting on My Full Reality, the cross-government interim delivery plan on myalgic encephalomyelitis (ME), also known as chronic fatigue syndrome (CFS), which seeks to improve the experiences and

outcomes of people living with this condition.

We are analysing the results of the consultation, and 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 and CFS 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, in due course.

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Source: UK House of Lords

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<https://questions-statements.parliament.uk/written-questions/detail/2024-03-20/hl3460>

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

[Written Answers]

Chronic Fatigue Syndrome: Research

Lord Hunt of Kings Heath

To ask His Majesty's Government what plans they have to provide funding for biomedical research into (1) the causes of, and (2) potential cures for, myalgic encephalomyelitis.

Lord Markham

The Department provides funding for research through the National Institute for Health and Care Research (NIHR). The NIHR welcomes funding applications for research into any aspect of human health, including on the causes of, and potential cures for, myalgic encephalomyelitis (ME). These applications are subject to peer review and judged in open competition, with awards being made based on 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.

In the last five years, the NIHR has allocated approximately 3.44 million pounds to support nine research projects on ME and chronic fatigue syndrome. The NIHR is also co-funding, with the Medical Research

Council, a 3.2 million pounds study ('DecodeME') which is the world's largest genetic study of the disease.

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