Policy paper

**Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS): the final delivery plan**

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**Applies to England**

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**Ministerial foreword**

I am delighted to publish this final cross-government delivery plan on myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), which while led by the Department of Health and Social Care, has been developed in close partnership with the Department for Education, the Department for Work and Pensions and NHS England, as well as, crucially, people with ME/CFS, carers, health and care professionals, researchers and research funders, charities and patient groups, and other interested organisations and individuals.

I would like to thank everyone involved to date for their time and commitment to this vitally important work. I would particularly like to thank the members of the cross-sector Task and Finish Group that met 4 times between January and April 2025. As with any government plan or strategy, we have not been able to include every ask of that group in the final delivery plan, which must of course reflect what is practically feasible and financially viable and affordable, especially within the challenging current fiscal climate. However, the views of Task and Finish Group members have been very much considered alongside those received in response to the earlier consultation on the interim delivery plan.

I recognise that care for people with ME/CFS has varied widely and, in the worst cases, has left some people feeling that their illness is not recognised by the health and care system. I know that those with severe or very severe ME/CFS, and their families and carers, have often felt particularly let down by those systems and I am painfully aware of patient safety concerns, and even tragically avoidable deaths of people with ME/CFS, in England. These must become never events. There are also inequalities in service provision that need to be addressed. We know that more research, better services and a better understanding of the condition all have the potential to make a huge difference to the quality of life of people with ME/CFS, whether that be those with symptoms on the milder end of the spectrum or those with very severe ME/CFS, and everyone in between. This final delivery plan marks an important milestone on the continuing journey to achieving those 3 high-level ambitions.

I know that the condition continues to blight the lives of so many children and adults across the country. In fact, the latest research findings recently concluded that the prevalence of people with ME/CFS in the UK may be as high as around 390,000[[footnote 1]](https://draft-origin.publishing.service.gov.uk/government/publications/myalgic-encephalomyelitischronic-fatigue-syndrome-mecfs-the-final-delivery-plan/myalgic-encephalomyelitischronic-fatigue-syndrome-mecfs-the-final-delivery-plan#fn:1) (or 0.6% of the population). The actions set out in this final delivery plan are intended not only to support the government’s health mission but also our growth mission, and these figures make a stark case for change on both fronts.

The interim delivery plan set out the problems to be addressed and draft actions to drive an expansion of research, better education of professionals, improvements in attitudes towards the condition and improvements to service provision. I was pleased to see that the public consultation on that interim plan attracted over 3,000 responses, which have helped us to firm up and expand on the number and/or ambition of the proposed actions I expect the final delivery plan to deliver in the months and years ahead. In some areas, for example on the development of e-learning modules on ME/CFS for healthcare providers and the general public, and the DecodeME study providing a genetic resource to better understand ME/CFS and stimulate future research, which had its funding extended to enable the research aims to be completed, significant progress has already been possible between publication of the interim and final delivery plans, and I thank those involved.

I know that people with ME/CFS, their families and carers have waited a long time for a new national delivery plan - some would say too long - and I was very keen that we published it now, on the back of the recently published 10 Year Health Plan, which sets out our vision for the NHS of the future, so that we and partners can start to turn much needed actions into practice. I acknowledge that some of the actions we set out in this final delivery plan will require further exploration, scoping and discussion post-publication, but I and the department, as well as other parts of government and the NHS, are happy to be held to account by the ME/CFS community, including those with lived experience, to ensure that we make progress against every action. Publication of this plan in no way marks the end of our journey. In fact, my view is that the real work, which we look forward to doing collaboratively with stakeholders, starts post-publication.

This final delivery plan covers the population of England. However, I know that the Scottish Government, the Welsh Government and the Northern Ireland Executive have all carefully considered the consultation responses on the interim delivery plan from their residents and what they have heard at the Task and Finish Group meetings, and the implications for local policy in the devolved nations.

I recognise that there are some overlaps - for example, in symptoms and/or interventions - between ME/CFS and some other long-term conditions like long COVID, postural orthostatic tachycardia syndrome and Ehlers-Danlos syndrome. It should be noted that, while we are very happy to explore overlaps and synergies with related conditions as the plan is implemented, we have maintained our commitment to focusing this plan only on ME/CFS.

I commend this final delivery plan to you and look forward to continued collaboration as we strive to bring about real and positive change for people with ME/CFS.

Ashley Dalton MP, Parliamentary Under-Secretary of State for Public Health and Prevention.

**Summary**

As was the case with the [interim delivery plan (IDP) on ME/CFS](https://www.gov.uk/government/consultations/improving-the-experiences-of-people-with-mecfs-interim-delivery-plan), this final delivery plan (FDP) was developed in consultation with a wide range of key stakeholders responsible for its delivery, as well as external stakeholders, through the engagement of the ME/CFS Task and Finish Group. The content of the FDP was, however, primarily informed by the [responses to the public consultation on the IDP](https://www.gov.uk/government/consultations/improving-the-experiences-of-people-with-mecfs-interim-delivery-plan), which were carefully considered and assessed for financial viability and feasibility.

The FDP continues to focus on 3 key themes in which we are seeking to drive change to improve care and support for people with ME/CFS:

* research
* attitudes and education
* living with ME/CFS

’Living with ME/CFS’ covers a range of different aspects of ME/CFS, including:

* quality of life
* support for children and young people (CYP)
* provision of health services
* provision of adult social care
* welfare
* employment support

While the FDP includes separate sections on all these themes, there is significant interplay of actions across the themes. Progress across the agreed actions, as well as further development post-publication, is required to deliver the much needed and meaningful change for people with ME/CFS that we are seeking to achieve.

Acknowledging the consultation respondents’ feedback on the need to develop specific, measurable, achievable, relevant, and time-bound (SMART) actions, the FDP includes tables summarising actions and action owners, progress updates (where relevant), measures of success or indicators of progress, and proposed delivery timelines across the 3 themes of the FDP.

**Research**

The research section reflects on the achievements of the 2-year Research Working Group and the results of the consultation, and sets out the vision for a co-ordinated, well-funded and inclusive research environment that reflects the complexity and severity of ME/CFS.

The consultation results showed support for the initial actions outlined in the IDP but with further action requested in relation to:

* funding
* a strategic approach to ME/CFS research
* further support for research capacity building
* retaining lived experience involvement throughout research
* the need to rebuild trust with people with ME/CFS

To address the breadth of the ME/CFS research challenge, the National Institute for Health and Care Research (NIHR) and the Medical Research Council (MRC), part of UK Research and Innovation (UKRI), play complementary roles by funding research across the entire pipeline. MRC funds foundational science and NIHR funds applied clinical and translational research. The actions presented in the research section have been developed in consultation with researchers and people with lived experience, and were selected as strategic interventions to support key aspects of the research pathway.

There is an opportunity for scientific links to advance treatment for post-acute infection syndromes and associated conditions such as ME/CFS and long COVID. We therefore encourage researchers to take insights from other post-acute infection conditions and apply these to ME/CFS where relevant to help develop effective treatments and interventions for people with ME/CFS. As part of this, we recognise there is a need to help build capacity and capability in the field and all relevant funding schemes are open to such proposals.

New investments announced in the FDP include £845,000 for Building Infrastructure for Patients, Researchers and Industry for Myalgic Encephalomyelitis (PRIME), an MRC-funded partnership award to build enabling infrastructure for ME/CFS biomedical research, building on previous investment in the DecodeME study, and the HERITAGE study (Health Effects fRom Infection sequelae: Tailoring services and Advancing GuidancE), a new £1.4 million NIHR research programme, which will explore the cost effectiveness of existing healthcare models for both ME/CFS and long COVID with the aim of improving quality of care. We are also launching a new funding opportunity for an NIHR Application Development Award focused on evaluating repurposed pharmaceutical interventions for post-acute infection syndromes and associated conditions, including ME/CFS.

Recognising that research is inherently a gradual and iterative endeavour, we are committed to a long-term vision that supports sustained progress. This includes a commitment to ongoing transparency, monitoring and evaluation, and working in partnership with researchers, charities and those with lived experience.

**Attitudes and education**

This section of the FDP reflects on the content and actions set out in the IDP, and key suggestions from the consultation respondents on how we could improve further. Most respondents supported this section in the IDP but felt it needed more depth, clarity and stronger actions. They stressed the need for:

* mandatory training
* updated resources
* more compassionate, informed care from professionals
* greater public awareness
* involvement of patients in developing training materials to address stigma and improve understanding of ME/CFS

The actions taken in the FDP will look to increase knowledge of ME/CFS for public sector professionals, as well as the wider public, through:

* guiding users to NHS England’s e-learning modules on ME/CFS
* a public awareness initiative led by the Department of Health and Social Care (DHSC)
* ensuring resources are updated and shared across workstreams and relevant stakeholders, including the Department for Work and Pensions (DWP), the Department for Education (DfE), royal colleges and wider

**Living with ME/CFS**

This section of the FDP summarises the aims of the IDP, consultation respondents’ feedback across the 6 sub-sections, and a set of improved actions. Although the vast majority of respondents agreed with the actions and content across all themes of the IDP, we heard we needed to go further on:

* improving quality and accessibility of health services and adult social care
* ensuring appropriate and timely support for CYP in education
* addressing issues regarding:
	+ the benefits assessment process
	+ finding and maintaining employment

In response, there are new or strengthened actions across these issues, some of which are specific to ME/CFS, and some which relate to wider initiatives to support people with long-term conditions, including ME/CFS. On health services, this includes:

* the development of a template service specification for mild and moderate ME/CFS
* exploration of a specialised service for very severe ME/CFS
* publication of a Clinical Knowledge Summary on ME/CFS
* actions relevant to wider health service improvement for people with long-term conditions, such as the 10 Year Health Plan and neighbourhood health plans

For CYP, DfE will embed ME/CFS-specific considerations into its broader approach to education and explore opportunities to raise awareness and promote understanding of ME/CFS across the education sector. There is a set of actions to support unpaid carers and their working relationships with professionals and to ensure they are included both in policy making and in decisions relating to care and treatment of those they care for. While no condition-specific actions were added on welfare and employment support, this section sets out further detail on DWP’s reform to the system of health and disability benefits, and DWP’s plans to improve employment support available for disabled people and people with health conditions.

**After publication of the FDP**

Following on from publication of this FDP, we will monitor the actions included in it. The DHSC secretariat will continue to engage with the Task and Finish Group in an appropriate form as required, to assess progress towards existing actions and to agree further actions where required. A new health services sub-group will be convened to focus on improving care for those with ME/CFS.

Across government, work will continue on the included actions and, where appropriate, beyond the scope of the actions outlined in this plan. We remain committed to ongoing development and improvement in areas where issues and challenges may not be fully addressed by the actions in this plan. We recognise the needs of those with ME/CFS and we remain dedicated to developing our approach as new research emerges and as we seek further engagement.

**Research**

The IDP set out 4 key problems related to research into ME/CFS:

1. There is low capacity and capability among the research community to respond to research needs in this area.
2. Historically, there has been low awareness of the need and scope for research into ME/CFS across the health and care research landscape.
3. There has been a relatively low amount of biomedical research funded on ME/CFS, compared with disease burden.
4. There is a lack of trust between different stakeholders, including a perception of bias, expressed by patient and carer groups, about prioritisation and the peer-review process when applied to ME/CFS research.

This section sets out our plan to deliver improvements in ME/CFS research. This includes:

* exploring links with other post-acute infection conditions
* our ambitions to stimulate further research in this area
* building a vibrant ME/CFS research community
* ensuring those with lived experience are at the heart of research
* announcing new research investments

**Progress since publication of the IDP**

The IDP increased awareness of the need for more ME/CFS research and encouraged research collaboration and multidisciplinary teams to address the research and evidence needs for ME/CFS.

Through the commitment and dedication of the members of the UK Clinical Research Collaboration (UKCRC) Research Working Group for ME/CFS, we have delivered on many of the actions for research set out in the IDP. This includes delivering workshops with research funders and the community to develop research questions to respond to the [James Lind Alliance (JLA) Priority Setting Partnership (PSP) Top 10 Priorities](https://www.jla.nihr.ac.uk/priority-setting-partnerships/ME-CFS). The NIHR has also completed and published an evidence review of national and international work underway in ME/CFS mapped against PSP research priorities to enable researchers to target proposals where there are research gaps. Further information about this work includes an [evidence map of ME/CFS research studies](https://fundingawards.nihr.ac.uk/award/NIHR159926) and [infographic of ME/CFS evidence](https://www.journalslibrary.nihr.ac.uk/sites/journalslibrary/files/journal_data/BTBD8846/NIHR136262_supp7.html) and shows how these address key themes in the JLA PSP research priorities.

Working with partners including UKRI research councils and other research funders, academic researchers and people with lived experience, a new [ME/CFS Researcher Toolkit](https://psp-me.co.uk/researcher-toolkit/) has been developed to support researchers in developing high-quality research proposals. Specifically, the NIHR offer includes:

* support on writing grants
* research design and methods
* guidance on involving patients and the public

**Exploring links with other post-acute infection conditions**

Research to better understand ME/CFS and inform the development of effective treatments and services has the potential to make a huge difference to the quality of life of people living with ME/CFS. NIHR and MRC are committed to funding this research.

We share the views of the research community, people with lived experience and charity representatives that the links between ME/CFS and long COVID should be explored, and that this offers an exciting new avenue for scientific discovery. We recognise that, while not all cases are directly linked to a specific infection, for a significant number of people the onset of ME/CFS is preceded by a viral illness or other infection. We want to explore these common causes and resulting symptom clusters. We therefore encourage researchers to take insights from other post-acute infection conditions and apply these to ME/CFS where relevant to help develop effective treatments and interventions for people with ME/CFS.

**Investment in research into ME/CFS and other post-acute infection conditions**

DHSC invests significantly in research through NIHR, the department’s research arm. NIHR infrastructure provides:

* world-class research expertise
* specialist facilities
* a research delivery workforce
* support services

These all help to support and deliver research across the NHS, and public health and social care systems. NIHR complements wider investments in health and care research by focusing its funding in early translational, clinical and applied health and social care research.

The Department for Science and Technology (DSIT) invests significantly in research through UKRI. MRC, a research council within UKRI, aims to improve human health and drive economic growth through:

* an understanding of the underlying mechanisms of biology and disease
* enabling earlier diagnosis
* advanced therapies
* precision prevention

DHSC and NIHR work closely with MRC to ensure that these basic science discoveries are translated into treatments and interventions which are tested in real world populations and health and care settings.

Between April 2019 and March 2024, the UK government, through NIHR and MRC, invested around £6.5 million in research into ME/CFS. This includes:

* £3.2 million towards the DecodeME study into the genetic underpinning of ME/CFS
* a study investigating how autoantibodies might modify blood flow in ME/CFS
* research on the development and assessment of interventions for younger children with ME/CFS
* the development of an activity pacing framework for the management of chronic pain and/or fatigue in adults

In particular, the DecodeME study will help increase our understanding of the condition and therefore contribute to the future development of diagnostic tests and targeted treatments for ME/CFS. We anticipate that DecodeME will empower future research by revealing genetic risk factors and facilitating future studies through access to samples and data.

Between April 2019 and March 2024, the UK government, through NIHR and MRC, invested over £57 million into long COVID research, with almost £40 million of this through 2 targeted research calls on long COVID. The funded projects aim to improve our understanding of the:

* diagnosis and underlying mechanisms of disease
* effectiveness of pharmacological and non-pharmacological interventions
* effectiveness of clinical care

We are encouraged by emerging findings of potential mechanisms underpinning both ME/CFS (through the DecodeME study) and long COVID, offering potential future pathways to therapeutic options for these patients.

**Stimulating further research into ME/CFS**

We are committed to working with the ME/CFS community to identify and address barriers to research, with the ambition of supporting and funding more research and capacity-building programmes. Despite our efforts to stimulate high-quality research in this area, we continue to receive a low number of applications. We also recognise that the number of ME/CFS researchers in the UK is currently very small so support is required for capacity and capability-building.

Later in 2025, DHSC, jointly with the NIHR and MRC, will be hosting a research showcase event for post-acute infection conditions research, including ME/CFS and long COVID. This event will:

* discuss recent evidence in the field, particularly new findings from the DecodeME study, and from long COVID studies which may open new avenues for investigation
* recognise the importance of research into ME/CFS and long COVID
* highlight important outstanding research questions
* spotlight the bespoke support available from NIHR and MRC for researchers in preparing applications

We hope the event will encourage researchers to join the ME/CFS and long COVID field and enable new collaborations across specialties and disciplines to stimulate further vital research.

We have gratefully received feedback and proposals from the community on different approaches to stimulate further research into ME/CFS. Since the publication of the IDP, we have met with researchers and people with lived experience on several occasions, which has been invaluable in building a shared understanding of some of the challenges preventing scientific progress. We have used this engagement to develop further interventions to increase research into ME/CFS.

Following stakeholder feedback, we have considered reserving funding specifically for ME/CFS research and discussed this with the community during the development of the IDP for ME/CFS as well as at subsequent meetings and roundtables on ME/CFS and long COVID. This is not usual practice for research funders as applications in all areas should compete for the funding available to uphold transparency and accountability. Welcoming applications on post-acute infection conditions to all funding programmes enables maximum flexibility both in terms of the amount of research funding a particular area can be awarded, and the type of research which can be funded.

DHSC, through NIHR, therefore actively encourages funding applications for translational research into any aspect of ME/CFS. Multiple sources of research funding are available. For example:

* the NIHR Research for Patient Benefit programme funds studies that aim to increase the effectiveness of services, provide value for money and benefit patients and the public. Applications that aim to increase the effectiveness of ME/CFS services and benefit patients would be welcome
* the NIHR Health and Social Care Delivery Research programme funds evaluative research to improve the quality, accessibility and organisation of health and social care services. We have heard that the experience of health and care services for people with ME/CFS is variable and sometimes of low quality, so research to improve health services for people with ME/CFS is particularly welcome
* the joint NIHR and MRC Efficacy and Mechanism Evaluation (EME) programme supports clinical trials, which evaluate the efficacy of new clinical interventions and, where appropriate, explore the underlying mechanisms to understand how they work
* the NIHR Health Technology Assessment (HTA) programme funds research into the clinical and cost effectiveness of treatments and tests. Both HTA and EME programmes welcome applications for clinical trials for:
	+ diagnostics
	+ decision-making tools
	+ new or repurposed therapeutics
	+ medical devices for ME/CFS
* the NIHR Programme Grants for Applied Research funds large collaborative, multidisciplinary programmes of applied research to solve health and social care challenges. A wide range of applications relating to ME/CFS would be welcome, including how to optimise ME/CFS services or provide enhanced support for those with severe ME/CFS
* the NIHR Academy provides training and support to health and care professionals at all stages of their research career from PhD to research professor

We recognise that ME/CFS research applications may require additional support to compete in open funding competitions. We therefore strongly encourage researchers to contact the NIHR Research Support Service (RSS) prior to submitting applications to the NIHR. RSS provides free, confidential, tailored support for researchers to develop an application to NIHR and can signpost researchers to methodological expertise where relevant, and support researchers to apply to the right NIHR research programme. We are working with RSS to enhance our support offer to those submitting applications on ME/CFS. In the event of an unsuccessful ME/CFS application, researchers will receive feedback specifically from the NIHR programme they applied to and/or RSS to support a reapplication.

Similarly, high-quality applications addressing ME/CFS are invited to any MRC research grant or fellowship schemes, as appropriate, based on the scientific or clinical area. An immediate route to building capacity and capability in the field is through MRC’s partnership grant opportunity, which provides funding to establish new, high-value collaborative activities or capabilities to stimulate future research. MRC staff welcome the opportunity to engage with prospective applicants to support preparation of competitive proposals. Enquiries relevant to ME/CFS can be made by email on mecfs@mrc.ukri.org, or by direct contacts for the relevant scheme. Once submitted, applications are judged in open competition and the primary considerations in funding decisions are scientific quality, future impact and importance to human health. Reflecting the major need in this space, research investigating ME/CFS has been a priority area for a number of years, through maintenance of a [research priority notice](https://www.ukri.org/opportunity/researching-me-cfs-priority-area/) to support high-quality and collaborative research into ME/CFS.

In the longer term, we hope to build up a solid foundation of research which might form the basis for applications to the MRC Centre of Research Excellence programme. This could support major challenge-led investments focusing on distinct, disruptive, or multidisciplinary and interdisciplinary activity that have the potential to prove transformative to the field within 14 years, with up to £42 million available to successful applicants over that period.

**Maximising value for ME/CFS research from research infrastructure**

In addition to funding research projects through programme awards and capacity building, MRC and NIHR also fund research infrastructure. NIHR infrastructure supports research funded by government and underpins the research funded by others, including medical research charities and the life sciences industry.

Specifically, we would like to highlight opportunities for the ME/CFS community to use the wide range of existing research infrastructure supported by NIHR, which is available to researchers even without direct NIHR funding. For example, researchers can connect with NIHR Biomedical Research Centres (BRCs) to explore opportunities for collaboration and support for early stage and experimental research. Although these centres do not have dedicated ME/CFS themes, several have areas of focus that strongly align with ME/CFS research priorities identified by the JLA PSP, including neurology, genomics, immunology, and precision medicine. Dedicated support for the development of ‘healthtech’ such as diagnostics, wearable devices or digital technology is also available through NIHR HealthTech Research Centres, centres of excellence which accelerate the development of healthcare technologies to improve the effectiveness and quality of health and care services.

Additionally, the NIHR Research Delivery Network (RDN) can assist researchers in setting up and delivering clinical trials across England both in the NHS and in the community. Researchers can contact their regional RDN office to explore how the network’s trial delivery expertise, patient recruitment services, and workforce can facilitate their study. The network is working with system partners in advancing workstreams that may be of particular interest to ME/CFS researchers, including:

* innovative trial methodologies to support participation for individuals living with a high burden of disease such as those with more severe ME/CFS
* expanding research delivery beyond hospital settings, bringing studies closer to home in community and primary care environments, or even at home

Similarly, the new UK-wide Commercial Research Delivery Centres support industry to bring and deliver trials to the UK. They do not focus on any specific disease but stand ready to support trials designed for people living with ME/CFS. Many also deliver trials in the community, including in primary care.

In parallel, UKRI-funded infrastructure includes major investments, such as:

* UK Biobank, which has already supported some ME/CFS relevant research
* the UK National Facility for Ultra-High Field Human Magnetic Resonance in Nottingham, due to open in 2026, which will offer important capabilities for UK researchers to underpin and enable novel health research, which might benefit novel programmes addressing ME/CFS

**Patient involvement**

Patient and public involvement in research improves research:

* relevance
* quality
* impact

Government research funders are committed to working with patients, service users, carers and communities to shape our work and research. For example, at NIHR people contribute at every stage of the research pathway, shaping:

* priorities and research questions
* the design of studies
* the evaluation of research proposals
* the conduct of research and the dissemination of results

They also play a vital role by volunteering to participate in studies and trials. We remain committed to ensuring that those living with ME/CFS, including children with ME/CFS, can be involved with, and benefit from, research.

Evidence indicates that:

* women are more likely to have ME/CFS
* women with ME/CFS tend to have more symptoms than men

Studying and understanding sex and gender differences and similarities is essential for improving the health of all people in the UK, including through areas such as evaluating the safety and effectiveness of diagnostics, medicines and care pathways, disaggregated by sex. For all NIHR-funded research, we are committed to exploring an approach which enables and encourages our research community to integrate sex and gender into research design, including in the disaggregation of research findings.

We are keen to involve people with lived experience. Where there are opportunities to be part of individual research projects, including input into the design of the research, these will be advertised on the [NIHR People In Research website](https://www.peopleinresearch.org/view-opportunities). We would strongly encourage people with ME/CFS to sign up to [NIHR’s Be Part of Research](https://bepartofresearch.nihr.ac.uk/), which is a free service that makes it easy to find and take part in vital health and care research across the UK.

**New investments**

In addition to increasing support for ME/CFS researchers to submit successful applications to MRC and NIHR, we are pleased to announce 2 new research investments and a new funding call relevant for ME/CFS research:

1. Research to improve health and care services. The NIHR HSDR Programme has funded a new, £1.4 million HERITAGE study, which will look at the overlap between ME/CFS and long COVID and explore the costs and effectiveness of different existing healthcare models for both conditions. This study aims to help improve the quality of care for both conditions by developing a national service framework (NSF) for long COVID and ME/CFS, which includes training and resources for specialist services and primary care across the UK.
2. Building a vibrant ME/CFS research community. MRC has awarded £845,000 to PRIME, a new partnership award that aims to build a solid foundation for a permanent, enabling infrastructure for ME/CFS biomedical research by building on previous investment in the DecodeME study.

**New funding opportunity: evaluating medicines and other interventions for post-acute infection conditions**

We are also delighted to announce a new funding opportunity for ME/CFS research: an NIHR Application Development Award competition. DHSC, through NIHR, is launching a new funding opportunity for a [development award focused on evaluating repurposed pharmaceutical interventions for post-acute infection syndromes and associated conditions](https://www.nihr.ac.uk/funding/post-acute-infection-syndromes-including-long-covid-and-myalgic-encephalomyelitischronic-fatigue-syndrome/2025354), including ME/CFS. This funding opportunity is a key component of our response to the need for further research-based evidence related to the diagnosis, management and treatment of post-acute infection conditions, including ME/CFS. We would like to thank the community for providing insights on potential therapeutics that may be repurposed in clinical trials for ME/CFS.

In support of this work, the [NIHR Innovation Observatory has completed a review](https://io.nihr.ac.uk/resources/reports/myalgic-encephalomyelitis-chronic-fatigue-syndrome-long-covid-and-fibromyalgia-an-overview-of-the-medicine-pipeline/) of relevant new and repurposed medicines in clinical development for the treatment of ME/CFS, as well as related conditions such as long COVID. The review focused on medicines with a UK licence which might be ready for later phase trials (phase 2 or phase 3 clinical trials). The scan identified 42 clinical trials investigating the effectiveness of repurposed medicines for ME/CFS, long COVID or fibromyalgia, with the majority focused on monotherapy treatments.

This funding will help researchers prepare for a larger, more advanced study (a phase 2 platform trial). It will also help them determine the optimal design for that study so that several existing drugs, non-drug treatments, or medical devices can be tested at the same time. Further information about this development award is published on NIHR’s website and includes how to apply for funding.

**Monitoring progress and delivering impact**

Recognising that research is inherently a gradual and iterative endeavour, we are committed to a long-term vision that supports sustained progress. This includes:

* a commitment to ongoing transparency, monitoring and evaluation
* working in partnership with the community to advance research in this critical area

As part of ongoing monitoring of the FDP, we will monitor ME/CFS funding and support closely and provide information to the Task and Finish Group on an annual basis. All NIHR funding is transparent, with research award details published online on NIHR’s funding and awards website and through [NIHR Open Data](https://nihr.opendatasoft.com/pages/homepage/?flg=en-gb), while all MRC grant awards are published through [Gateway to Research](https://gtr.ukri.org/).

We know that more research leading to a better understanding of the condition has the potential to make a huge difference to the quality of life of people with ME/CFS. To maximise the impact of the research we fund, we will work closely with policymakers and the health service to ensure that learnings from research are translated into policy and practice.

As set out in the IDP, our aim is to support the development of a sustainable pipeline of research, the findings of which feed into policy and practice to change the lives of people with ME/CFS. To achieve this, we will:

* promote the need for research, and encourage and support researchers from a wide range of relevant disciplines to apply for new and existing funding opportunities
* champion the co-production of research with people with personal experience

**Attitudes and education**

This section of the IDP sets out 6 priority problem statements:

1. Many children and adults with ME/CFS feel that they have not been believed, supported or treated equally across all settings and professional groups.
2. There is limited objective evidence for what current attitudes are towards ME/CFS among most health, social care and other professionals.
3. Many people with personal experience do not feel that professionals always fully acknowledge or understand the impact of ME/CFS on their daily life.
4. There remain concerns about how best to manage and approach ME/CFS in some services, despite the updated 2021 [National Institute for Health and Care Excellence (NICE) Guideline on ME/CFS (NG206)](https://www.nice.org.uk/guidance/ng206/resources).
5. There is limited appropriate undergraduate and postgraduate healthcare professional training on ME/CFS.
6. There are limited appropriate educational opportunities on ME/CFS for other professional groups (for example, social care, education, welfare and employers).

The section sets out the impact the IDP aims to achieve, including:

* people with ME/CFS feeling they are believed understood and treated with respect, feeling safe and supported by services and professionals in line with other long-term health conditions
* ensuring family, other unpaid carers and supporters of people with ME/CFS are listened to and involved in decisions

Examples of best practice in relation to attitudes and education of professionals set out in the IDP include ensuring that:

* professionals communicate clearly, follow NICE guideline NH206, and recognise the serious impact of ME/CFS on people’s lives
* training includes real-life experiences, highlights fluctuating symptoms and cognitive issues, and promotes inclusive employment
* education is accessible, practical and informed by people with ME/CFS

The actions in the IDP include the requirement that:

* DHSC will consider how to increase our knowledge of public sector professionals’ current attitude towards ME/CFS
* NHS England will develop an e-learning module on ME/CFS, which will be aimed at health and social care professionals and available to members of the public
* NHS England and NHS Health at Work Network will update their webpages in line with NICE guidance
* DHSC to consider developing a shared learning resource on ME/CFS, which could be held in an education hub
* the Medical Schools Council (MSC) encourages shared learning and NHS England’s e-learning package on ME/CFS to all UK medical schools and encourages medical schools to provide undergraduates with direct patient experience
* DHSC will use networks to raise awareness of NHS England’s e-learning modules more widely
* DfE will encourage special educational needs and disability (SEND) and medical condition organisations to:
	+ signpost the NHS England e-learning on ME/CFS on their websites
	+ update guidance on education for children unable to attend school due to health needs
	+ share social care guidance developed by Action for ME
	+ signpost NHS England’s e-learning on ME/CFS to providers
* the British Association of Social Workers (BASW) will support and promote the work of stakeholders to raise awareness and knowledge within the social work profession about the needs of people with severe and very severe symptoms of ME/CFS, including unpaid carers
* the General Medical Council (GMC) will include ME/CFS in the scope of its Medical Licensing Assessment (MLA)
* GMC will consider whether appropriate teaching on ME/CFS can be better incorporated into undergraduate and postgraduate medical training and education as part of its Future of Education and Career Development programme
* the Royal College of Physicians (RCP) will ensure that its training on ME/CFS keeps pace with research and guidance in the core postgraduate training for primary and secondary care physicians
* healthcare practitioners from across disciplines and people with personal experience, including carers, will come together to produce a ‘Language Matters in ME/CFS’ guide
* DHSC will increase awareness among people with ME/CFS and their unpaid carers of:
	+ what support is available from adult social care and how to access it
	+ how to feed back on or make a complaint about care
	+ how best to raise public awareness of ME/CFS
* DHSC and DWP (where appropriate) will work with stakeholders to disseminate information and guidance to increase awareness of support available and how to access it among all disabled people, people with health conditions, employers and relevant organisations

The responses to the IDP consultation proposed further improvement related to:

* training
* language
* health services
* resources
* overlooked physical symptoms
* negative experiences patients have faced
* stronger actions

Respondents suggested that the plan should include:

* defined timelines
* measurable outcomes
* statutory enforcement
* robust monitoring

The respondents suggested comprehensive and mandatory training, developed in collaboration with patient groups, particularly for:

* healthcare professionals
* employers
* DWP staff
* school special educational needs co-ordinators (SENCOs)

Requests from the Task and Finish Group include ensuring learning resources, such as the NHS England e-learning modules, are shared more widely for expert input, available to allied health professionals, and made mandatory for health and social care professionals. Members also suggested that indicators should be developed for measuring the effect of e-learning on changes in practice. Furthermore, members recommended including training on ME/CFS as part of mandatory safeguarding training for CYP and adults, and raised ensuring mental capacity assessments are suitable for those with severe ME/CFS.

Further, some members emphasised the importance of raising awareness among different sectors but also highlighted the need to empower clinicians to treat patients and the treatable traits of ME/CFS such as with postural orthostatic tachycardia syndrome (PoTs).

Members suggested a need to educate beyond healthcare professionals. ME/CFS training needs to reach:

* exam boards as well as teachers
* head teachers
* school nurses
* SENCOs

The training should specifically include the necessary adaptations while acknowledging post-exertional malaise, such as extending timelines at schools.

As such, we have agreed new actions:

* DHSC to develop and run a public awareness initiative on ME/CFS to promote wider awareness and understanding of the condition and the support available to people with ME/CFS and their families. This will be run in collaboration with internal and external stakeholders and is expected to improve the wider awareness and understanding of ME/CFS
* to increase the uptake of NHS England e-learning modules and create greater awareness and visibility of the condition across the sector, DHSC will issue targeted communications regarding ME/CFS e-learning and other relevant resources through wider sector networks, such as:
	+ Health and Wellbeing Boards
	+ adult social care provider networks
	+ representative bodies
	+ charities
* GMC will consider whether appropriate teaching on ME/CFS can be better incorporated into undergraduate and postgraduate medical training and education as part of its Future of Education and Career Development programme
* the British Psychological Society is currently developing a Good Practice guideline for working with patients with ME/CFS based on NICE NG206 (2021) in conjunction with ME/CFS charities and in co-production with patients and psychological professionals with lived experience of ME/CFS. This will include sections in relation to appropriate psychological support in general along with, for example, detailing specific information in relation to working with severe and very severely affected ME/CFS patients and with patients across the life span

The previous IDP action ‘NHS England will develop an e-learning module on ME/CFS, which will be aimed at health and social care professionals and available to members of the public’ has been updated to include an additional 2 modules, covering:

* primary care, which has universal access
* severe ME/CFS (which includes both severe and very severe ME/CFS), access to which will be limited to users with NHS, GOV, and ac.uk email addresses

While not listed as an action in this section, it is important to note that under ‘Support for children and young people with ME/CFS’ in the ‘Living with ME/CFS’ section, the first new action makes reference to DfE exploring opportunities to raise awareness and promote understanding of ME/CFS across the education sector, including:

* engaging with stakeholders
* disseminating best practice
* ensuring that guidance and communications reflect the needs of children with complex medical conditions

**Living with ME/CFS**

In this section, the IDP identified 6 key areas to address, including:

* quality of life
* support for CYP
* provision of health services
* provision of adult social care
* welfare
* employment support

We received consultation responses on all these areas, and worked with relevant departments and organisations to improve and agree further actions.

**Quality of life**

This section of the IDP set out 2 problem statements:

1. Quality of life is often significantly reduced for adults and children with ME/CFS
2. Quality of life is often significantly reduced for family and unpaid carers supporting
someone with ME/CFS

The section sets out the impact on quality of life that the IDP aims to achieve, including ensuring that:

* people with ME/CFS feel they can participate in meaningful activities within their abilities
* greater public awareness leads to people with ME/CFS and their carers feeling supported, believed and less isolated

Examples of best practice in relation to quality of life set out in the IDP include:

* wider society recognising ME/CFS as a disability
* making reasonable adjustments for people living with ME/CFS

Overall, the consultation respondents agreed with the contents in this section, though many felt it lacked detail, omitted key content, or did not fully reflect their experiences. Respondents called for:

* clearer actions
* better recognition of ME/CFS severity levels
* support tailored to the complex and fluctuating nature of the condition

Key areas identified for improvement included:

* addressing misunderstanding and stigma
* the severity of the impact on individuals and carers
* the need for financial and domestic support
* better employment and education guidance
* compulsory training for professionals
* a more realistic and empathetic portrayal of the lived experience of ME/CFS in both language and strategy

While all the comments from the Task and Finish Group were relevant to this section of the FDP, it is also acknowledged that several remarks touched on issues extending beyond the immediate scope of this section. The comments for this section are more relevant in other sections such as attitudes of professionals in order for those living with ME/CFS to feel heard, believed and not stigmatised and accessing appropriate services at the right time, as well as other comments as outlined throughout this document.

It is important to note that all actions, such as those relevant to unpaid carers, services, public awareness and language, will have an impact on quality of life for those living with ME/CFS.

**Support for children and young people with ME/CFS**

The IDP set out 2 problem statements:

1. CYP with ME/CFS struggle to get the right support to help them succeed in education and training.
2. CYP with ME/CFS and their families can face inappropriate safeguarding referrals to children’s social care and investigations.

The IDP recognised that ME/CFS can impact CYP differently, both within their age cohorts and when compared to adults with ME/CFS. The IDP acknowledged how disrupted their education can be and highlighted a legal duty on schools to make arrangements for supporting pupils with medical conditions such as ME/CFS, including additional duties where children or young people’s ME/CFS constitutes a disability, or where CYP have special educational needs.

The IDP aimed to see improved and effective in-setting support for schools and colleges, appropriate education for those who are not able to attend school, support for those in adult training and higher education, and support for families affected by ME/CFS. It also set out best practice behaviours and actions to help to improve the experience of education and social care for children with ME/CFS and their families.

The IDP agreed that:

* the Law Commission will review existing social care legislation relating to disabled children, to improve clarity for families about the support that they are legally entitled to, ensuring that local authorities know what they are expected to provide, and families know how to access support
* DHSC will engage stakeholders to discuss timely diagnosis and support for children who have ME/CFS and their families as well as best practice in relation to safeguarding responsibilities

It should be noted that, as set out under ‘Attitudes and education of professionals’, DfE also committed to encourage SEND and medical condition organisations to:

* signpost the NHS England e-learning on ME/CFS on their websites
* update the guidance on education for children with health needs who cannot attend school
* share guidance developed by Action for ME with wider children’s social care professionals
* signpost NHS England’s e-learning on ME/CFS to providers

In the consultation, 98.5% of respondents selected ‘strongly agree’ or ‘agree’ to the contents outlined in the ‘Support for children and young people with ME/CFS’ section of the IDP. However, respondents made suggestions on where we could improve actions, particularly regarding:

* improving awareness to prevent harm from false accusation of fabricated illness
* adaptations to physical environments and integration of pacing to support education
* the pressure and harm of physical attendance
* the need for education and recognition of ME/CFS as a disability to improve access to support in schools
* the difficulty accessing timely support for children
* financial pressures for families and support for adapting education

As such, in addition to the actions agreed in the IDP, we have agreed that DfE will embed ME/CFS-specific considerations into its broader approach to education, including by sharing relevant training, resources and guidance with alternative provision settings and local authorities. In addition, DfE will explore opportunities to raise awareness and promote understanding of ME/CFS across the education sector. This includes engaging with stakeholders, disseminating best practice, and ensuring that guidance and communications reflect the needs of children with complex medical conditions.

In support of this, the DfE published [Arranging education for children who cannot attend school because of health needs](https://www.gov.uk/government/publications/education-for-children-with-health-needs-who-cannot-attend-school) and, alongside this, published [a guide for local authorities and schools](https://www.gov.uk/government/publications/alternative-provision) on 5 February 2025. This replaces the 2013 statutory guidance on alternative provision and reflects stakeholder calls for improved access to appropriate provision for children with ME/CFS.

While there have been no changes to the legislation or core policy on alternative provision, the updated guidance reflects the current educational landscape and aligns with related policy developments. It reinforces the importance of delivering provision that is appropriate, effective and safe - regardless of who arranges it - and highlights the need for early intervention and personalised support.

Key areas of focus in the guidance include:

* ensuring access to education - emphasises that pupils with ME/CFS should not be left without suitable education and clarifies the shared responsibilities of schools and local authorities
* personalised and flexible education - includes guidance on adapting provision to individual needs, including part-time arrangements and phased returns
* safeguarding and oversight - reinforces the importance of safeguarding, placement oversight and managing cross-border placements
* strategic planning and funding - encourages local authorities to plan for alternative provision capacity, including for medical needs, and to use high needs funding appropriately

All children, regardless of circumstance or setting, should expect to receive the same high standard of education. If a child is too unwell to attend school, local authorities have a duty under section 19 of the Children’s Act 1996 to provide suitable and (normally) full-time education for children of compulsory school age who, because of exclusion, illness or other reasons, would not receive suitable education.

Where full-time education is not possible due to a child’s health needs, local authorities must arrange part-time education on whatever basis they consider to be in the child’s best interests. Any part-time education should be reviewed regularly, with the aim of eventually increasing the number of hours up to full-time as soon as the child’s health allows.

DfE is committed to building an inclusive, whole-school system that supports all CYP to remain and succeed in mainstream education. Central to this is DfE’s ambition to improve opportunities for children with SEND, as well as those who may require alternative provision.

DfE wants to see alternative provision settings play a key role in this inclusive system by working collaboratively with mainstream schools to identify children’s needs early and to help design appropriate interventions and support.

Many of the relevant issues are being addressed through DfE’s ongoing reform programme, including updates to attendance and absence code policy. However, these reforms are still in development and not yet ready for public discussion.

For actions on access to health services for children and young people with ME/CFS, see ‘Provision of health services’ below.

**Provision of health services**

This section of the IDP set out 4 problem statements:

1. Children and adults with ME/CFS often struggle to get adequate investigations and the correct diagnosis in a timely manner from primary or secondary care, as well as obtain ongoing appropriate management support, including advice, supportive treatment and review.
2. Existing ME/CFS services are not standardised in terms of what they offer children and adults with ME/CFS and their data collection methods vary.
3. Children and adults with moderate, severe or very severe ME/CFS often struggle to access healthcare for other health needs.
4. ME/CFS services can find it difficult to recruit and retain appropriately trained staff.

The IDP acknowledged the significant variability of experience and services provided, with particular gaps to be addressed for people with severe or very severe ME/CFS, and illustrated the benefits of access to appropriate health services and support.

NHS England’s recent stocktake of ME/CFS and long COVID services concluded in early 2025. It aimed at providing a nationwide overview of service delivery in commissioning and contracting, and confirmed that the widely recognised challenges were:

* significant variation in care delivery across England
* a lack of comprehensive activity data

In summary, the IDP aimed to:

* improve diagnosis and condition management support for children and adults with ME/CFS, including access to healthcare more widely
* provide a more standardised service offer and better data
* ensure that professional staff have the skills, experience and resources required to appropriately support people with ME/CFS

While some of the above aims have significant links with actions in other sections of the IDP, particularly regarding the education of healthcare professionals, the 2 key actions agreed in the IDP were that:

* DHSC will work with stakeholders to consider how to better support health commissioners and providers to understand:
	+ the needs of people with ME/CFS
	+ what local service provision should be available
	+ how existing national initiatives to improve accessibility of health services can be adapted or best utilised for people with severe or very severe ME/CFS
* DHSC will engage stakeholders to discuss timely diagnosis and support for children who have ME/CFS and their families as well as best practice in relation to safeguarding responsibilities

As set out in the [IDP consultation outcome](https://www.gov.uk/government/consultations/improving-the-experiences-of-people-with-mecfs-interim-delivery-plan), 97.8% of the consultation respondents selected ‘agree’ or ‘strongly agree’ to the contents outlined in the ‘Provision of health services’ section of the IDP. However, many respondents suggested where we needed to go further to address key issues, particularly related to:

* the failure of the health system
* inconsistency and lack of help
* inappropriate health services for people with severe or very severe ME/CFS
* the need for early help and management options
* the need for clinicians who believe their patients and do not ignore physical symptoms
* the importance of compliance with NICE guidelines on ME/CFS

To that end, in addition to the actions from the IDP, we have agreed the following new actions, some of which are specific to ME/CFS, and some of which relate to wider health initiatives that will benefit people with long-term conditions, including those with ME/CFS.

**NHS England will co-design resources for systems to improve services, including the development of the template service specification for mild and moderate ME/CFS**

This work has commenced, and stakeholders will be consulted on the outputs through a new health services sub-group of the ME/CFS Task and Finish Group, as part of which stakeholders will have an opportunity to provide feedback. The template service specification will:

* fully take into account NICE guidelines on ME/CFS
* be disseminated to all integrated care boards (ICBs) to inform their commissioning decisions and support quality of local service provision to match local needs

**DHSC, with NHS England, will explore whether a specialised service should be prescribed by the Secretary of State for Health for very severe ME/CFS**

Initial discussions have taken place and further development is required, including the establishment of a clinical committee to provide expert clinical advice to ministers. NHS England also remains committed to working with a wide range of patients, patient groups and other stakeholders in the development of its commissioning of specialised services. Ultimately, prescribing a specialised service will be a ministerial decision and subject to funding availability.

**NICE has commissioned a Clinical Knowledge Summary topic on ME/CFS**

[The Clinical Knowledge Summary on ME/CFS](https://cks.nice.org.uk/topics/myalgic-encephalomyelitis-chronic-fatigue-syndrome-me/cfs/) has been developed and was published in July 2025. While Clinical Knowledge Summaries are not equivalent to NICE guidance, we understand that they are well used, particularly in primary care.

More widely, NICE is responsible for keeping its published guidelines, including the ME/CFS guideline, under surveillance to ensure that they reflect developments in the evidence base. For instance, in January 2025, NICE undertook a surveillance review on dietary management and strategies in ME/CFS but found no new evidence of sufficient quality that affected the current guideline recommendations. NICE is changing the way that it develops guidelines to ensure that they respond more rapidly to the latest evidence and newly recommended technologies to help speed up access for patients.

**The 10 Year Health Plan set out how we will deliver an NHS fit for the future, creating a truly modern health service designed to meet the changing needs of our changing population**

The plan is centred around delivering the 3 shifts:

* hospital to community
* analogue to digital
* sickness to prevention

Services will be moved closer to, and into, people’s homes, providing faster diagnosis and faster access to treatment for patients with long-term conditions. The plan has been developed following extensive stakeholder engagement with over 270,000 contributions. Further detail is set out in the recently published plan.

**A National Neighbourhood Health Implementation Programme (NNHIP) has been launched**

Many places are already making progress on neighbourhood health and this programme seeks to build on success to date, taking a ‘test, learn and grow’ approach. The initial focus for the first places involved in the programme, will be creating neighbourhood health systems and processes for adults with multiple long-term conditions and rising risk. In addition, we will work with places on the enablers and other aspects of neighbourhood health as described in the 10 Year Health Plan. It will also be working at scale to share, spread and accelerate learning across the country.

Invitations to get involved in the NNHIP were recently sent out to systems. The deadline for applications is 8 August 2025.

A set of targeted outcomes will be rigorously monitored, with ongoing insights rapidly captured and evaluated to test, learn and refine.

**Led by NHS England, neighbourhood multidisciplinary teams for CYP could help with earlier identification and referral into relevant ME/CFS services and link in with local support services where available**

NHS England has published [Guidance on neighbourhood multidisciplinary teams for children and young people](https://www.england.nhs.uk/long-read/guidance-on-neighbourhood-multidisciplinary-teams-for-children-and-young-people/). This guidance sets out examples and principles of integrating care for CYP by providing timely access to specialist advice, including paediatric and mental health expertise, through primary care led team working. This will deliver care closer to home and improve the outcomes and experience for CYP, as well as their families and carers.

Multidisciplinary teams for CYP can help streamline appropriate referrals and access, and provide support to CYP as well as their families and carers, while waiting for diagnostic assessments and treatment.

**Provision of adult social care**

This section of the IDP set out the following problem statement: adults with ME/CFS and unpaid carers can struggle to access informed and appropriate social care support.

The section sets out the impact the IDP aims to achieve, including:

* people with ME/CFS and their unpaid carers understanding the support available including how to access it, with advocacy and personalised planning as needed
* care being person-centred to meet individual needs and preferences and delivered by adult social care staff that have knowledge about ME/CFS and its specific requirements

Examples of best practice, as advised by the Living with ME/CFS Working Group, in relation to provision of adult social care, as set out in the IDP, include the requirements that:

* social care staff should offer advocacy and reasonable adjustments during assessments, tailor support to individual needs and avoid reablement unless advised by a specialist
* home care should consider sensory needs
* unpaid carers must be offered assessments
* personalised, informed care is essential
* more research is needed to improve support for those with severe and very severe ME/CFS

The actions in the IDP included that DHSC will:

* increase awareness of support available from adult social care and how to access it among people with ME/CFS and their unpaid carers by collaborating with stakeholders to disseminate information and guidance (adult social care services), by September 2024
* increase awareness among people with ME/CFS and their unpaid carers about how to feed back or make a complaint about care, treatment or service they have received by sharing information about their rights under the NHS Constitution and how to navigate the NHS complaints process (health services), by the end March 2024
* identify how best to raise public awareness of ME/CFS, by the end of March 2025
* with DWP where appropriate, work with stakeholders to disseminate information and guidance to increase awareness among all disabled people, people with health conditions, employers and relevant organisations of support available and how to access it, by September 2024

Overall, respondents agreed with the contents in this section of the IDP, though many felt it lacked detail, missed key content or didn’t reflect their experiences. Key concerns included:

* poor awareness and signposting of support
* inadequate training for care providers
* a lack of joined up services across health, social care and financial support

Many rely on family due to insufficient government support, and the system often fails to accommodate the fluctuating nature of ME/CFS. Respondents called for:

* more flexible, long-term care
* advocacy support
* simplified assessments
* increased funding to improve access and quality of care, especially during key transitions such as moving into adulthood

Underlying all these issues was a call for more funding to improve the quality and accessibility of care. Respondents also stressed the importance of changing the narrative around ME/CFS care to one that includes hope and the potential for improvement, while still being realistic about the ongoing needs of those affected.

Requests from the Task and Finish Group include:

* e-learning modules should be made mandatory for health and social care professionals
* the inclusion of training on ME/CFS as part of mandatory safeguarding training for CYP and adults, including adaptations to prevent healthcare providers from assuming ‘self neglect’, coercive control and/or psychological abuse from family members
* relevance for mental capacity assessments in severe ME/CFS too, as people have been made unwell due to force-feeding

As such, we have agreed that DHSC will:

* ensure that carers’ voices are included in all policymaking about ME/CFS, recognising carers as experts by experience and vital advocates
* ensure health and social care professionals are equipped with the skills and resources to engage in positive working relationships with carers
* ensure that unpaid carers are involved in decisions relating to the care and treatment of the person they care for, including discharge planning
* as part of the 10 Year Health Plan, take steps to improve identification of carers, including those caring for people with ME/CFS, as well as to explore ways to improve support for carers so that it is easier for them to provide care. The 10 Year Health Plan details support mechanisms for carers, such as streamlining care responsibilities and recognising the responsibilities of unpaid carers. The 10 Year Health Plan describes the vision for care in 2035, though we expect to see these changes much sooner
* explore with Think Local Act Personal (TLAP) the inclusion of people with ME/CFS in TLAP’s work with people who draw on adult social care and support
* launch an independent commission into adult social care as part of our critical first steps towards delivering a national care service

**Provision of welfare support**

The IDP set out the following problem statement regarding the provision of welfare support: children and adults with ME/CFS and their family and unpaid carers can struggle to access benefits and find the process difficult to navigate.

Actions set out in the IDP included that DWP is committed to making its services easier to access for everyone, irrespective of their condition. The IDP referenced [Transforming support: the health and disability white paper](https://www.gov.uk/government/publications/transforming-support-the-health-and-disability-white-paper), published in March 2023, which intended to make it easier for people to apply for benefits and improve people’s experience of assessments and application process.

The majority of individual respondents to the consultation agreed with the contents outlined in the ‘Provision of welfare support’ section of the IDP. Messages and suggestions for further improvement to the IDP content from the survey respondents emphasised:

* the need for support during the assessment process
* a lack of understanding and awareness of ME/CFS from assessors
* that healthcare professionals should be involved in the decision-making process

As such, we have agreed new actions aiming to address these key issues raised in the consultation responses.

DWP is working to develop proposals for reform to the system of health and disability benefits and will set them out in a green paper aiming to improve the benefits assessment process. DWP also has wider workstreams which, while not condition-specific, also apply to ME/CFS. This includes the [Get Britain Working white paper](https://www.gov.uk/government/publications/get-britain-working-white-paper) and Keep Britain Working Health and Disability Benefit reform.

The FDP aims to ensure that:

* people with ME/CFS and their unpaid carers have a full understanding of how to access the benefits system and of the claims process
* the right decisions are made the first time
* support is provided where needed throughout the application process

To go further on this action, DHSC, in collaboration with DWP, will include all relevant information about available DWP support as part of a new public awareness initiative, and disseminate that to relevant stakeholders. We will measure the success through feedback on the new DHSC-led awareness initiative to be monitored and reviewed by May 2026.

**Provision of employment support**

The IDP set out the following problem statement regarding supporting people with ME/CFS and their unpaid carers to stay in work or secure employment.

1. Inclusive and flexible job opportunities (paid or unpaid) are limited for people with ME/CFS and recruitment processes often are not accessible.
2. Access to informed and appropriate human resources support, including occupational health, varies in the workplace for people with ME/CFS and unpaid carers.

The IDP aims to offer support with employment by helping people with ME/CFS, as appropriate to the stage of their illness, feel supported to:

* manage their condition
* change how they work
* leave on grounds of ill health retirement

Carers should also be supported to enter, maintain or return to employment. We want employers to be able to show flexibility, compassion and understanding of disability and health conditions such as ME/CFS, so that people feel more supported by their employer, including providing information and advice and access to occupational health services.

The majority of respondents to the consultation agreed with the IDP but thought we could improve the level of detail, particularly in regard to:

* flexible employment
* better recognition of severe ME/CFS by employers
* the drive to increase employment of disabled people
* the lack of employment support through the Work Capability Assessment (WCA)

Further key messages included suggestions for DWP to:

* develop guidance for employers
* improve flexible working offers
* recognise ME/CFS as a severe condition, with a lack of treatments
* adhere to the disability definition in the [Equality Act 2010](https://www.legislation.gov.uk/ukpga/2010/15/contents)

Respondents want a detailed and effective strategy for these actions, particularly when it comes to recognition by employers, helping people with ME/CFS and unpaid carers to access employment support, and reasonable adjustments. As such, we have updated the relevant action.

The Pathways to Work offer announced in the green paper and backed by £1 billion of funding per year by the 2029 to 2030 financial year will improve the work, health and skills support available for disabled people and people with health conditions, including those with ME/CFS. The offer will include:

* a support conversation that will help identify the best next steps, including a range of personalised and more intensive support
* specialist one-to-one support. This will build on evidence from recent pilot schemes, which has shown that, for some people, offering regular in-depth personalised appointments with a consistent adviser can help people who are ready to move towards or into work
* more intensive longer-term work, health and skills support for those who are ready. This will build on evidence from programmes like the Work and Health Programme, Work Choice, Individual Placement and Support for those with severe mental illness or substance dependency, and evidence from successful skills training
* periodic engagement for people who are not yet ready for more work-focused engagement. Content and frequency will vary depending on individual need and - if and when they are ready - we will signpost or refer to other support

DWP is consulting on aspects of the employment support package in the green paper and hope that a wide range of voices, including those with or familiar with ME/CFS, will respond to the consultation.

In the Pathways to Work green paper, DWP is consulting on the future of the Access to Work scheme. It is also considering the role of employers in creating accessible and inclusive workplaces, as well as how it can shape the market for aids, appliances and assistive technology to reduce their cost and spread their adoption. Once this is established, DWP will consider timelines and work closely with stakeholders to ensure an appropriate transition.

Since publication of the IDP, DWP has already established further initiatives to help support employers to deal more effectively with disability and long-term health conditions in both recruitment and employment. DWP established the voluntary Disability Confident scheme to encourage employers to create disability inclusive workplaces and to take action to improve how they recruit, retain and develop disabled employees.

When an employer signs up to the Disability Confident scheme, they agree to commitments which include anticipating and providing reasonable adjustments as required. DWP ministers have committed to reforming the Disability Confident scheme and the department will be holding discussions with key stakeholders over the summer to inform this. An important consideration of this will be how the impact and outcomes of engaging with the scheme could be strengthened and measured in a meaningful way.

DWP wants to make changes to ensure it is maximising the opportunities to create accessible and inclusive workplaces for disabled people and people with health conditions. This includes working with other areas of government to develop the digital support offer to employers, building on the Support with Employee Health and Disability Service (SEHD). This is a digital resource aimed at small and medium-sized employers that helps them to feel more confident having conversations about health and disability, understand and fulfil their legal obligations, and signposts to sources of expert knowledge. SEHD was developed with input from employers from smaller business and disabled people’s organisations and charities.

Furthermore, the Keep Britain Working Review, led by Sir Charlie Mayfield, is already underway and due to report in autumn 2025. This is looking at:

* the role of UK employers in creating and maintaining healthy and inclusive workplaces
* what more employers could do to tackle economic inactivity caused by ill-health and disability
* what the government should do to encourage or require that as part of the Get Britain Working white paper

**Agreed actions**

The tables below set out all actions to be taken forward, including actions from the IDP and new or enhanced actions that aim to address key challenges raised through the consultation on the IDP and subsequent engagement through the ME/CFS Task and Finish Group.

The tables summarise:

* actions and action owners
* progress updates (where relevant)
* measures of success or indicators of progress
* proposed delivery timelines across the 3 themes of the FDP:
	+ research
	+ attitudes and education
	+ living with ME/CFS

While the original structure of the plan has been retained for the most part, we acknowledge there is significant interplay of actions across all themes. Refer to more detailed descriptions of actions in corresponding sections of the plan.

While some actions relate to specific deliverables, others point to further exploratory and scoping work to be carried out as part of the implementation phase, post-publication. While the latter actions require further development, they will continue to be driven and informed by the overarching vision of the plan and will reaffirm our commitment to improve care and support for people with ME/CFS and their carers. We will continue to build on the foundations of these actions well beyond the publication of this plan. Further developments may, in some cases, be subject to ministerial decisions and outcomes of future Spending Reviews. Action owners are responsible and accountable for further development of actions where required, and those developments will be captured, refined and reported on as part of the progress monitoring process set out under ‘Next steps’. Where actions are assigned to NHS England, after its abolition the responsibility for those actions will sit with the new joint organisation that will bring NHS England and DHSC together.

**Research**

| **Action and action owner** | **Progress update** | **Timeline and measure of success** |
| --- | --- | --- |
| UK Clinical Research Collaboration (UKCRC) Research Working Group has committed to rapid actions which will provide the foundation of evidence generation and insight into the medium and long-term actions | The rapid actions have been completed, and ongoing actions have been identified in collaboration with researchers, charity groups and people with lived experience | CompletedActions were delivered and discussed with the Task and Finish Group |
| DHSC will support the Research Strategy sub-group to hold workshops with funders, academics and people with ME/CFS on how to develop research questions | Workshops were organised by the Research Working Group members | CompletedWorkshops were held, all were well attended, and key issues were considered |
| DHSC will work with research funders to commission a landscaping review of national and international work underway in ME/CFS | Recent research in ME/CFS was commissioned, shared with the Task and Finish Group and published | CompletedWe will monitor funding disbursed for ME/CFS closely |
| The Medical Research Council (MRC) and National Institute for Health and Care Research (NIHR) will raise awareness of research funding opportunities for researchers and highlight research priorities publicly and with decision-making bodies | The ME/CFS Researcher Toolkit was publishedMRC continues to maintain a funding ‘priority area’ in ME/CFS spanning all funding schemes and continues to engage with potential applicants for funding programmesDHSC hosted a roundtable in September 2024 with the research community and people with lived experience, resulting in a commitment to host a research showcase event to discuss recent evidence, particularly from the DecodeME study | CompletedWe will monitor funding disbursed for ME/CFS closely |
| As part of the UKCRC Research Working Group, a charity and patient group collaboration will support funders to raise awareness of mechanisms for effective patient and public involvement and engagement (PPIE) in research | This was incorporated into the ME/CFS Researcher Toolkit | Completed We will monitor funding disbursed for ME/CFS closely |
| DHSC will support the Research Working Group to develop case studies of research which show good practice, including effective PPIE | This was incorporated into the ME/CFS Researcher Toolkit | CompletedWe will monitor funding disbursed for ME/CFS closely |
| DHSC will support the Research Working Group to engage with the initiatives to educate clinicians and/or practitioners about ME/CFS | Dr David Strain (University of Exeter) contributed to the Research Working Group as well as NHS England’s educational module | CompletedSee update below for progress on the module |
| DHSC and NIHR will continue working with the Research Support Service (RSS) to enhance our support offer for potential applicants for ME/CFS research funding | (New action)Working with NIHR to enhance the support offer to ME/CFS researchers | Internal NIHR monitoring on a 12-monthly basis to develop an appropriate process and understand whether researchers are seeking support from RSS |
| The NIHR will commission an NIHR Innovation Observatory Review of relevant new and repurposed medicines in clinical development for the treatment of ME/CFS | (New action)The research community has provided helpful insights on potential therapeutics and the NIHR Innovation Observatory has completed a horizon scan which focused on medicines with a UK licence which might be ready for later phase (in phase 2 or phase 3) clinical trials | Completed - the report has been publishedNIHR will consider these insights to develop a new Application Development Award |
| NIHR and MRC will support researchers to apply for an Application Development Award focused on evaluating repurposed medicines and non-pharmaceutical interventions for post-acute infection syndromes and associated conditions, including ME/CFS | (New action)In discussion with NIHR, to develop a new Application Development Award to help accelerate the necessary learning to explore the feasibility of a phase 2 platform trial to evaluate repurposed medicines and other non-pharmaceutical interventions for post-acute infection syndromes | Internal NIHR monitoring on how many applications are submitted for the Application Development Award[Application Development Award](https://www.nihr.ac.uk/funding/post-acute-infection-syndromes-including-long-covid-and-myalgic-encephalomyelitischronic-fatigue-syndrome/2025354) has been launched and welcomes applications until 2 December 2025 |
| DHSC, NIHR and UKRI research will host a joint showcase event to publicise the results from the DecodeME study, as well as highlight important outstanding research questions and encourage researchers to join the ME/CFS and long COVID fields | (New action)In discussion with NIHR and MRC on scope of event and so we can maximise the opportunity to encourage researchers to join the ME/CFS field (capability building) | Expected completion in 6 months - anticipated in autumn 2025 following publication of results from DecodeME studyIncrease in applications to research funders following public showcase, demonstrating commitment and stimulating interest in post-acute infection conditions research |
| DHSC and NIHR will commission the HERITAGE research project through NIHR Health Services and Delivery programme to look at the overlap between ME/CFS and long COVID, and explore costs and effectiveness of different existing healthcare models for both conditions | (New action)Work underway to understand current service provision and where there may be gaps | Internal NIHR monitoring and formal publication of findings following researchNIHR has funded the HERITAGE study with research findings to be published over the course of the project |
| The MRC will ensure robust input from ME/CFS research community in UK Research and Innovation’s (UKRI) panel assessment | (New action)Work underway to bring in ME/CFS expertise to MRC panel process where appropriate | UKRI’s monitoring in 6 months |
| The NIHR, as part of post-monitoring of FDP, will report annually to the Task and Finish Group of appropriate metrics for research applications received and awarded | (New action)In discussion with NIHR on feasibility of reporting metrics on number of applications for ME/CFS research received and awarded | Annual internal reporting to Task and Finish Group as part of post-monitoring of the FDP |

**Attitudes and education**

| **Action and action owner** | **Progress update** | **Timeline and measure of success** |
| --- | --- | --- |
| DHSC will consider how to increase our knowledge of public sector professionals’ current attitudes towards ME/CFS | DHSC to scope options to take the action forward | Implementation expected by March 2026The most appropriate approach is identified, and work commissioned |
| NHS England will develop an e-learning module on ME/CFS, which will be aimed at health and social care professionals and available to members of the public | Session 1 (introduction) and session 2 (primary care) completed, with universal accessSession 3 (severe ME/CFS including very severe ME/CFS) completed, with access limited to users with NHS, GOV and ac.uk email addressesNHS England will make further assessment based on optic and learner feedback for future sessions | CompletedReview of learner feedback and user statistics 3 months post-launch |
| NHS England and the NHS Health at Work Network will update their webpages on ME/CFS | Complete | CompletedThe NHS webpages on ME/CFS are up to date and in line with NICE guidelines |
| DHSC, in collaboration with internal and external stakeholders, to develop and run a public awareness initiative on ME/CFS to promote wider awareness and understanding of the condition and support available to people with ME/CFS and their families | (New action) | Implementation expected by May 2026Expected to improve the wider awareness and understanding of ME/CFS and support availableFeedback on the initiative to be monitored and reviewed |
| DHSC will ask relevant stakeholders to:a) consider developing a shared learning resource on ME/CFS, which could be held in an education hubb) request that the Medical Schools Council (MSC) encourages shared learning and the NHS England e-learning package on ME/CFS to all UK medical schools and encourages medical schools to provide undergraduates with direct patient experiencec) use its networks to raise awareness of NHS England’s e-learning module on ME/CFS | Discussed potential education hub with the Task and Finish Group - to be explored furtherDHSC discussed raising awareness of NHS England’s e-learning with relevant professional bodiesThe Royal College of General Practitioners, the Chartered Society of Physiotherapy and the Royal College of Occupational Therapists agreed to share and promote NHS England’s e-learning modules. DHSC will continue to reach out to networks including the Royal College of Nursing to promote NHS England’s e-learning modulesNICE has added e-learning to its [tools and resources page](https://www.nice.org.uk/guidance/ng206/resources), with further modules to be added as they become availableDHSC to develop and run a public awareness initiative on ME/CFS, and signpost to e-learning and NICE guidelines as part of the initiative | Sharing of resources with a wider stakeholder group and a public awareness initiative (by May 2026) are expected to improve both the public and professionals’ understanding of ME/CFSE-learning to be shared with stakeholders in July 2025NHS England’s user statistics and feedback on DHSC-led awareness initiative to be monitored and reviewed |
| The Department for Education (DfE) will encourage special educational needs and disability (SEND) and medical condition organisations to signpost the NHS England e-learning on ME/CFS on their websites, update the guidance on education for children with health needs who cannot attend school, share guidance developed by Action for ME with wider children’s social care professionals, and signpost NHS England’s e-learning on ME/CFS to providers | DfE continues to update and signpost relevant stakeholders and organisations on key updates and developments, including e-learningDfE updated and published the revised guidance ‘Arranging education for children who cannot attend school because of health needs’ in December 2023, which stakeholders have welcomedDfE published a guide for local authorities and schools on 5 February 2025 | OngoingGreater awareness of ME/CFS within the education sector |
| The British Association of Social Workers (BASW) will support and promote the work of stakeholders to raise awareness and knowledge within the social work profession, about the needs of people with severe and very severe symptoms of ME/CFS, including unpaid carers | To be taken forward post-publication | By September 2025Greater awareness of severe and very severe ME/CFS within the social work profession |
| DHSC will issue targeted communications regarding ME/CFS e-learning and other relevant resources through wider sector networks, such as the Health and Wellbeing Boards, adult social care provider networks, representative bodies and charities | (New action)DHSC compiling the list of relevant networks, with a view to disseminate key resources through multiple existing channels (such as journals and newsletters) | By September 2025 (ongoing for future developments and communications)Increased uptake of NHS England’s e-learning module (user statistics review)Greater awareness and visibility of the condition across the sector |
| The General Medical Council (GMC) will include ME/CFS in the scope of its Medical Licensing Assessment (MLA) | GMC is currently engaging with stakeholders as part of a wider review of its education framework (see action below) | Changes to the framework will be from 2029 onwards, and GMC to consult on its approach to medical education over the next 2 yearsME/CFS included in the MLA content map |
| GMC to consider whether appropriate teaching on ME/CFS can be better incorporated into undergraduate and postgraduate medical training and education as part of its Future of Education and Career Development programme | (New action)As part of the listening and consultation phases, GMC will decide what changes need to be made to its standards, outcomes and guidance, and how they will be implemented | GMC’s new education framework will be developed with partners from across the healthcare to ensure it has the greatest positive impact for the public and professionThe programme will run until 2029The wider issue of health inequalities will be explored as part of the framework review, which may have implications for this clinical area |
| The Royal College of Physicians (RCP) will ensure that its training on ME/CFS keeps pace with research and guidance in the core postgraduate training for primary and secondary care physicians | RCP will, for now, rely on NHS England’s e-learning modules, which are considered suitable by RCP | Aim for all RCP members to undertake the e-learning by the end of 2025 |
| Healthcare practitioners from across disciplines and people with personal experience, including carers, will come together to produce a ‘Language Matters in ME/CFS’ guide, led by an independent clinician and supported by DHSC | DHSC discussed with the Task and Finish Group and invited nominations for a clinician to lead this work and collaborate closely with DHSC and patients with lived experience | Expected by November 2025The guide is developed and fully considers the consultation respondents’ feedback on language |
| DHSC will increase awareness among people with ME/CFS and their unpaid carers of support available from adult social care and how to access it, and feed back on or make a complaint about care, as well as identify how best to raise public awareness of ME/CFS | DHSC to include all relevant information for carers, including support available, as part of the new public awareness initiative, and disseminate to relevant stakeholdersThe 10 Year Health Plan includes changes that will positively impact people with ME/CFS and their carers, with emphasis on providing faster diagnosis and access to care | Feedback on the new DHSC-led awareness initiative (expected implementation by May 2026) to be monitored and reviewed |
| DHSC and DWP (where appropriate) will work with stakeholders to disseminate information and guidance to increase awareness among all disabled people, people with health conditions, employers and relevant organisations of support available and how to access it | DHSC, in collaboration with DWP, to include all relevant information on available DWP support, as part of the new public awareness initiative, and disseminate to relevant stakeholders | By May 2026Feedback on the new DHSC-led awareness initiative to be monitored and reviewed |
| The British Psychological Society is currently developing a Good Practice guideline for working with patients with ME/CFS based on NICE NG206 (2021) in conjunction with ME/CFS charities and in co-production with patients and psychological professionals with lived experience of ME/CFS. This will include sections in relation to appropriate psychological support in general along with, for example, detailing specific information in relation to working with severe and very severely affected ME/CFS patients and with patients across the life span | Ongoing | Due to be published in 2026 |

**Living with ME/CFS**

| **Action and action owner** | **Progress update** | **Timeline and measure of success** |
| --- | --- | --- |
| The Law Commission will review existing social care legislation relating to disabled children, to improve clarity for families about the support that they are legally entitled to | To be developed post-publication | OngoingThe legislation clarifies the support available and expectations from local authorities |
| DHSC and NHS England will work with stakeholders to consider how to better support healthcare commissioners and providers to understand the needs of people with ME/CFS, what local service provision should be available and how existing national initiatives to improve accessibility of health services can be adapted or best utilised for people with severe or very severe ME/CFS | NHS England completed a stocktake of existing ME/CFS services and established a working group to determine how additional support can be provided to commissioners of ME/CFS services (refer to new actions on health services below) | Refer to new actions on health services below |
| NHS England will co-design resources for systems to improve services including the development of the template service specification for mild and moderate ME/CFS | (New action)Work commenced, stakeholders to be engaged through a new health services sub-group of the Task and Finish Group, to seek feedback | Engagement, drafting and testing by December 2025The template service specification will fully take into account NICE guidelines on ME/CFS, and be disseminated to all integrated care boards (ICBs) to inform their commissioning decisions and support quality of local service provision to match local needs |
| DHSC, with NHS England, will explore whether a specialised service should be prescribed by the Secretary of State for very severe ME/CFS | (New action)Initial discussions with NHS England have already taken place. Requires further development and expert clinical advice | Subject to ministerial decisionTimelines will be developed once the future direction is confirmed |
| NICE to commission a Clinical Knowledge Summary topic on ME/CFS, developed by Clarity Informatics Ltd, as well as to keep the ME/CFS guideline under surveillance to ensure it reflects developments in the evidence base | (New action)NICE has commissioned a Clinical Knowledge Summary on ME/CFS, which has been developed and published recentlyOngoing guideline surveillance review process | Clinical Knowledge Summary to provide improved and evidence-based support on ME/CFS for professionals working in primary careNo current plans to update NICE’s ME/CFS guideline (may change if there is significant new evidence) |
| DHSC and NHS England launched a National Neighbourhood Health Implementation Programme (NNHIP) on 9 July 2025Many places are already making progress on neighbourhood health and this programme seeks to build on success to date, taking a test, learn and grow approachThe initial focus for the first places involved in the programme will be creating neighbourhood health systems and processes for adults with multiple long-term conditions and rising riskIn addition, we will work with places on the enablers and other aspects of neighbourhood health as described in the 10 Year Health Plan. It will also be working at scale to share, spread and accelerate learning across the country | (New action)Invitations to get involved in the NNHIP were sent out to systems | The deadline for applications to be submitted by systems is 8 August 2025There will be a rigorous monitoring of a set of targeted outcomes, with ongoing rapid insights capture and evaluation to test, learn and refine |
| NHS England will establish neighbourhood multidisciplinary teams for children and young people (CYP), which could help with earlier identification and referral into relevant ME/CFS services and link in with local support services where available | (New action)NHS England has published Guidance on neighbourhood multidisciplinary teams for children and young people | Care to be delivered closer to home and improved outcomes and experience for CYP, as well as their families and carers |
| DHSC and NHS England have developed the 10 Year Health Plan to deliver the 3 shifts: hospital to community, analogue to digital and sickness to preventionServices will be moved closer to, and into, people’s homes, providing faster diagnosis and faster access to treatment for patients with long-term conditions | (New action)The plan was published on 3 July 2025 and set out how to get the NHS back on its feet and get the nation’s health thriving once again | The plan was published on 3 July 2025 and set out policies to implement the 3 shifts |
| DHSC will engage stakeholders to discuss timely diagnosis and support for children who have ME/CFS and their families as well as best practice in relation to safeguarding responsibilities | To be taken forward in parallel with NHS England’s actions on ME/CFS services and neighbourhood multidisciplinary teams for children and young people | Ongoing - dependent on timelines and outcomes of linked actions |
| DHSC will:a) ensure that carers’ voices are included in all policymaking about ME/CFS, recognising carers as experts by experience and vital advocatesb) ensure health and social care professionals are equipped with the skills and resources to engage in positive working relationships with carersc)  ensure that unpaid carers are involved in decisions relating to the care and treatment of the person they care for, including discharge planning | (New action)Carers to be involved in any stakeholder engagement on ME/CFS policyDHSC exploring with NHS England how NHS England’s e-learning module can help to train staff to identify and communicate effectively with carers | OngoingME/CFS carers are actively engaged and contribute to future policy developmentHealth and social care staff are trained to identify and communicate effectively with carers of patients with ME/CFS - review of learner feedback relevant to carers |
| DHSC, as part of the 10 Year Health Plan, will take steps to improve identification of carers, including those caring for people with ME/CFS, as well as explore ways to improve support for carers so that it is easier for them to provide care | (New action)The 10 Year Health Plan details support mechanisms for carers, such as streamlining care responsibilities and recognising the responsibilities of unpaid carers | The 10 Year Health Plan describes the vision for care in 2035, though we expect to see these changes much sooner |
| DHSC will explore with Think Local Act Personal (TLAP) the inclusion of people with ME/CFS in TLAP’s work with people who draw on adult social care and support | (New action) | By December 2025Greater inclusivity of those with lived experience and better personalisation of care |
| DHSC has launched an independent commission into adult social care as part of our critical first steps towards delivering a national care service | (New action) | Timelines will be set out in the commissionThe independent commission into adult social care, chaired by Baroness Louise Casey, will work with people who draw on care and their families, staff, parliamentarians, local government, and the public, private and third sectors to make clear recommendations for how to rebuild the adult social care system to meet the current and future needs of the population |
| DfE will embed ME/CFS-specific considerations into its broader approach to education, including by sharing relevant training, resources and guidance with alternative provision settings and local authoritiesDfE will explore opportunities to raise awareness and promote understanding of ME/CFS across the education sector, including through engaging with stakeholders, disseminating best practice and ensuring that guidance and communications reflect the needs of children with complex medical conditions | (New action) | OngoingMore inclusive education and flexible learningAppropriate, effective and safe education provision |
| DWP is committed to making its services easier to access for everyone, irrespective of their condition | DWP announced the Pathways to Work offer in its recent green paper and is currently consulting on aspects of the employment support packageA review of the Disability Confident scheme has been commissioned with an aim to make it more robust, including plans to engage with key stakeholders and those with lived experience to inform the reviewThe Keep Britain Working Review was set up in the Get Britain Working white paper, looking at the role of UK employers in creating and maintaining healthy and inclusive workplacesAs part of the Pathways to Work green paper, DWP is consulting on the future of the Access to Work schemeDWP is building on the Support with Employee Health and Disability Service (SEHD). This is a digital resource aimed at small and medium-sized employers that helps them to feel more confident having conversations about health and disability | Timelines will be developed once the future direction confirmed following the consultationThe Keep Britain Working Review is due to report in the autumn of 2025Improved employment support available for disabled people and people with health conditions, including those with ME/CFSDWP ministers have commissioned a review of the Disability Confident scheme and will consider how the impact and outcomes of engaging with the scheme could be strengthened and measured |

**Next steps**

The publication of this FDP marks an important milestone that provides the foundations for improvements in all key areas that affect people with ME/CFS. We will monitor the actions, and the DHSC secretariat will continue to engage with the Task and Finish Group in an appropriate form as required, to assess progress towards existing actions and to agree further actions where required. The Task and Finish Group includes representatives from ME/CFS charities, people with lived experience and those responsible for actions in the FDP, including government departments, arm’s-length bodies and professional organisations.

A new health services sub-group will be convened to focus on improving care for those with ME/CFS. Appropriate and timely care for people with ME/CFS on all parts of the severity spectrum must improve. This FDP provides a framework for a sustainable approach which will ensure consistent and reliable care for all people with ME/CFS. We will continue to work with stakeholders across government, the NHS and beyond to progress the agreed actions set out in this plan with the aim of raising awareness and promoting understanding of ME/CFS across various sectors. We will also continue to actively engage with the All-Party Parliamentary Group on ME and collaborate with the 3 devolved UK nations, which participated in the development of this FDP.

1. Samms GL and Ponting CP. [‘Unequal access to diagnosis of myalgic encephalomyelitis in England](https://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-025-22603-9) BMC Public Health 2025: volume 25, article number 1417 (viewed on 21 July 2025) [↩](https://draft-origin.publishing.service.gov.uk/government/publications/myalgic-encephalomyelitischronic-fatigue-syndrome-mecfs-the-final-delivery-plan/myalgic-encephalomyelitischronic-fatigue-syndrome-mecfs-the-final-delivery-plan#fnref:1)