

Source: UK Department of Health and Social Care

Date: May 12, 2026

URL:

<https://www.gov.uk/government/news/thousands-of-mecfs-patients-to-benefit-from-first-genomics-study>

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

[Press Release]

Thousands of ME/CFS patients to benefit from first genomics study

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People with chronic fatigue syndrome, also known as ME, to benefit from world-first genomics study.

\* The government is investing 4.75 million pounds in the world's largest study of its kind to offer new hope to around 390,000 people living with the condition in the UK

\* For the first time, scientists will be able to build a high-resolution genetic map of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), paving the way for better diagnostics and future treatments

\* The funding builds on the government's earlier investment in the DecodeME study, which created the world's largest ME/CFS research cohort

CFS patients in the UK are set to benefit from a world-first genomics study into the condition, also known as ME, which affects hundreds of thousands of people nationwide, the government has announced today.

Backed by 4.7 million pounds of government funding, the study will enable the SequenceME programme to sequence the genomes of up to 6,000 ME/CFS patients, generating a world-first high-resolution genetic map of the illness.

This first-of-its-kind programme cements the UK's position at the forefront of global genomic research, building on a track record of scientific firsts stretching from the Human Genome Project to the COVID-19 genomic surveillance effort.

This breakthrough could unlock the biological causes of the condition for the first time ever, paving the way for better diagnostics and new treatments for those who live with the disease.

ME/CFS causes debilitating fatigue, sleep difficulties and cognitive impairment. Around a quarter of those diagnosed are severely affected, leaving them housebound or unable to work. Despite the scale of its impact, there is limited understanding of the causes and biological mechanisms driving the condition.

Dr Zubir Ahmed, Health Innovation and Safety Minister, said:

'For too long, people with CFS have faced a condition that is poorly understood, difficult to diagnose and without effective treatments.

'This government is determined to change that, and today's investment is a historic breakthrough in doing so. British scientists are leading the world in genomic research, and this investment puts them at the cutting edge of a challenge that affects hundreds of thousands of people in this country.

'Through this world-first genomics study, we are giving scientists the tools they need to understand the biological causes of this illness - laying the groundwork for better diagnostics and new treatments that hundreds of thousands of patients deserve.

The SequenceME programme brings together the University of Edinburgh, Action for ME, the European Bioinformatics Institute (EBI) and Oxford Nanopore Technologies, combining world-leading expertise in genomics, patient advocacy and bioinformatics, to deliver a dataset unlike anything previously available anywhere in the world.

The investment builds directly on previous funding by the government for the DecodeME study, which established the world's largest and most deeply characterised ME/CFS research cohort and laid the scientific foundations for large-scale genomic analysis.

DecodeME was funded by the Department of Health and Social Care through the National Institute for Health and Care Research (NIHR), jointly with the Medical Research Council.

This announcement forms part of the government's wider commitment to improving care and research for people with ME/CFS, building on the ME/CFS final delivery plan published in July 2025.

<https://www.gov.uk/government/publications/mecfs-the-final-delivery-plan>

NIHR is also funding 2 projects to explore the feasibility of a clinical trial that tests multiple interventions for the treatment of post-acute infection syndromes, including ME/CFS.

In addition, NIHR's 1.4 million pounds HERITAGE study aims to help improve the quality of care for these conditions by developing a national service framework for long COVID and ME/CFS. This includes training and resources for specialist services and primary care across the UK.

Aisling Baker-Ford, who is 32, lives in Ayrshire and was diagnosed with ME in 2022, said:

'I was diagnosed with ME in 2022 after a 2 and a half year battle with a range of specialists - even a neurologist telling me 'it is all in my head'. This unfortunately is a very common occurrence for people like me with this condition.

'I hope this funding allows further understanding and to identify significant genetic links of this condition. I hope [for] more awareness of ME and how it can affect someone's life from all levels of the condition and not just the worst, most severe cases. For many people with ME your symptoms can go from severe to moderate to even mild if you are 'lucky'.

'At the moment I am going through the best period I have had since my diagnosis, but people like myself live in constant fear of a relapse, a day where you wake up and cannot physically get yourself out of bed because you know those severe symptoms will always come back around.

Caroline, who is 56, lives in south-west England and has a diagnosis of ME, said:

'I am absolutely delighted with the announcement of funding for SequenceME. Those of us afflicted with this life-changing illness have waited a very long time to have our condition taken seriously enough to warrant funding for research. That this is now happening is both wonderful and such a relief.

'Hopefully for generations going forward - our children, grandchildren and great grandchildren, a diagnosis of ME won't mean a lifetime of suffering in silence and disbelief. There could be new ways to treat symptoms, or better still, a cure. Thank you from the bottom of my heart on behalf of all the ME community, for listening and helping those of us who live with ME take part in research and have some hope for the

future.

#### Quotes from stakeholders

Sonya Chowdhury, Chief Executive, Action for ME, said:

'We are delighted to receive this investment in SequenceME and long COVID to enable us to start sequencing DNA samples. This project builds on DecodeME and creates even greater value from the samples provided by people with ME/CFS.

'However, there is more to do, and this must be only a start to the significant investment in ME/CFS research that is so desperately needed to bring funding to the levels seen in other illness areas. ME/CFS research has been neglected for decades; research in ME/CFS and overlapping illnesses like long COVID must become a priority. We are very grateful not only to DHSC but also to our charity partners and donors who have helped make this possible.

Dr Charles Shepherd, Honorary Medical Adviser to the ME Association, said:

'The ME Association is delighted by the government decision to invest 4.75 million pounds in new research funding to allow vital research into the role of genetics in ME/CFS to continue.

'Building on the findings from DecodeME, SequenceME should provide a better understanding of the underlying disease process, in particular how the immune and nervous systems respond to a triggering infection in ME/CFS.

'For people with ME/CFS there is now real hope that we have a route to finding a much-needed diagnostic biomarker blood test and effective forms of treatment.

Professor Chris Ponting, DecodeME investigator, University of Edinburgh, said:

'By deeply sequencing the complete genomes of 6,000 DecodeME participants using advanced long-read technology, this project will allow us to pinpoint individual genes disrupted in ME/CFS, moving beyond broader chromosomal signals identified to date. Crucially, it offers the potential to uncover patterns of familial inheritance and to break down this complex disease into its underlying biological causes - bringing us closer to more precise diagnosis and, ultimately, targeted treatments.

Published 12 May 2026

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Medscape,

<https://www.medscape.com/viewarticle/me-cfs-genetics-study-wins-4-75-million-government-backing-2026a1000fl9>

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Source: UK House of Commons

Date: May 27, 2026

URL:

<https://questions-statements.parliament.uk/written-questions/detail/2026-05-14/1497>

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

[Written Answers]

ME/CFS: Health Services

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Liz Jarvis

To ask the Secretary of State for Health and Social Care, what timetable his Department has set for implementing the commitments relating to research, attitudes and education, and support for people living with ME/CFS contained within the Government's policy paper entitled 'ME/CFS: the final delivery plan'; whether his Department plans to publish regular progress reports or annual reviews on implementation; what assessment he has made of whether NHS bodies have sufficient workforce capacity and resources to deliver the commitments contained within the plan; and whether any delivery timelines or implementation milestones have been revised since the plan's publication.

Mrs Sharon Hodgson

The final delivery plan on myalgic encephalomyelitis/ chronic fatigue syndrome (ME/CFS), published in July 2025, contains 44 actions for the Department of Health and Social Care, NHS England, other Government departments, and other organisations to implement. Of these commitments, over half have been delivered already, with many more actions progressing well.

Progress on research-related actions will be reported on annually, to the ME/CFS Post-Implementation Stakeholder Engagement Group and officials intend to provide the first of those annual updates on progress against all the actions included in the final delivery plan to stakeholders in the coming months.

To help support healthcare professionals in the diagnosis and management of ME/CFS, the Department has worked with NHS England to develop an e-learning programme for healthcare professionals, with the aim of supporting staff to be able to provide better care and improve patient outcomes. All sessions of the e-learning programme are now available at the following link, with sessions one, two, and three having universal access, whilst the final session on managing severe ME/CFS is only available to healthcare professionals:

<https://learninghub.nhs.uk/catalogue/mecfselearning?nodeId=7288>

The Medical Schools Council will promote the e-learning programme to all United Kingdom medical schools and will encourage those medical schools to provide undergraduates with direct patient experience of ME/CFS. Additionally, the Department has taken steps towards developing the awareness campaign that was committed to in the plan.

NHS England, with support from the Department, is developing a template service specification for mild and moderate ME/CFS, which will aim to support the commissioning, provision and evaluation of services for patients. Following stakeholder feedback, this template now includes reference severe ME/CFS. This template is intended to be published alongside a Language Matters Guide. The impact on National Health Service bodies, outside of NHS England, is expected to be minimal. The decision has been made to delay the action to consider whether a specialised service should be commissioned for very severe ME/CFS until April 2027. Currently, this is the only action that has been delayed.

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A House of Lords debate on the treatment of, and research into, severe myalgic encephalomyelitis will take place on Thursday 18 June 2026. The debate has been secured by Baroness Scott of Needham Market, following close work with Action for ME.

Go to,

<https://www.actionforme.org.uk/house-of-lords-debate-severe-me/>  
<https://whatson.parliament.uk/event/ca155522>

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Source: Government Whips' Office

UK House of Lords

Date: June 18, 2026

URL: <https://www.lordswhips.org.uk/speakers-lists/15062026>

WebTV:

<https://parliamentlive.tv/Search?Member=Baroness+Scott&House=Lords&Start=18%2F06%2F2026&End=18%2F06%2F2026>

[Speakers' Lists for Debates]

Baroness Scott of Needham Market to ask His Majesty's Government what their policy is towards the (1) treatment of, and (2) research into, severe myalgic encephalomyelitis. (Question for Short Debate to be taken as Lunch Break business, 1 hour).

Physical Speakers (4), in alphabetical order:

L Kamall

B Merron (Minister)

B Pidgeon

B Scott of Needham Market

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Source: UK House of Lords

Date: June 4, 2026

URL:

<https://questions-statements.parliament.uk/written-questions/detail/2026-05-14/hl134>

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

[Written Answers]

ME/CFS: Health Education

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Baroness Scott of Needham Market

To ask His Majesty's Government how people with lived experience of myalgic encephalomyelitis will be involved in the design and delivery of the awareness campaign.

Baroness Merron

Officials from the Department are engaging directly with a number of stakeholders, including representatives with lived experience of myalgic encephalomyelitis, also known as chronic fatigue syndrome (ME/CFS), and representatives from patient groups and charities, in the development of the awareness campaign. These stakeholders are members of the ME/CFS post-publication stakeholder engagement group, formerly the Task and Finish Group. Officials, together with these stakeholders, are considering the most effective options in the design and delivery of this campaign.

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Source: UK House of Lords

Date: June 5, 2026

URL:

<https://questions-statements.parliament.uk/written-questions/detail/2026-05-14/hl133>

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

[Written Answers]

ME/CFS: Research

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Baroness Scott of Needham Market

To ask His Majesty's Government what discussions they have had with life sciences sector organisations about accelerating research into myalgic encephalomyelitis; and what steps they plan to take to support that work by 2027.

Baroness Merron

The Government is committed to funding high-quality research to understand the causes, consequences, and treatment of myalgic encephalomyelitis, also known as chronic fatigue syndrome (ME/CFS). We recognise the value of collaborating across the life sciences sector to deliver the most impactful research. The Department funds research through the National Institute for Health and Care Research (NIHR).

The Government has outlined its approach to supporting research into ME/CFS in the Final Delivery Plan, published in July 2025. Since this was published, the NIHR and the Medical Research Council (MRC) has hosted a showcase on post-acute infection conditions, bringing together people with lived experience, researchers, clinicians, funders, and the life sciences sector to stimulate further research.

Recently, 4.75 million pounds of Government funding has been invested in SequenceME, which will carry out whole genome sequencing for up to 6,000 patients with ME/CFS. SequenceME brings together the University of Edinburgh, Action for ME, the European Bioinformatics Institute, and Oxford Nanopore Technologies, demonstrating the value of collaboration across the life sciences sector. We hope that this study will build a high-resolution genetic map of ME/CFS, paving the way for better diagnostics, including biomarkers, and future treatments. SequenceME builds on the 3.2 million pounds investment from the NIHR and MRC in DecodeME.

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Source: UK House of Commons

Date: June 5, 2026

URL:

<https://questions-statements.parliament.uk/written-questions/detail/2026-05-13/802>

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

[Written Answers]

ME/CFS: Health Services  
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Shockat Adam

To ask the Secretary of State for Health and Social Care, what assessment he has made of the adequacy of regional provision of services for patients with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome; and what steps he is taking to increase the availability of specialist services.

Mrs Sharon Hodgson

The commissioning of specialised services for myalgic encephalomyelitis, also known as chronic fatigue syndrome (ME/CFS), is the responsibility of local integrated care boards (ICBs). ICBs are expected to commission services that meet the needs of their local populations, in line with national standards, service specifications, and clinical access policies set by NHS England. Prioritisation of service provision remains at the discretion of local ICBs, which may result in variations of services across different regions.

The Department, working with NHS England, is developing a national template service specification for mild and moderate ME/CFS to support commissioners and providers in planning and delivering services. The template is intended as a guide to best practice, rather than a mandatory or prescriptive service model, and is being designed to

support local adaptation in line with population need and existing service configurations. This could help to reduce variation between services, although decisions on how to implement the template remains at the discretion of ICBs.

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Source: UK House of Lords

Date: June 8, 2026

URL:

<https://questions-statements.parliament.uk/written-questions/detail/2026-05-14/hl136>

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

[Written Answers]

ME/CFS: Research

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Baroness Scott of Needham Market

To ask His Majesty's Government what assessment they have made of the whether current strategic prioritisation of myalgic encephalomyelitis (ME) research is proportionate to the disease burden; and whether they plan to revise the research strategy to address any ME research gaps.

Baroness Merron

There has not been a specific assessment of whether the current strategic prioritisation of research into myalgic encephalomyelitis, also known as chronic fatigue syndrome (ME/CFS), is proportionate to the disease burden. As outlined in the ME/CFS Final Delivery Plan, published in July 2025, there has historically been a relatively low amount of research funded on ME/CFS, compared with disease burden. We are implementing the ME/CFS Final Delivery Plan to expand research activity, and there are no plans to revise this approach.

The Department funds research through the National Institute for Health

and Care Research (NIHR). Since the publication of the delivery plan, we have hosted a showcase on post-acute infection conditions, bringing together people with lived experience, researchers, clinicians, and funders to stimulate further research. A summary of this showcase has been published on the NIHR Open Research. The NIHR has awarded two application development awards to investigate the feasibility of a new clinical trial that tests multiple interventions for the treatment of post-acute infection syndromes, including Long Covid and ME/CFS.

In addition, we recently announced 4.75 million pounds of Government funding for SequenceME, which will carry out whole genome sequencing for up to 6,000 patients with ME/CFS. The NIHR welcomes research into any aspect of health and care, including ME/CFS. Applications are subject to peer review and judged in open competition, with awards made on the basis of the importance of the topic to patients and health and care services, including how the research addresses evidence gaps, value for money, and scientific quality.

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Source: UK House of Lords

Date: June 8, 2026

URL:

<https://questions-statements.parliament.uk/written-questions/detail/2026-05-13/hl54>

<https://questions-statements.parliament.uk/written-questions/detail/2026-05-13/hl55>

<https://questions-statements.parliament.uk/written-questions/detail/2026-05-13/hl56>

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

[Written Answers]

ME/CFS: Health Services

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Baroness Scott of Needham Market

To ask His Majesty's Government what interim measures they plan to put

in place to support people with severe and very severe myalgic encephalomyelitis following the delay to the establishment of specialist services.

To ask His Majesty's Government what guidance they have issued to integrated care boards about commissioning appropriate provision for patients with myalgic encephalomyelitis/chronic fatigue syndrome before specialist services are established.

To ask His Majesty's Government what guidance is in place for hospitals, community services and integrated care boards about the care and management of people with severe and very severe myalgic encephalomyelitis; and how compliance with the guidance is monitored.

Baroness Merron

Officials in the Department and NHS England, together with stakeholders, are currently considering interim measures to support patients with very severe myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). This is ahead of my Rt Hon. Friend, the Secretary of State for Health and Social Care, considering whether a specialised service should be prescribed for very severe ME/CFS.

These measures include referencing severe and very severe ME/CFS in a new template service specification that is being developed for mild and moderate ME/CFS. This template service specification, therefore, aims to provide support for ME/CFS service providers and commissioners to improve care and support for people living with all levels of severity of ME/CFS.

Integrated care boards (ICBs) are expected to commission services for people with ME/CFS across all levels of severity, including those with severe and very severe ME/CFS, in line with national standards, service specifications, and clinical access policies set by NHS England. Prioritisation and funding remain at the discretion of ICBs.

Additionally, the National Institute for Health and Care Excellence (NICE) has developed guidance on the diagnosis and management of ME/CFS, including mental health support for people with ME/CFS and their families. NICE guidelines are evidence-based, informed by clinical

expertise, and represent best practice. Although NICE guidelines are not mandatory, so ICBs are not routinely monitored on their compliance, healthcare professionals are expected to take them fully into account.

NHS England, with support from the Department, has developed an e-learning programme to support healthcare professionals in the care of people with ME/CFS of all levels of severity. All four sessions of the e-learning programme are now available, with sessions one, two, and three having universal access, whilst the fourth session, which includes support and clinical management of severe ME/CFS, is only available to healthcare professionals. Further information is available on the NHS.UK website. As the e-learning programme is not mandatory, take-up at healthcare professional level is not routinely monitored.

The Medical Schools Council will promote the e-learning programme to all United Kingdom medical schools and will encourage those medical schools to provide undergraduates with direct patient experience of ME/CFS.

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Source: UK House of Lords

Date: June 9, 2026

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<https://questions-statements.parliament.uk/written-questions/detail/2026-05-14/hl135>

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

[Written Answers]

ME/CFS: Health Services

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Baroness Scott of Needham Market

To ask His Majesty's Government how the template service specification for mild and moderate myalgic encephalomyelitis (ME) will address the needs of people with severe and very severe ME; and whether a separate specification will be developed for those groups.

Baroness Merron

As part of the development of the template service specification for mild and moderate myalgic encephalomyelitis, also known as chronic fatigue syndrome (ME/CFS), which was committed to in the final delivery plan on ME/CFS, published in July 2025, officials have engaged with a sub-group of the ME/CFS post-publication stakeholder engagement group. As part of this engagement, officials from the Department, together with NHS England, have made the decision to include reference to severe ME/CFS in that template service specification based on feedback received from this group. It will also include a reminder that integrated care boards are expected to commission services that meet the needs of the local population, including for all levels of severity of ME/CFS.

There are currently no plans to develop a separate specification for severe and very severe ME/CFS.

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These URLs are important...

<https://lordsbusiness.parliament.uk/ItemOfBusiness?itemOfBusinessId=170871&sectionId=38&businessPaperDate=2026-06-18>

<https://lordslibrary.parliament.uk/myalgic-encephalomyelitis-me-an-overview/>

<https://whatson.parliament.uk/event/cal55522>

<https://parliamentlive.tv/event/index/30b9bf60-8208-4530-84dd-47210e4170c9>

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Source: UK House of Lords

Date: June 18, 2026

URL:

<https://hansard.parliament.uk/lords/2026-06-18/debates/A11EF1BB-6132-4EDB-A2AF-9A6A12737865/SevereMyalgicEncephalomyelitis>

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

[Debates]

Severe Myalgic Encephalomyelitis

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Baroness Scott of Needham Market

To ask His Majesty's Government what is their policy towards the (1) treatment of, and (2) research into, severe myalgic encephalomyelitis.

My Lords, I am grateful to have secured time for this debate on the treatment of and research into severe ME. I am particularly grateful to Action for ME, whose work with those living with ME and advocacy to improve care, treatment and understanding has been tireless. Someone very close to me has ME, and I know from our personal experience what so many other families know: that ME is not just a matter of policy documents, clinical pathways or departmental responsibilities; it is about lives changed beyond recognition. It is about people who were active, engaged, ambitious and full of plans who suddenly find that the most ordinary of tasks become impossible.

ME is a complex, chronic and disabling condition that affects multiple systems in the body, characterised by debilitating fatigue that does not improve with rest, cognitive dysfunction, pain and hypersensitivity to light, sound and movement. Even the most minimal activity can cause a serious worsening of symptoms in some people. Around 1.35 million people in the UK are estimated to be living with ME, although the true number may well be higher because of underdiagnosis and limited research. Around one in four of those with ME are severely affected. To be clear, that means they are housebound or bedbound, unable to carry out daily independent activities and totally reliant on others for personal care. Those with very severe ME may have extreme symptoms and are dependent on full-time care. Many are unable to process or tolerate food and are dependent on nutritional and hydration support. We need to be clear about the scale and the seriousness of this issue.

There have been some welcome developments recently with regard to ME. The Government's ME/CFS delivery plan, published in July last year, was an important step. It finally recognises the needs of people with ME and has signalled a greater willingness to address an illness that has been

neglected for so long. However, that recognition, welcome though it is, is not delivery. In March this year the Department of Health and Social Care confirmed that work to explore a specialist NHS service for people with severe ME will not begin until at least April 2027. That is not delivery of the service; it is simply the exploration of one.

For many illnesses a delay of a year would be troubling, but for people with severe ME it may be devastating, leading to further deterioration in their health and, crucially, signalling to them that once again their illness is being forgotten. In practice, the delay will mean that patients continue to be passed between services that simply do not know what to do, or, even worse, continue being harmed by care that is totally inappropriate to their needs. Recent prevention of future deaths reports into the deaths of Maeve Boothby O'Neill and Sarah Lewis raise serious concerns about the lack of specialist services, insufficient clinical understanding and failures to meet even the most basic care needs. These reports should weigh heavily on all of us and, I am sure, also weigh heavily on the Minister.

Those reports make it clear that it is not just a question of future improvement but of patient safety now. More deaths from ME must be prevented. I know the Minister will say the delivery plan is a starting point, and I accept that, but sadly it is a plan without funding, timelines or accountability, and it risks becoming just another document that people living with ME are told to welcome while their daily reality remains unchanged.

I would like the Government to set out what interim support will be available for patients with severe ME before exploratory work on a specialised service begins in April next year. We need clear interim measures, dedicated accountability within the department and within the NHS, and proper co-design with people with severe and very severe ME, along with their families, carers and the charities that support them.

There is also the question of research. I welcome the Government's recent announcement to invest 4.75 million pounds to enable the Sequence ME and Long Covid study to completely sequence the whole genomes of the 6,000 ME patients already collected. However, ME remains significantly underresearched when compared with its prevalence, severity and economic impact. For comparison, the UK spends 20 times less on ME research compared to multiple sclerosis, despite the fact that ME is twice as

prevalent. Private investment has historically been limited because of the lack of established biomarkers and an underdeveloped clinical research pipeline, and this is precisely why the Government need to act. There is an opportunity here for the UK to lead in post-infectious disease research, with ME as a central part of that agenda. Along with Action for ME, I call on the Government to commit to accelerating biomedical research into ME through the life sciences sector by 2027, and this should include targeted support for diagnostics, biomarkers, treatment development, clinical trials and research into severe and very severe ME. The proposed innovation and research duty in the NHS modernisation Bill provides a clear opportunity to strengthen that commitment.

There is a very practical problem with data. At present, poor coding and inconsistent diagnosis mean that the NHS does not have a reliable picture of how many people have ME, where they are, how severe their illness is or what support they need. This makes proper service planning almost impossible, and it makes it too easy for people with ME, particularly severe and very severe, to remain invisible to the system, and they are left without adequate and safe care. I am very conscious that there are excellent clinicians, researchers, carers and voluntary organisations doing everything they can to support people with ME. My criticism is not of those individuals but of a system that has not given those with ME, especially severe ME, the services and the care they need.

I want to finish with a number of questions for the Minister. First, can she outline what interim support will be put in place for people with very severe ME before April next year? Will she consider setting up an expert advisory panel on severe ME which can give guidance to hospitals when they admit severe ME patients? Will the department look at providing clear nutritional guidance for patients with severe ME? Perhaps it could think about establishing a remote, virtual ME clinic along the lines of virtual wards. Will the Government commit to accelerating biomedical research into ME, including research into severe and very severe ME? How will the Government ensure that the delivery plan is backed by clear accountability, funding, timelines and local commissioning duties? People with ME have waited far too long, first to be believed and now for research and treatment.

Lord McCrea of Magherafelt and Cookstown

My Lords, I want to make a very short intervention in this debate. I thank the noble Baroness, Lady Scott, for introducing a very important debate. As she pointed out, an estimated 1.25 million people across the United Kingdom are living with ME. Many of those are suffering severely affected and unable to carry out the daily activities which others take for granted and therefore require significant support with personal care. The level of care services is inconsistent across the United Kingdom, leaving those in need with major gaps in provision, causing serious deterioration in their personal well-being.

I therefore join in asking the Minister whether she can tell the House what interim support will be provided for people with severe ME, bearing in mind the delay to the expiration of the nationally commissioned service until April 2027. ME remains significantly underresearched considering how prevalent it is within society. Therefore, can the Minister's department take action to accelerate ME research, thereby gathering the necessary evidence base for better care? The dignity of many suffering from severe ME depends on appropriate services across the UK. I trust that this short debate highlights the importance of the issue, and I wholeheartedly support the noble Baroness, Lady Scott, in her debate today.

Baroness Walmsley

My Lords, I congratulate my noble friend Lady Scott of Needham Market on her very moving speech. She comprehensively covered the major issues that are before patients with ME.

The prevention of future deaths report into the death of Maeve Boothby-O'Neill emphasised that there is no known cure into myalgic encephalomyelitis—not only no cure but no known cause, no known reason why some are susceptible to developing ME and no known reason why one in four sufferers develop severe problems. It was clear that despite three periods in hospital, the NHS was unable to reverse Maeve's malnutrition and sadly she died. One might think that apart from lots more research into causes, prevention, diagnosis and effective treatment, there is nothing that can be done to care for sufferers appropriately. But there is.

I note that in a recent survey by Action for ME, just 10.8% of respondents with severe or very severe ME said they felt supported by the NHS. I began to wonder what “good” looks like, so I looked at the NICE guidelines and there it was. But I recently heard from a carer of a patient with severe ME. She said: “There is almost no help available on the NHS for patients of this severity. We waited six months for an NHS specialist appointment. The consultation lasted 10 minutes over the phone. The consultant, whose primary speciality was diabetes, reviewed blood tests, said they were normal and suggested my partner take a multivitamin. The clinic was disbanded the following day due to the consultant’s retirement, with no handover to an alternative service. Our experience with primary care has been equally concerning. Most GPs we have encountered have little understanding of severe ME, how profoundly disabling it can be or best practice for care. To give one example, a GP recently suggested to me that my partner try ‘talking therapies’ when he was unable to tolerate sound”.

My first question to the Minister is therefore: do the Government know how many ME services are implementing the NICE guidelines? If not, what is being done to find out? What is being done to support those that are not implementing the NICE guidance to do so? Obviously, we need to take several steps back from the quality of care to find out how this disease develops. Clearly, the Government should commit to accelerating biomedical research into ME, including the severe and very severe conditions. This should include targeted funding for diagnostics, biomarkers, treatment development, clinical trials and other post-infectious disease research, as my noble friend demanded. But there are also off-label, low-risk interventions, including cannabis-based medicines, which patients may be willing to try but cannot access on the NHS.

As we have just heard, ME remains significantly underresearched relative to its prevalence. Severe sufferers often cannot work from an early age. Those who are bed-bound require constant care at home, which also limits the economic activity of their carers. Improving economic evidence is important as it encourages grant-making decisions. Better cost of illness data would help demonstrate the wider social and economic impact of ME, including costs to the NHS, social care, the welfare system, families and carers, and the wider economy. State-funded research into this would pump-prime investment by charities, academics and

pharmaceutical companies. It sends a message that ME matters.

The condition is increasingly being understood within the broader field of post-infectious conditions such as long Covid, but we must avoid the danger of the two conditions being confused. However, I welcome the announcement of a 1.4 million pounds NICE research programme to explore the cost effectiveness of existing healthcare for ME and long Covid to improve the quality of care. Major UK research studies, including DecodeME, LOCOME and Sequence ME & Long Covid, are helping to build momentum. As my noble friend said, there is now an opportunity for the Government to position the UK as a leader in post-infectious disease research, with ME right at the heart of it. Is there a coherent plan for a broad range of research to cover all aspects of ME, or is it a bit here and a bit there? Are we lagging behind other countries and losing an important economic opportunity?

We will also need targeted support to translate biomedical science into commercially viable diagnostics and treatments. In this context, a recent report from your Lordships' Science and Technology Committee into the need for more support for science-based companies trying to scale up is certainly worth a read. It is called Bleeding to Death: the Science and Technology Growth Emergency. In other situations, there has been successful repurposing of pharmaceutical interventions developed for other diseases. Dexamethasone was an example during the Covid pandemic, and it certainly saved lives. There is a new funding opportunity for an NIHR award focused on evaluating repurposed pharmaceutical interventions. I wonder whether these grants might be applied to treat post-acute infection syndromes and associated conditions, including ME. Can the Minister say whether there has been any progress on this?

We have a once-in-a-lifetime opportunity to do something for ME patients now. The sensory overload suffered by some sufferers means that they must restrict their stimulus by lying in a quiet, dark room, and their care needs to be physically gentle. This means that the environment in which care is delivered is as critical to their health outcomes as the treatment itself. The current definition of patient information in the NHS modernisation Bill risks creating a significant safety blind spot. While the single patient record is welcome and designed to consolidate a patient's medical history, current guidance omits the contextual clinical data providing accommodations to make services accessible to all patients. Without formal, recorded and transferable data on

reasonable accommodations, these patients face preventable harm, wasted clinical resources—when no sensory adjustments mean that appointments fail—and having to re-advocate for their safety needs at every new touchpoint.

By amending the definition of patient information to include reasonable accommodations, we could ensure that the SPR acts as a true safety net, not just for ME patients but for those with learning or communication difficulties. Including this provision does not merely add data; it formalises the duty of care, ensures clinical safety and embeds equity into the very architecture of the future NHS digital infrastructure. Will the Government accept an amendment to correct this omission?

Lord Evans of Rainow

My Lords, I thank the noble Baroness, Lady Scott, for securing this important debate. I join others in paying tribute to the patients, families, clinicians, researchers and charities who have worked tirelessly to improve understanding of myalgic encephalomyelitis. For too long, people living with this condition have faced scepticism and inadequate support.

While significant challenges remain, it is right to acknowledge that progress has been made. There is now a much greater recognition that ME is a serious and often profoundly debilitating condition requiring appropriate clinical care and support. We on these Benches welcome the publication of the ME delivery plan in 2025. Many of the origins of that work lie in the commitments made by the previous Conservative Government in 2022 to develop a cross-government approach to ME. It is encouraging that the plan contains a broad range of actions across health services and educational research. We also welcome reports that a substantial number of those actions are complete or in progress.

However, publication of a plan is only the beginning. What matters to patients is whether they experience tangible improvements in their daily lives. The plan contains 44 actions, but patients and charities have raised understandable concerns about how delivery will be monitored in practice, who will ultimately be accountable for implementation, and how responsibilities will be managed as NHS England functions transfer into the Department of Health and Social Care. I therefore hope the Minister

can tell the House today when the promised progress report will be published and who will be responsible for ensuring delivery across government and the NHS.

Nowhere are these questions more urgent than for those living with severe and very severe ME. These are often the patients with the greatest needs and the least ability to advocate for themselves. It is therefore concerning that the only delayed action within the delivery plan relates to consideration of specialised services for this group, with the decision now not expected until April 2027. The evidence presented by charities and campaigners illustrates why this matters. Preliminary findings from Action for ME's recent survey suggest that many people with severe and very severe ME are unable to access existing specialist services because they are simply too unwell to attend them. Large numbers report receiving little or no ongoing support from either specialist services or primary care, while many face serious challenges in meeting basic needs, including nutrition. This matters not only because of the immediate impact on the patient's quality of life but because early intervention and appropriate support can prevent longer-term deterioration.

If people have access to advice, treatment, system management and practical support at an earlier stage, there is a greater chance of helping them maintain their independence and remain connected to education or employment where appropriate. Delays in accessing support can leave people becoming progressively more unwell, making recovery and participation in everyday life considerably harder. That is why timely and effective services are so important, not only for those who are already severely affected but for those at risk of reaching that point.

It is also important to recognise that ME disproportionately affects women. Evidence consistently suggests that women are significantly more likely to be diagnosed with ME than men. Can the Minister therefore say what assessment the Government have made of the reasons behind this disparity and whether the needs of women living with ME are being specifically considered as the delivery plan is implemented?

Recent prevention of future deaths reports have also highlighted serious concerns regarding the care available to some of the most severely affected patients. The Government have stated that integrated care boards remain responsible for commissioning appropriate services in the

meantime. Can the Minister therefore explain what assessment has been made of the current provision for severe and very severe ME, whether significant variation exists across the country, and what interim support will be available before any decision on a nationally commissioned service is reached in 2027?

We must also not lose sight of the critical importance of research. We welcome the support provided for the DecodeME survey. Its early findings identify potential genetic links involving the immune and nervous systems, representing an encouraging step forward in understanding the biological mechanisms underlying this condition. Yet ME remains significantly under-researched relative to its prevalence and impact. The Government have rightly spoken about the UK's ambition to lead in life sciences and post-infectious disease research. There is a strong case for ensuring that ME forms part of that agenda, including through support for research into diagnostics, biomarkers, treatments and clinical trials.

In closing, I ask the Minister three questions. When will the Government publish their next formal update on the delivery of the ME plan? What interim support will be provided for people with severe and very severe ME before April 2027? Can she assure the House that the decision on specialised services will not be subject to further delay? Those living with ME have waited a long time to be heard. They deserve not only recognition and promises, but delivery.

The Parliamentary Under-Secretary of State, Department of Health and Social Care (Baroness Merron)

My Lords, I am most grateful to the noble Baroness, Lady Scott, for securing this important debate, which matters so much to so many, and for her clear introduction to these matters. I am also grateful to all the other noble Lords who spoke for their thoughtful and probing insights. The debate has certainly underlined the profound impact that myalgic encephalomyelitis—ME/CFS—has on those living with the condition, but also on their families, friends, carers and communities.

Noble Lords have spoken very movingly about the reality, and I am grateful for the welcomes across the House for a number of government actions. I recognise what noble Lords have described, which is—to pick

up a few points—a lack of awareness, variability in services, the stigma faced by those with ME/CFS and the need to go further. We recognise all of that.

The fact is that the system has not worked as it should for people. But that is why, early on, the Government prioritised publication of our final delivery plan on ME/CFS, which we published in July last year. I assure noble Lords that we work closely with those most impacted by the effects of this debilitating condition, including those with lived experience. I add my thanks to charities and campaigners for their work, because they have given voice to this subject. We want to ensure that patients are truly heard by a system that can respond to those voices, because historically that has not been the case. So the plan sets out a clear direction for improvement, and it focuses on three key ambitions: boosting research, improving understanding and education, and strengthening the care and support people receive.

The noble Baroness, Lady Scott, and the noble Lord, Lord Evans, raised a number of questions about funding timelines and accountability. I confirm that the department has overall responsibility for progress against the final delivery plan, and officials are actively tracking progress. It is very much worth noticing that three-quarters of the plan's actions have been completed or commenced or are currently ongoing. I say to the noble Lord, Lord Evans, that an update on the delivery of the final delivery plan will be communicated next month.

We know, as has been spoken about, that a lack of research has meant that those with ME/CFS have been left feeling undervalued, frustrated and overlooked. That is why the final delivery plan commits to stimulating research, including through new funding opportunities, better support for researchers and building capacity and research. We have gone beyond the actions in the final delivery plan, as all noble Lords were good enough to reference, by investing 4.75 million pounds in SequenceME, which will create the first high-resolution genetic map for ME/CFS. I believe that this will offer new hope to patients and pave the way for better diagnostics and future treatment, which, after all, is what we need.

All noble Lords asked for further commitments. To the points I have just made, I add that the Government are investing in turbocharging clinical trials research. Key to this is enabling new treatments to get to

patients faster; and the NIHR has funded projects to explore the feasibility of a clinical trial for treatments for ME/CFS and other post-acute infection conditions, as noble Lords have asked for. Of course, funding and support is available for researchers, and the Medical Research Council and the NIHR welcome funding applications for research into ME/CFS and other post-acute infection conditions. Addressing gaps in knowledge and awareness around this condition is also crucial, because people who live with ME/CFS have to be seen and feel seen. They need to be reassured, and they need evidence that they are going to be taken seriously. I am therefore glad to say that NHS England has developed an e-learning programme, which consists of four modules and seeks to improve the understanding of healthcare professionals, and to support them to provide the right care at the right time for those who need it, including those with severe ME/CFS.

Experiences of care vary widely—that should not be inevitable, but we recognise that they do—but I believe that those with ME/CFS deserve a high standard of care, no matter who they are or where they are. We will seek to improve that through the development of a new template service specification for mild and moderate ME/CFS, and that will expand to include the severe nature of the condition. The template will focus minds and demonstrate to integrated care boards the ways in which NICE guidelines can be implemented. Key here too is that it will provide good practice examples for ICBs, so they can model their own services on where it is being successful.

There is, as I said at the beginning, much more to be done. We are working at pace to implement this final delivery plan, and we will work continually with stakeholders to make sure that it meets the mark. The noble Baroness, Lady Scott, and the noble Lord, Lord McCrea, asked about interim support. We are not just committed to considering a specialised service for those with a very serious version of the condition; we are also exploring what preparatory work can be taken forward ahead of April next year. We want to progress the work at pace once the transformation in respect of NHS England has been concluded. In the meantime, we are considering a range of potential interim measures to support those with severe ME/CFS, including further promotion of the e-learning modules that I referred to, making sure they span very severe and severe ME/CFS, alongside the recommendations that have been presented to government directly by patient groups.

The noble Baroness, Lady Scott, asked about setting up an expert advisory panel. We do not currently have plans for such a panel for those with severe ME/CFS, but I assure the noble Baroness that we engage very closely with experts from NHS England, clinicians and experts in the charity sector so that we can develop a much broader approach to supporting patients with ME/CFS.

In response to the question about exploring whether a specialised service should be commissioned for very severe ME/CFS, any decision on whether this committee would be convened remains at the discretion of the Secretary of State. I say to the noble Lord, Lord Evans, that we recognise that ME is more likely to affect women and that early results in the DecodeME study have found that women with ME/CFS tend to have more symptoms and co-occurring conditions than men. That will be taken into account. Again, I am most grateful to the noble Baroness, Lady Scott, for her work and advocacy in this area.

Baroness Walmsley

Before the Minister sits down, I asked what support is being given to those services that are unable to fulfil the NICE guidelines, and about the Government's attitude to including reasonable adjustments in the information on the single patient record.

Baroness Merron

I would be pleased to take those two points away and look at them, particularly the second, which is a very practical suggestion. I am grateful to the noble Baroness, as ever, and I will gladly write to her.

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[Debates]

Severe Myalgic Encephalomyelitis  
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Baroness Scott of Needham Market

To ask His Majesty's Government what is their policy towards the (1) treatment of, and (2) research into, severe myalgic encephalomyelitis.

My Lords, I am grateful to have secured time for this debate on the treatment of and research into severe ME. I am particularly grateful to Action for ME, whose work with those living with ME and advocacy to improve care, treatment and understanding has been tireless. Someone very close to me has ME, and I know from our personal experience what so many other families know: that ME is not just a matter of policy documents, clinical pathways or departmental responsibilities; it is about lives changed beyond recognition. It is about people who were active, engaged, ambitious and full of plans who suddenly find that the most ordinary of tasks become impossible.

ME is a complex, chronic and disabling condition that affects multiple systems in the body, characterised by debilitating fatigue that does not improve with rest, cognitive dysfunction, pain and hypersensitivity to light, sound and movement. Even the most minimal activity can cause a serious worsening of symptoms in some people. Around 1.35 million people in the UK are estimated to be living with ME, although the true number may well be higher because of underdiagnosis and limited research. Around one in four of those with ME are severely affected. To be clear, that means they are housebound or bedbound, unable to carry out daily independent activities and totally reliant on others for personal care. Those with very severe ME may have extreme symptoms and are dependent on full-time care. Many are unable to process or tolerate food and are dependent on nutritional and hydration support. We need to be clear about the scale and the seriousness of this issue.

There have been some welcome developments recently with regard to ME. The Government's ME/CFS delivery plan, published in July last year, was an important step. It finally recognises the needs of people with ME and

has signalled a greater willingness to address an illness that has been neglected for so long. However, that recognition, welcome though it is, is not delivery. In March this year the Department of Health and Social Care confirmed that work to explore a specialist NHS service for people with severe ME will not begin until at least April 2027. That is not delivery of the service; it is simply the exploration of one.

For many illnesses a delay of a year would be troubling, but for people with severe ME it may be devastating, leading to further deterioration in their health and, crucially, signalling to them that once again their illness is being forgotten. In practice, the delay will mean that patients continue to be passed between services that simply do not know what to do, or, even worse, continue being harmed by care that is totally inappropriate to their needs. Recent prevention of future deaths reports into the deaths of Maeve Boothby O'Neill and Sarah Lewis raise serious concerns about the lack of specialist services, insufficient clinical understanding and failures to meet even the most basic care needs. These reports should weigh heavily on all of us and, I am sure, also weigh heavily on the Minister.

Those reports make it clear that it is not just a question of future improvement but of patient safety now. More deaths from ME must be prevented. I know the Minister will say the delivery plan is a starting point, and I accept that, but sadly it is a plan without funding, timelines or accountability, and it risks becoming just another document that people living with ME are told to welcome while their daily reality remains unchanged.

I would like the Government to set out what interim support will be available for patients with severe ME before exploratory work on a specialised service begins in April next year. We need clear interim measures, dedicated accountability within the department and within the NHS, and proper co-design with people with severe and very severe ME, along with their families, carers and the charities that support them.

There is also the question of research. I welcome the Government's recent announcement to invest 4.75 million pounds to enable the Sequence ME and Long Covid study to completely sequence the whole genomes of the 6,000 ME patients already collected. However, ME remains significantly underresearched when compared with its prevalence, severity and economic impact. For comparison, the UK spends 20 times less on ME research

compared to multiple sclerosis, despite the fact that ME is twice as prevalent. Private investment has historically been limited because of the lack of established biomarkers and an underdeveloped clinical research pipeline, and this is precisely why the Government need to act. There is an opportunity here for the UK to lead in post-infectious disease research, with ME as a central part of that agenda. Along with Action for ME, I call on the Government to commit to accelerating biomedical research into ME through the life sciences sector by 2027, and this should include targeted support for diagnostics, biomarkers, treatment development, clinical trials and research into severe and very severe ME. The proposed innovation and research duty in the NHS modernisation Bill provides a clear opportunity to strengthen that commitment.

There is a very practical problem with data. At present, poor coding and inconsistent diagnosis mean that the NHS does not have a reliable picture of how many people have ME, where they are, how severe their illness is or what support they need. This makes proper service planning almost impossible, and it makes it too easy for people with ME, particularly severe and very severe, to remain invisible to the system, and they are left without adequate and safe care. I am very conscious that there are excellent clinicians, researchers, carers and voluntary organisations doing everything they can to support people with ME. My criticism is not of those individuals but of a system that has not given those with ME, especially severe ME, the services and the care they need.

I want to finish with a number of questions for the Minister. First, can she outline what interim support will be put in place for people with very severe ME before April next year? Will she consider setting up an expert advisory panel on severe ME which can give guidance to hospitals when they admit severe ME patients? Will the department look at providing clear nutritional guidance for patients with severe ME? Perhaps it could think about establishing a remote, virtual ME clinic along the lines of virtual wards. Will the Government commit to accelerating biomedical research into ME, including research into severe and very severe ME? How will the Government ensure that the delivery plan is backed by clear accountability, funding, timelines and local commissioning duties? People with ME have waited far too long, first to be believed and now for research and treatment.

Lord McCrea of Magherafelt and Cookstown

My Lords, I want to make a very short intervention in this debate. I thank the noble Baroness, Lady Scott, for introducing a very important debate. As she pointed out, an estimated 1.25 million people across the United Kingdom are living with ME. Many of those are suffering severely affected and unable to carry out the daily activities which others take for granted and therefore require significant support with personal care. The level of care services is inconsistent across the United Kingdom, leaving those in need with major gaps in provision, causing serious deterioration in their personal well-being.

I therefore join in asking the Minister whether she can tell the House what interim support will be provided for people with severe ME, bearing in mind the delay to the expiration of the nationally commissioned service until April 2027. ME remains significantly underresearched considering how prevalent it is within society. Therefore, can the Minister's department take action to accelerate ME research, thereby gathering the necessary evidence base for better care? The dignity of many suffering from severe ME depends on appropriate services across the UK. I trust that this short debate highlights the importance of the issue, and I wholeheartedly support the noble Baroness, Lady Scott, in her debate today.

Baroness Walmsley

My Lords, I congratulate my noble friend Lady Scott of Needham Market on her very moving speech. She comprehensively covered the major issues that are before patients with ME.

The prevention of future deaths report into the death of Maeve Boothby-O'Neill emphasised that there is no known cure into myalgic encephalomyelitis—not only no cure but no known cause, no known reason why some are susceptible to developing ME and no known reason why one in four sufferers develop severe problems. It was clear that despite three periods in hospital, the NHS was unable to reverse Maeve's malnutrition and sadly she died. One might think that apart from lots more research into causes, prevention, diagnosis and effective treatment, there is nothing that can be done to care for sufferers appropriately. But there

is.

I note that in a recent survey by Action for ME, just 10.8% of respondents with severe or very severe ME said they felt supported by the NHS. I began to wonder what “good” looks like, so I looked at the NICE guidelines and there it was. But I recently heard from a carer of a patient with severe ME. She said: “There is almost no help available on the NHS for patients of this severity. We waited six months for an NHS specialist appointment. The consultation lasted 10 minutes over the phone. The consultant, whose primary speciality was diabetes, reviewed blood tests, said they were normal and suggested my partner take a multivitamin. The clinic was disbanded the following day due to the consultant's retirement, with no handover to an alternative service. Our experience with primary care has been equally concerning. Most GPs we have encountered have little understanding of severe ME, how profoundly disabling it can be or best practice for care. To give one example, a GP recently suggested to me that my partner try 'talking therapies' when he was unable to tolerate sound”.

My first question to the Minister is therefore: do the Government know how many ME services are implementing the NICE guidelines? If not, what is being done to find out? What is being done to support those that are not implementing the NICE guidance to do so? Obviously, we need to take several steps back from the quality of care to find out how this disease develops. Clearly, the Government should commit to accelerating biomedical research into ME, including the severe and very severe conditions. This should include targeted funding for diagnostics, biomarkers, treatment development, clinical trials and other post-infectious disease research, as my noble friend demanded. But there are also off-label, low-risk interventions, including cannabis-based medicines, which patients may be willing to try but cannot access on the NHS.

As we have just heard, ME remains significantly underresearched relative to its prevalence. Severe sufferers often cannot work from an early age. Those who are bed-bound require constant care at home, which also limits the economic activity of their carers. Improving economic evidence is important as it encourages grant-making decisions. Better cost of illness data would help demonstrate the wider social and economic impact of ME, including costs to the NHS, social care, the welfare system, families and carers, and the wider economy. State-funded research into

this would pump-prime investment by charities, academics and pharmaceutical companies. It sends a message that ME matters.

The condition is increasingly being understood within the broader field of post-infectious conditions such as long Covid, but we must avoid the danger of the two conditions being confused. However, I welcome the announcement of a 1.4 million pounds NICE research programme to explore the cost effectiveness of existing healthcare for ME and long Covid to improve the quality of care. Major UK research studies, including DecodeME, LOCOME and Sequence ME & Long Covid, are helping to build momentum. As my noble friend said, there is now an opportunity for the Government to position the UK as a leader in post-infectious disease research, with ME right at the heart of it. Is there a coherent plan for a broad range of research to cover all aspects of ME, or is it a bit here and a bit there? Are we lagging behind other countries and losing an important economic opportunity?

We will also need targeted support to translate biomedical science into commercially viable diagnostics and treatments. In this context, a recent report from your Lordships' Science and Technology Committee into the need for more support for science-based companies trying to scale up is certainly worth a read. It is called Bleeding to Death: the Science and Technology Growth Emergency. In other situations, there has been successful repurposing of pharmaceutical interventions developed for other diseases. Dexamethasone was an example during the Covid pandemic, and it certainly saved lives. There is a new funding opportunity for an NIHR award focused on evaluating repurposed pharmaceutical interventions. I wonder whether these grants might be applied to treat post-acute infection syndromes and associated conditions, including ME. Can the Minister say whether there has been any progress on this?

We have a once-in-a-lifetime opportunity to do something for ME patients now. The sensory overload suffered by some sufferers means that they must restrict their stimulus by lying in a quiet, dark room, and their care needs to be physically gentle. This means that the environment in which care is delivered is as critical to their health outcomes as the treatment itself. The current definition of patient information in the NHS modernisation Bill risks creating a significant safety blind spot. While the single patient record is welcome and designed to consolidate a patient's medical history, current guidance omits the contextual clinical data providing accommodations to make services accessible to

all patients. Without formal, recorded and transferable data on reasonable accommodations, these patients face preventable harm, wasted clinical resources—when no sensory adjustments mean that appointments fail—and having to re-advocate for their safety needs at every new touchpoint.

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Lord Evans of Rainow

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While significant challenges remain, it is right to acknowledge that progress has been made. There is now a much greater recognition that ME is a serious and often profoundly debilitating condition requiring appropriate clinical care and support. We on these Benches welcome the publication of the ME delivery plan in 2025. Many of the origins of that work lie in the commitments made by the previous Conservative Government in 2022 to develop a cross-government approach to ME. It is encouraging that the plan contains a broad range of actions across health services and educational research. We also welcome reports that a substantial number of those actions are complete or in progress.

However, publication of a plan is only the beginning. What matters to patients is whether they experience tangible improvements in their daily lives. The plan contains 44 actions, but patients and charities have raised understandable concerns about how delivery will be monitored in practice, who will ultimately be accountable for implementation, and how responsibilities will be managed as NHS England functions transfer into

the Department of Health and Social Care. I therefore hope the Minister can tell the House today when the promised progress report will be published and who will be responsible for ensuring delivery across government and the NHS.

Nowhere are these questions more urgent than for those living with severe and very severe ME. These are often the patients with the greatest needs and the least ability to advocate for themselves. It is therefore concerning that the only delayed action within the delivery plan relates to consideration of specialised services for this group, with the decision now not expected until April 2027. The evidence presented by charities and campaigners illustrates why this matters. Preliminary findings from Action for ME's recent survey suggest that many people with severe and very severe ME are unable to access existing specialist services because they are simply too unwell to attend them. Large numbers report receiving little or no ongoing support from either specialist services or primary care, while many face serious challenges in meeting basic needs, including nutrition. This matters not only because of the immediate impact on the patient's quality of life but because early intervention and appropriate support can prevent longer-term deterioration.

If people have access to advice, treatment, system management and practical support at an earlier stage, there is a greater chance of helping them maintain their independence and remain connected to education or employment where appropriate. Delays in accessing support can leave people becoming progressively more unwell, making recovery and participation in everyday life considerably harder. That is why timely and effective services are so important, not only for those who are already severely affected but for those at risk of reaching that point.

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Recent prevention of future deaths reports have also highlighted serious concerns regarding the care available to some of the most severely affected patients. The Government have stated that integrated care

boards remain responsible for commissioning appropriate services in the meantime. Can the Minister therefore explain what assessment has been made of the current provision for severe and very severe ME, whether significant variation exists across the country, and what interim support will be available before any decision on a nationally commissioned service is reached in 2027?

We must also not lose sight of the critical importance of research. We welcome the support provided for the DecodeME survey. Its early findings identify potential genetic links involving the immune and nervous systems, representing an encouraging step forward in understanding the biological mechanisms underlying this condition. Yet ME remains significantly under-researched relative to its prevalence and impact. The Government have rightly spoken about the UK's ambition to lead in life sciences and post-infectious disease research. There is a strong case for ensuring that ME forms part of that agenda, including through support for research into diagnostics, biomarkers, treatments and clinical trials.

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The Parliamentary Under-Secretary of State, Department of Health and Social Care (Baroness Merron)

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Noble Lords have spoken very movingly about the reality, and I am grateful for the welcomes across the House for a number of government

actions. I recognise what noble Lords have described, which is—to pick up a few points—a lack of awareness, variability in services, the stigma faced by those with ME/CFS and the need to go further. We recognise all of that.

The fact is that the system has not worked as it should for people. But that is why, early on, the Government prioritised publication of our final delivery plan on ME/CFS, which we published in July last year. I assure noble Lords that we work closely with those most impacted by the effects of this debilitating condition, including those with lived experience. I add my thanks to charities and campaigners for their work, because they have given voice to this subject. We want to ensure that patients are truly heard by a system that can respond to those voices, because historically that has not been the case. So the plan sets out a clear direction for improvement, and it focuses on three key ambitions: boosting research, improving understanding and education, and strengthening the care and support people receive.

The noble Baroness, Lady Scott, and the noble Lord, Lord Evans, raised a number of questions about funding timelines and accountability. I confirm that the department has overall responsibility for progress against the final delivery plan, and officials are actively tracking progress. It is very much worth noticing that three-quarters of the plan's actions have been completed or commenced or are currently ongoing. I say to the noble Lord, Lord Evans, that an update on the delivery of the final delivery plan will be communicated next month.

We know, as has been spoken about, that a lack of research has meant that those with ME/CFS have been left feeling undervalued, frustrated and overlooked. That is why the final delivery plan commits to stimulating research, including through new funding opportunities, better support for researchers and building capacity and research. We have gone beyond the actions in the final delivery plan, as all noble Lords were good enough to reference, by investing 4.75 million pounds in SequenceME, which will create the first high-resolution genetic map for ME/CFS. I believe that this will offer new hope to patients and pave the way for better diagnostics and future treatment, which, after all, is what we need.

All noble Lords asked for further commitments. To the points I have just made, I add that the Government are investing in turbocharging clinical

trials research. Key to this is enabling new treatments to get to patients faster; and the NIHR has funded projects to explore the feasibility of a clinical trial for treatments for ME/CFS and other post-acute infection conditions, as noble Lords have asked for. Of course, funding and support is available for researchers, and the Medical Research Council and the NIHR welcome funding applications for research into ME/CFS and other post-acute infection conditions. Addressing gaps in knowledge and awareness around this condition is also crucial, because people who live with ME/CFS have to be seen and feel seen. They need to be reassured, and they need evidence that they are going to be taken seriously. I am therefore glad to say that NHS England has developed an e-learning programme, which consists of four modules and seeks to improve the understanding of healthcare professionals, and to support them to provide the right care at the right time for those who need it, including those with severe ME/CFS.

Experiences of care vary widely—that should not be inevitable, but we recognise that they do—but I believe that those with ME/CFS deserve a high standard of care, no matter who they are or where they are. We will seek to improve that through the development of a new template service specification for mild and moderate ME/CFS, and that will expand to include the severe nature of the condition. The template will focus minds and demonstrate to integrated care boards the ways in which NICE guidelines can be implemented. Key here too is that it will provide good practice examples for ICBs, so they can model their own services on where it is being successful.

There is, as I said at the beginning, much more to be done. We are working at pace to implement this final delivery plan, and we will work continually with stakeholders to make sure that it meets the mark. The noble Baroness, Lady Scott, and the noble Lord, Lord McCrea, asked about interim support. We are not just committed to considering a specialised service for those with a very serious version of the condition; we are also exploring what preparatory work can be taken forward ahead of April next year. We want to progress the work at pace once the transformation in respect of NHS England has been concluded. In the meantime, we are considering a range of potential interim measures to support those with severe ME/CFS, including further promotion of the e-learning modules that I referred to, making sure they span very severe and severe ME/CFS, alongside the recommendations that have been presented to government directly by patient groups.

The noble Baroness, Lady Scott, asked about setting up an expert advisory panel. We do not currently have plans for such a panel for those with severe ME/CFS, but I assure the noble Baroness that we engage very closely with experts from NHS England, clinicians and experts in the charity sector so that we can develop a much broader approach to supporting patients with ME/CFS.

In response to the question about exploring whether a specialised service should be commissioned for very severe ME/CFS, any decision on whether this committee would be convened remains at the discretion of the Secretary of State. I say to the noble Lord, Lord Evans, that we recognise that ME is more likely to affect women and that early results in the DecodeME study have found that women with ME/CFS tend to have more symptoms and co-occurring conditions than men. That will be taken into account. Again, I am most grateful to the noble Baroness, Lady Scott, for her work and advocacy in this area.

Baroness Walmsley

Before the Minister sits down, I asked what support is being given to those services that are unable to fulfil the NICE guidelines, and about the Government's attitude to including reasonable adjustments in the information on the single patient record.

Baroness Merron

I would be pleased to take those two points away and look at them, particularly the second, which is a very practical suggestion. I am grateful to the noble Baroness, as ever, and I will gladly write to her.

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