



# Invest in ME Research

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## **Observations on DHSC Interim Consultation document: the interim delivery plan on ME/CFS**

This document carries comment from UK charity Invest in ME Research (IiMER) on the Draft Interim Delivery Plan on ME/CFS recently published by DHSC.

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## Introduction

We have written before in 2022 [[1](#)], and similarly over the years -

..without research, we remain in a world without the one factor that would overcome stigma, misinformation and flawed policies - scientific evidence.

This leads to non-existent or poor services, apathy and indifference, and sometimes negligence - and an easy excuse to maintain the ignorance.

Years of experience force us to acknowledge that waiting and expecting others to act or assemble the appropriate building blocks for progress in understanding and treating ME with any sense of urgency will be a long wait - no matter what appearances may be presented.

We have to continue to develop our strategy ourselves and demonstrate what, and how to do things.

.....

To develop research we need a strategy - which is why we have proposed and funded the idea of a Centre of Excellence for ME in UK and Europe - a hub for development of research ideas and collaboration.

.....

The only UK clinical trial for ME will resume in 2023.

The strategy is to make as much use of the opportunities presented by the trial as possible as this provides for building capacity, bringing in new researchers and expertise into the field, and adding on more research as part of the total project work.

Additional projects and funding are being added – [see this recent update](#), with other benefits include development of robust outcome measures.

The value of a UK/European centre of excellence for ME is clear and it is notable that this has been developed by patients and carers and a forward looking research institute and university.

What is also important when considering making progress is that one does not have to reinvent what has already been set up to develop capacity and expertise.

Likewise, there is little point in funding odd, disparate projects that are not connected to a strategy of research.

Instead, the existing research base and the new ideas and research being generated to support a strategy of research should be supported with additional funds. This is how we see that the urgency that is required for research into ME can be addressed.

On 15<sup>th</sup> July 2022, Invest in ME Research received an invitation from Professor Lucy Chappell, Chief Scientific Adviser, Department of Health and Social Care asking you to join the UK Clinical Research Collaboration ME/CFS Research Working Group.

Well over a year has passed since that and our first invitation to a meeting in September 2022.

A year on the DHSC published an Interim Consultation document: the interim delivery plan on ME/CFS [[2](#), [3](#)], on 9 August 2023.

### Summary

- A year has passed with nothing yet achieved that can be termed a change for people with ME
- The only tangible output seems to be this report [[3](#)]
- The report contains little, if anything, that was not already known
- Some actions contained in the report will be welcomed, if actually enacted with a sense of urgency
- Many actions contained in this report still seem nebulous for the most part with intent and suggestion being portrayed as concrete decisions
- A survey has been added to the report that seeks views on the interim set of actions
- Urgency is not a priority overall
- No funding has been promised for research
- The existing research centre in Norwich Research Park has not been recognised and its potential for rapid progress in research is therefore lost, with further delays to progress
- There is much doubt about what will definitely be implemented, what the content of planned education and information will include, and no definite research strategy

### Background

A recap on our involvement until September 2023 is here [\[4\]](#) - a timeline of submissions and comments in order to follow the flow of involvement from the charity in the UK Clinical Research Collaboration (UKCRC) ME/CFS Research Working Group.

The structure and composition of these working groups, terms of reference and how things were to be conducted, and the objectives, had already been formulated prior to the charity's invitation to join being received.

IiMER has only been involved in the Research Working Group and the only input we have had to the Interim Report was to supply comments in November 2022 to an initial stand-alone research chapter. The charity played no further part in forming the interim plan nor had input to any of the other working groups.

During the discussions in the Research Working Group IiMER requested advanced viewing of this full interim plan prior to publication so that we could comment. This request was declined.

If others in the working groups have been shown the interim documents prior to publication, then IiMER first viewed the documents associated with this interim report at the same time as the public.

With the 9 August 2023 announcement one is provided with the following web pages/documents –

- A overview news story page from Minister of State for Health, Will Quince [\[5\]](#)
- A Consultation description containing links to two other documents [\[6\]](#)
- A page called Consultation document: the interim delivery plan on ME/CFS [\[7\]](#) which can be printed as a 27 page pdf document and which seems to have the questions in the survey that people with ME are asked to complete, yet does not allow answers to be entered on this document
- The My full reality: the interim delivery plan on ME/CFS itself [\[3\]](#) containing the actual report with detail and which can be printed as a 69 page pdf
- A survey that people are invited to complete and return concerning the content of the report [\[8\]](#) that can be printed as a 36 page pdf document
- An online version of the survey [\[9\]](#). The survey contains 56 questions

- An 'easy read version of this consultation' which then has links to two more documents [[10](#)]
  - o Our plan to improve the lives of people with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS): what do you think? [[10a](#)]- a 74-page pdf document that invites the survey to be completed
  - and
  - o Our plan to improve the lives of people with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) [[10b](#)] a 24 page overview of the 'plan of action'

The interim delivery plan was developed around 3 key themes: research, attitudes and education, and living with ME/CFS (this being then further sub-divided into topics covering children and young people, social care, health, welfare, employment and quality of life). Working groups were formed for each theme.

## Analysis of Interim Report/Observations and Summary

We reviewed the main document [[3](#)] and completed and submitted the survey [[8](#)]

and how unwieldy we found the format of these documents to be.

If patients manage to read and comprehend these documents following the 9 August 2023 announcement then probably they will not argue with much of what is included in this interim report document [[3](#)] in chapters 2, 3 and 4.

The report illustrates some of the current situation with ME and, whether intended or not, it exposes to some extent the scandal with ME that has been allowed to endure in the UK over the last decades and that has resulted in the current dreadful situation.

Nothing we have seen in the document should be new to people with ME. In fact, the description of the issues existing with regard to ME might well have been written a decade or more ago. Invest in ME Research has been advocating and arguing the issues indicated in the document for 17 years.

We have been asked to comment on these kind of consultations over many years – even as individuals commenting on the CMO report of 2002. The result has always been the same - of not knowing enough, not enough research capacity, calls for more funding and awareness. The perennial feature is that there are no lasting actions resulting from these reports.

The documents do fail to deliberate on why this state of affairs has been left for so long. That would be understandable if the actions to resolve these issues were fully agreed, set in motion and funded. Otherwise, one needs to understand why nothing has been done if one is to rectify these issues.

In the Ministerial Foreword it is written that –

*'we do not know enough about ME/CFS, which must change if we are to improve experiences and outcomes secondly, that we must trust and listen to those with personal experience of ME/CFS'*

with no sense of irony that governments never provide any recognition (let alone accountability) for the reasons as to why such a situation exists for people with ME and their families.

We mentioned this in response to requests for comments on the research chapter back in November 2022. Nothing changed.

The ministerial foreword continues –

*'This interim delivery plan sets out the current problems to be addressed and agreed actions to drive an expansion of research, better education of professionals, improvements in attitudes towards the condition and improvements to service provision.'*

Yet the report is actually not so clear on providing guarantees that actions will be taken.

Much is still relatively fuzzy in terms of detail as to how actions will be taken and the level of commitment to ensure that actions are taken.

In some action points the content of planned education and information is not described. This is important as people with ME have decades of experience of

being confronted with flawed approaches to their condition based on false information and misinformation in educational offerings.

Likewise, benefit changes and measures on recognition of the debilitating effects of the disease do not seem to clarify an actual environment for enforcing desirable amendments to what exists currently.

There is, also, no definite long-term research strategy and a complete absence of any funding commitments.

While this ministerial foreword may not be noted as much more than cosmetics it does raise concern as to how much of the problem has really been appreciated by DHSC.

The ministerial foreword continues –

*'With the right advice, care and adaptations provided by the NHS, social care, education, the welfare system and employers, I am confident that people with ME/CFS can be supported to manage their symptoms as effectively as possible, contribute more to our society and maximise their quality of life.'*

The above has not happened up until now despite the issues described in this interim report being known for many years. Simply regurgitating more words to cover the issues will not, by themselves, change mindsets. The objective should be to regain health not fit into an ideology that prioritises returning to work (aka avoiding benefit payments).

The document makes assumptions that e-learning educational modules will be produced and that the NHS will comply, adopt these, and make medical schools use them. It also states that the Royal College of Physicians will ensure that its training on ME/CFS keeps pace with research and the latest guidance.

We wonder how this will be ensured. There is no historical evidence to believe that these things will materialise or carry suitably representative content that will make a difference. There is no detail on what will be in these proposed training courses or with which research they are intent on keeping pace.

In addition, there is no guarantee that medical schools or NHS will fall in line.

IiMER has been funding medical students to intercalate with research projects already and we would hope that medical schools would introduce correct information about ME in their curricula - but there is no certainty that this will be funded or even accepted. We approached the GMC thirteen years ago to raise this subject of medical education [[14](#)] and were informed that the GMC does not

specify what should be taught to undergraduates about any specific conditions. This was decided by the medical schools when drawing up their own curricula. More clarity needs to be assigned to the statement that 'The General Medical Council will include ME/CFS in the scope of the Medical Licensing Assessment that will be launched in 2023'.

In our first input in September 2022, we called for a specialism for ME to be developed [21]. This was ignored and not supported. The charity had already tried to pursue this by gaining university and hospital support for establishing an academic clinical consultant role (pre-pandemic). A specialist role for ME would encourage more people to pursue careers as clinicians specialising in ME and would allow a consistency in diagnosis using standard criteria (updated as evidence allows). Having specialists in ME allows more acceptance, knowledge and education about this disease to be maintained.

Under **The case for change** chapter everything that is written has been known about for years. Therefore, if this is all known and accepted then why is there a need to use even more time to request a survey and then spend time analysing the responses? Is it thought that this will change?

The report's economic case refers to another report that was written eight years ago and calculated that cost to the UK of ME/CFS as £3.3 billion. If this was known eight years ago then why is the question not been posed (nor answered) as to why nothing has been done about it?

If the answers to these questions are not given then why would this interim report be considered as likely to succeed in changing things for the better for people with ME?

Also, in **Background** section in the document, it is stated that

'The MRC has provided £4.15 million of ME/CFS research funding since 2013'.

This is a pittance compared to other diseases and in relation to the disease burden mentioned above and the damage to peoples' lives.

In our **Status of ME** report in **2018** which was submitted to the parliamentary inquiry on ME [17] we proposed –

To realise real progress and develop effective treatments for ME then Invest in ME Research propose ring-fencing funding of at least £20 million a year for five years for a strategy of biomedical research into ME.
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This **£100 million** would likely end all of the years of suffering of people with ME and give hope for the future.

This is a relatively small amount

Of course, the proposals were not listened to.

It should also be noted that the MRC highlight notice for ME has been handled negligently, and (until we mentioned this in our first meetings in 2022) had failed to be followed up or updated and had been ignored by governments, CMOs, NHS, and the MRC itself.

This paragraph in the interim report is important and should be remembered –

In this interim delivery plan, an 'action' is a specific task that an organisation or person has agreed to do, within a certain timescale. Some suggested actions have been categorised as 'best practice' instead, because they describe how systems, organisations or people should behave or operate, all the time.

Under Best practice in the section on **Attitudes and Education Working Group** it states that professionals should ask questions to explore and acknowledge.....

'obligations towards people with ME/CFS **should** be understood...

'when exercising their judgement, professionals and practitioners **should** take the updated NICE guideline.....

'employers **should** promote inclusive employment of people with ME/CFS.....

There are 55 '**should**'s in the interim document – many around actions expected to be taken. We would prefer the certainty of '**will**' be done, followed by when.

A report such as this, especially for a subject such as ME – a condition that has been so ignored and abused by establishment organisations over the years – needs to have certainty and clarity on actions to be taken.

The vaguery of how a system, organisation or people '**should behave or operate**' is not language to be used when controlling what happens to peoples' lives.

In **About welfare services** it states DWP provides a wide range of disability-related financial support, including benefits, tax credits, payments, grants, and concessions.

However, this ignores the real problem - the lack of understanding of ME and the disbelief and apathy and ignorance of the particular condition and how patients are affected that has characterised the DWP approach to people with ME.

We would like to believe the statement –

'DWP will give people confidence that they will receive support, for as long as it is needed, regardless of whether they are working.'

Yet, when experience demonstrates that they have repeatedly shown profound ignorance to the effects of ME, we have no confidence that they will continue any other but an ideological approach to sanctioning those with ME, forcing more stress on many vulnerable people and their families.

We understand that the current chancellor, Jeremy Hunt, has now intimated that those who do not seek work may be sanctioned! It is unbelievably crass and ideologically constipated policies such as this (from a former health secretary, no less) that make us concerned that the end-result of giving

*'.....people confidence that they will receive support, for as long as it is needed, regardless of whether they are working'*

are nice soundbites that will be overridden by the destructive implementation of populist government headlines.

Of course, this is why it is easy in a report such as this to publish comments that things will change and raise hopes. It is what is delivered that matters.

The document states that after publication of the final delivery plan, a new ME/CFS delivery group will meet every 6 months to agree how to monitor performance, discuss progress with the delivery plan actions, share learning and consider how to address challenges.

This is of interest to us as past experience has shown how any sense of urgency is lost the longer things drag on.

Without clear objectives followed by fixed actions to resolve, then this may just turn into the same fiasco as the hapless and pathetic MRC expert panels that used to meet and achieved nothing for people with ME.

However, the main emphasis of this response should be on what actions are being taken – and when?

So section **5 Agreed Actions** need to be reviewed.

### Interim Report Actions

So what of these actions?

The Interim delivery plan report states that it outlines 21 actions to improve understanding, research and care for those living with ME - set by the three working groups.

The first six recommendations relate to the research working group.

IiMER has only sat in the Research Working Group and has not been able to input to other parts of this report.

The report states that the Research Working Group will work with research funders to identify metrics and milestones to ensure that a sustainable pipeline of research is becoming reality.

We do not see how this can be achieved when already Sajid Javid stated that there is no new funding for research when DHSC began this. This will undermine everything.

No substantial research capacity will be built unless adequate funding is provided – up front. No research capacity will be worth anything if the research is not joined up.

The report states that the UKCRC Research Working Group has committed to rapid actions that will provide the foundation of evidence generation and insight into the medium and long-term actions.

The term 'rapid' is used five times in the document - all related to the Research working group – and it is a misnomer. In over a year of meetings no actions have been produced or taken.

We already have a foundation for evidence generation – though without funding. IiMER called for using what has already been developed and then expand and augment the centre in Norwich with additional funding to act as a focal point for research, which will then be useable as a way to achieve the other objectives.

This has been ignored. Instead, time will be spent reinventing what exists and ignoring the opportunity for rapid development of the current base.

An action was to hold workshops with funders, academics and patients.

Action 1. The Department of Health and Social Care (DHSC) will support the Research Strategy subgroup to hold workshops with funders, academics and people with ME/CFS on how to develop research questions to respond to the PSP Top 10+ priorities and initiate new clinical studies. This will help increase research funded in this area by bringing new and existing researchers to the field to discuss feasible, clear and meaningful research applications.

Although mentioned by IiMER and well-advertised beforehand, the annual IiMER research colloquium (this year #BRMEC12) was ignored, despite researchers from 40 top institutes around the world attending during a week of events.

We proposed in our first meeting that the recently funded Dutch research plan could be examined and used as a starting point for future research and build on that – or collaborate?

No action was taken other than to suggest an international research landscape review (action 2 below). Time has passed and still nothing performed.

Action 2. DHSC will work with research funders to commission a landscaping review of national and international work underway in ME/CFS, map PSP research priorities against these and establish evidence gaps. This will enable researchers to target proposals at identified gaps and funders to consider which are most needed.

IiMER first suggested using the already existing Dutch Research Agenda (funded by the Dutch government with a 10-year plan and 28 million Euros) as a basis going forward. Now there is a proposal for a long drawn-out process to create yet more documentation that will inevitably take more time – and likely telling us nothing that we could not already foresee and producing nothing that we could not already provide. In any case, this will mean little if there is no funding or if

the flawed peer review process operated by MRC in the past continues (*'This will enable .... funders to consider which are most needed'*).

Action 3. The Medical Research Council and the National Institute for Health and Care Research will raise awareness of research funding opportunities for researchers and highlight the PSP Top 10+ ME/CFS research priorities publicly and with decision making bodies. This will provide further guidance to researchers, including those new to the field, as to how to find and apply for funding in a competitive process. Raising awareness of the PSP Top 10+ priorities will emphasise the value of those priorities to researchers, those involved in funding decisions, patients and the public to enable high-quality applications to be prioritised for funding.

This is so self-evident that it is not really an action.

Funders should raise awareness of research funding opportunities for researchers!?!?!?

Really?

How incompetent can an organisation be if it does not raise awareness of one of its primary reasons to exist?

Yet it was IiMER who pointed out to the working group that an MRC highlight notice had existed since 2013. It had not been promoted or actioned – 'left on the shelf and forgotten' was our comment.

As we stated in one of the meetings this has been totally ineffective, mainly because the MRC had done nothing to follow it up or maintain any campaign around it. Why would one expect this to be any different?

Researchers know where to go to find grants. IiMER already receive automated emails informing us of new research funding for projects from NIHR.

However, what is the incentive if the peer reviewing system is flawed or regularly denies applications? And, of course, there is no new money available (as indicated by the outgoing minister of health at the beginning of this exercise in 2022).

To think this is a change is a little disingenuous.

Even if funding were available, even if researchers came en masse to apply for a huge trough of funding, it may still not be joined up whichever research priorities

one decides to put forward. Without a joined-up strategy of research it will end up as disparate pieces of research funded with no connection and, above all, no strategy merely maintains the current status quo, even if there was funding available.

Action 4. As part of the 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, ensuring diversity across protected characteristics, geographical areas and severity and duration of disease. This will increase the co-production of research, ensure proposals are informed by personal experience, targeted to patient need, and increase competitiveness of proposals for funding.

Why is this really something that is different from what happens currently? In any case it is unlikely to achieve anything if no projects are funded. Hardly an action point. If a charity is funding research then this is likely already covered.

Action 5. DHSC will support the Research Working Group to develop case studies of research that show good practice, including effective PPIE. This will show exemplars to researchers and funders to improve future the research application and review process.

This is hardly an action that is pertinent or unique to ME. Why is this not common practice? How would DHSC support the working group?

Action 6. DHSC will support the Research Working Group to engage with the initiatives to educate clinicians and practitioners about ME/CFS (for example, the NHS England elearning module to be developed on ME/CFS). This will ensure that researchers, researcher clinicians and research funders are supported to engage with new educational resources on ME/CFS.

This last action concerned education of clinicians and GPs about ME.

But this has no inevitability that NHS or clinicians will accept this – even if approved by patients as valid. Even the NICE guidelines contained a disclaimer (only picked up by IIMER [22]) that the guidelines were not mandatory and were open to interpretation.

Appropriate diagnostic criteria and robust outcome measures that enable valid comparison between studies should be the areas that could help make a good deal of difference – in the absence of adequate funding. This is what this Research Working Group could have helped progress in the last year. This is what IIMER and Quadram Institute has been discussing with EMERG and NIH and the Quadram Institute has been preparing for this with the only clinical trial for ME in UK that restarts this year – yet all of the combined input on this subject was ignored.

Under **Attitudes and education of professionals** were listed actions concerning healthcare professionals -

Action 7. DHSC will consider how to increase our knowledge of public sector professionals' current attitudes towards ME/CFS, to help show where there are gaps in understanding that need to be targeted - by September 2024.

and

Action 8. NHS England will develop an e-learning module on ME/CFS, which will be aimed at professional staff working in health and social care services but can also be accessed by other professionals and members of the public. The development process will involve a range of stakeholders, including professionals and people with personal experience of ME/CFS - by end March 2024.

and

Action 9. NHS England and the NHS Health at Work Network will update their webpages on ME/CFS - by end March 2024.

This may be a stretch.

The cynicism and stigma about ME is institutionalised in UK thanks to so little action being taken in the past to correct it. This attitude is likely to continue until GPs can refer to some research findings that help them in their practice.

An example was in the Pulse article of August 2022 by Dr Copperfield [\[23\]](#) – somebody whom we view as hardly flattering with his articles on ME.

Writing about long covid (a condition that GPs at least, in general, accept - unlike the way in which they have regarded ME) and Lc clinics his comments and replies illustrate the task ahead without research evidence. This from doctors already working in the NHS -

"This was brought home to me recently by one of the few patients I have actually sent to a Long Covid clinic. After the obligatory and labyrinthine pre-referral polyinvestogram hoop-jumping exercise, he was distinctly unimpressed by his eventual assessment and treatment, which apparently amounted to a phone-call, an emailed PowerPoint and a weblink.

This is definitely not the fault of the Long Covid clinic. **We're dealing here with a disease with no clear definition, no diagnostic test and no specific treatment. Try running a clinic on that basis."**

Comment on this article by 'A GP':

"But GP cynicism is based on 2 major issues.

Firstly, LCovid patients are a huge heterogeneous group. Yes, some are previously healthy people struck down by a virus they never fully recover from, but let's be honest, many are the Usual Suspects that GPs could have predicted would develop LCovid a mile away.

Secondly, LCovid clinics are perceived by GPs as a work intensive exercise in futility. Extensive pre-referral investigations (many of dubious value clogging up an already overloaded system), lengthy compulsory time-stealing referral forms, frequent infuriating bounce-backs and re-referral, lengthy waits, then eventually.....hallelujah!..... an LCovid diagnosis.

With no effective treatment, and frustrated patients returning to their GP disappointed and looking for a non-existent Plan B.

**It's an extraordinarily expensive time-devouring pointless circular journey back to the GP. If there are no effective treatments we should be honest with the patient, make the LCovid diagnosis ourselves, and follow latest guidelines on self-help, exercise, diet, support groups etc as we have done with postviral patients for years.**



This is not ignorance or prejudice, it's hard-headed real-world pragmatism. And most patients accept and appreciate that honesty."

Sound familiar?

Changing healthcare staff's views on ME will be more difficult than this interim report would have one believe due to the lack of research and funding that has allowed this disease to be so misunderstood.

It is not mentioned with what the NHS will update their web pages or who will oversee this and ensure that the ME-related information is kept up to date. Is one merely going to see the established organisations and their pet projects mentioned?

In any case why is this an action and not just a routine concept – for all healthcare?

Action 10. On education about ME/CFS, DHSC will:

ask relevant stakeholders to consider developing a shared learning resource (such as case studies or videos) on ME/CFS which could be held in an education hub, as a central resource for education and training purposes, by the end of March 2024

request that the Medical Schools Council encourage shared learning and the NHS England e-learning package on ME/CFS to all UK medical schools and encourage medical schools to provide undergraduates with direct patient experience of ME/CFS, to raise awareness among medical students, by the end of March 2024

use its networks to raise awareness of the new NHS England e-learning module on ME/CFS once completed and to encourage stakeholders to do this also along with the updated NICE guideline on ME/CFS (NG206)

Encourage ? Nothing is being mandated.

Why not use (or even mention) IIMER/Quadram/UEA's example of funding medical students intercalating in research projects [\[24\]](#)? Funding for this could help the next generation of medical professionals.

Action 11. 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, once completed in 2023, so that staff who interact with those with ME/CFS in education can access it

signpost e-learning on ME/CFS, once developed by NHS England to providers

The lessons from covid show that home tuition is possible using remote access. IiMER also showed the possibilities using technology such as the AV1 robot which was tested in 2018 [[26](#)]

So nothing new – no action, just encouragement and more words

Action 12. The British Association of Social Workers 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, for example by sharing case studies, publishing articles and circulating guidance, by the end of March 2024.

We await to hear more on who will be given the opportunity to provide this information.

Action 13. The General Medical Council will include ME/CFS in the scope of the Medical Licensing Assessment that will be launched in 2023.

The Medical Licensing Assessment (MLA) will test the core knowledge, skills and behaviours of doctors who want to practise in the UK.

There is no detail on what will be in these training courses or which research they are intent on keeping pace with. We hope that medical schools will introduce correct information about ME in their curricula - IiMER has been funding medical students to intercalate with research projects already for years - but no certainty that this will be funded or even accepted. We approached the GMC thirteen years ago to raise this subject of medical education [[14](#)] and were informed that the GMC does not specify what should be taught to undergraduates about any specific conditions. This is decided by the medical schools when drawing up their

own curricula. 'The General Medical Council will include ME/CFS in the scope of the Medical Licensing Assessment that will be launched in 2023'.

Action 14. The Royal College of Physicians will ensure that their training on ME/CFS keeps pace with research and guidance in the core postgraduate training for primary and secondary care physicians, by the end of March 2024 and ongoing.

This will be interesting to see. What will this include? Will it be in place by March 2024? Who will verify that this is fit for purpose? It is easy just to promise and this is no concrete commitment of a real change that will benefit patients (or doctors). We will see if this really does provide benefits to patients and doctors.

Action 15. Healthcare practitioners from across disciplines and people with personal experience will come together to produce a 'Language matters in ME/CFS' guide to further the learning and insights gained from the interim delivery plan process. This will support both professional and patient understanding of effective use of language in the context of ME/CFS, while an aligned document will help people with personal experience get the best from their consultations. The work will be led by an independent clinician, supported by a DHSC secretariat, by the end of July 2024.

This is vague. If clinicians still do not understand this disease, do not believe it exists and still hold ignorant views of patients then will one 'independent' clinician really be expected to make a difference?

Also, this is about workplace protocols and discrimination. Whatever disease a healthcare professional is dealing with the views of patients should never be ignored or ridiculed. This is basic professionalism not specific to ME. Google easily provides ample information about the benefits of listening to patients.

Yet we have been here before and still nothing happens.

In 2013 Invest in ME Research arranged a meeting with Dr Martin McShane – NHS Commissioning Board Authority, Director - Domain 2- Improving the quality of life for people with Long Term Conditions). This followed communication

between the charity and the then prime minister, David Cameron. The IiMER web page regarding this meeting [\[27\]](#) makes interesting reading in the light of the interim report's actions.

Dr McShane identified three strands coming from our discussions.

1. Empathy and Respect (anger felt by patients and carers was understandable)
2. Services (some in the country supportive)
3. Research

The parents of the severely ill child added 4th important strand.

4. Medical practitioners are faced with a lot of conditions.

Instead of suspicion they should accept their limitations and show respect.  
Patient /carer experiences/expertise should be acknowledged

Dr McShane suggested ways to promote these.

CMO leads the agenda

(IiMER mentioned that CMOs had been invited to every single one of the eight IiMER annual conferences - without any sign of leading or an agenda for ME)

Academic Health Science Networks can help and could look at the Norwich proposal with the charity

Dr McShane commented that to change the quality of life with long term conditions we have to accept what we do not know.

That meeting could have led to change. Yet it is still being discussed.

### In **Broader actions to improve awareness and understanding**

Action 16. DHSC will collaborate with stakeholders to:

increase awareness among people with ME/CFS and their unpaid carers of support available from adult social care and how to access it 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

and

Action 17. 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, by September 2024.

The urgency, or lack of, is again shown here. Three years to raise public awareness!

The problem surely does not reside in ignorance from patients about the condition. It lies in DWP staff and the ideology behind government policy on benefits. There is little point in being aware of available support if it is denied due to ignorance (and/or apathy) about the condition.

### In **Improving statutory support**

Action 18. 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 - timescale to be determined.

Action 19. 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 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 - by July 2024.

Action 20. 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 - by July 2024.

No detail here to end the horror stories inflicted on families with children with ME.

But what will result from this engagement? What is the objective? There is recognition here of long standing problems so one waits to see if actions are really taken.

Action 21. DWP is committed to making its services easier to access for everyone, irrespective of their condition. How this will happen is set out in Transforming support: the health and disability white paper

(<https://www.gov.uk/government/publications/transforming-support-the-health-and-disabilitywhite-paper>), published in March 2023.

People with ME/CFS, as well as other people with disabilities, will benefit from the changes underway, which are intended to:

- make it easier for people to apply for benefits

- improve people's experience of assessments by exploring ways to simplify the claim and assessment process to improve transparency, support greater

- understanding and increase trust in the system look at ways to enhance assessment expertise

- improve the information provided about benefits and the application process improve how evidence is used

- reduce unnecessary assessments

We have very little confidence in DWP policies attempting to understand ME or facilitate life for people with ME to avoid stressful and coercive treatment of benefit applications and renewals. One can only wait and appraise the situation in the future – and then hold the government and minister accountable for any divergence from these explicit promises.

### Next Steps

**The Next steps** chapter 6 talks of continuing to monitor progress and capitalise on opportunities to work together via **a new ME/CFS delivery group** - including officials from the relevant government departments and arm's length bodies, people with personal experience (including unpaid carers), staff working in services, representatives of professional bodies, charities and relevant experts.

'The ME/CFS delivery group will meet every 6 months to agree how to monitor performance, discuss progress with the delivery plan actions, share learning and consider how to address any challenges.'

Who has been pre-selected to be in The ME/CFS delivery group? When does this group begin work? We predict that this group will consist of the same entities who always end up selecting themselves.

We will demand that this group operates with full transparency, that all meeting documents will be published in full (including minutes of meetings to be given out to everyone once they are made up). We will insist that any divergences from agreed actions and dates will require an explanation to the minister of health together with an adequate action plan and schedule to implement the action, and that this will be made available to all.

We will insist that failure to complete agreed actions will result in immediate review of the full schedule of actions.

We shall see if this works. The result that cannot be accepted is for failure to improve the situation by allowing any organisation or individual to continue to kick this particular can down the road indefinitely.

### Comments on Interim plan survey

The accompanying survey [8, 9] that people with ME are asked to complete is an exercise in irrelevance.

The questions posed in the survey document have been answered in this interim report – and have been known for decades.

Working groups were set up with patient representatives and organisations who were deemed to be responsible enough to provide this information regarding experiences.

Using a year to create this report and survey, which will just confirm what we all know and have known for decades, and then spending time and resource to confirm what is already known by collating submissions from this survey, merely delays progress and provides more of what we have already had. If the interim report has achieved anything it is to underline even further that action needs to be taken now.

The first 20 questions of the survey relate to the person or organisation submitting the response.

Yet one wonders what is significance of answering the question

*"How would you describe the severity of your symptoms, on average over the past 3 months?"*

if a patient has had this disease for 20 years or more?

What is the value of asking -

*'How would you describe the severity of their symptoms, on average over the past 3 months'*

when somebody has been bed bound for 10 years?

How can this mean anything if the context is not appreciated?

Why is the last 3 months perceived as being of some magical quality or meaning?

The survey asks details of diagnosis but misses the opportunity to obtain relevant information such as –

- how long was it before diagnosis?
- who gave your diagnosis?
- Were you forced to take cbt/get?
- What follow-up treatment have you had?
- etc.



So one wonders what use this data is to anyone – and, of course, it could have been asked a year ago (or long before).

Question 21-22 ask for comments on the research

The plan concludes that the research community has a low capacity and capability to respond ME/CFS research needs, and that awareness of those research needs is low. The level of biomedical research on ME/CFS that has been funded is also low.

The government is keen to build on the work already done by the National Institute for Health and Care Research and Medical Research Council, such as the DeCodeME study, and the James Lind Alliance Priority Setting Partnership's top ten research priorities.

The plan sets out proposed commitments to action in three areas: research strategy, capacity and capability in the research community and building awareness and trust between stakeholders

None of this is new – we have been saying it for years – the ministers of health, the CEO of MRC, the CMOs of UK, the head of the NHS, other areas of healthcare – have all been told this by IiMER for over a decade.

The plan does not set out action to combat these – it has no urgency on research, which is the key to everything.

As with all of these proceedings there is again the ubiquitous reference to the DeCode project – running almost as a subplot through the interim report - yet ignoring completely the work done in Norwich Research Park, including the only clinical trial for ME in the UK [[25](#)]

Questions 22-24 – relate to Attitudes and education

Question 25-26 relate to Living with ME/CFS Quality of Life

Questions 27-28 relate to Support for children and young people with ME/CFS

Questions 29-30 relate to Health Services for people with ME/CFS

Questions 31-32 relate to Adult social care

Questions 33-34 relate to Welfare support

Questions 35-36 relate to Employment

Questions 37 -40 relate to Agreed Actions

### QUESTION 41 – 54 **Relate to 'Use of language in ME/CFS'**

And here we wonder what on earth those compiling this survey were thinking!

There is no sense in adding questions in this survey that relate to discriminatory comments made against people with ME.

This has been known for years and no action has been taken by successive governments or the Chief Medical Officers of UK or the NHS to correct the situation.

It is already known how stigmatised people with ME have been made – aided by the apathy, ignorance and misinformation from governments, research councils, NHS, Royal Colleges, media and even some actions of some organisations purporting to represent people with ME.

This interim report should not include such comments in this document and then give credibility by putting it in the public domain and inviting comments.

It just continues to reinforce decades of stigma about ME.

The government should be answering this type of garbage itself and defending patients – and we present a statement to counter this using extracts from the DHSC's very own interim report [[20](#)]

Years of experience from letters to CMO, MRC, Doh, NHS – just from IiMER – would have covered these questions. We know what the stigma is, why it has been allowed to fester, and why no establishment organisation has done much about it.

The interim report would have been of value if it had clearly stated these reasons, then followed with the actions that would be enforced to overcome them.

### Conclusion

A year on from the start of this and there seems little real progress and no actions taken.

The lack of urgency in all of this is disappointing, to say the least, despite being stressed in the input that we presented at our first meeting in September 2022 –

The summary from the first input by IiMER stated [21] –

'We stressed that the time line for delivery should be short as many patients had already been dealing with the disease for decades – so urgency in getting research funded and started is crucial and should be stressed in the objectives.

We need to decide things urgently and produce an earlier fast track for research and hopefully there would be phases which allow early starts on research support.'

<https://www.investinme.org/ukcrc-input01.shtml>

So, to summarise, a lot of work has already been performed and we can synergise the research in order to make more rapid progress.

We believe this way forward holds out the best hope of rapidly moving things along and should form part of the efforts of this Working Group.

The draft proposal received is instead suggesting more subgroups but the reality is that nothing may get done. Adding on extra working groups may do nothing but prolong **discussions without any certainty of achieving anything more than documentation.**

It is not a green field site as no funding is guaranteed.

We need to get going with research and increase the capacity – which then generates more interest, funding, collaboration.

**This is urgent and the UKCRC Working Group needs quickly to move from a mode of documentation to one of action.**

We should use what we have created already as a base and model.

So our suggestions are –

- Use what has already been developed and expand and augment the centre in Norwich with additional funding to act as a focal point for research, which will then be useable as a way to achieve the other objectives
- Use the Dutch research agenda as a basis to develop the above. Avoid unnecessary duplication and build on a European model for research, which may in turn attract more funding.
- Push back to the UK government stating that funding is required up front to initiate this (as has been performed by the Dutch government and the NIH in the USA already)

Comparatively quick wins to kick start actions elsewhere.

But predicated on the need for funding up front.

We needed to push back to the UK government immediately stating that funding is required up front to initiate this (as has been performed by the Dutch government and the NIH in the USA already).

We called on the entire group to push back to the minister of health (who had stated there was no new funding for this) and inform clearly that nothing could or would be achieved unless adequate funding was provided for research into ME. We should stop at this point if not provided.

Nobody supported that.

The only tangible output that we have seen is this interim plan, a proposed 'toolkit' for researchers (essentially just a spreadsheet with links on funding possibilities and other information on the web), a promise for a workshop to be held for researchers and others, and more meetings.

From the interim report document there are a number of proposals that would seem to have some support promised from areas including education, benefits and services – but still far too much vagueness around real commitment, content and schedules.

We commented last year that our input to the Research Working Group seems to have been distributed very late to working group members – if at all - or ignored completely. We reminded the secretariat of that this year also. Nothing changed. There is a feeling that everything we have called for is ignored and an underlying

emphasis is being placed on making the deCode base the only thing that will get further funding.

We do not feel confident in the progress, pace or direction of this DHSC work and this interim report is not enough to dispel that doubt.

Falling in line with a model for change set by others with no sense of urgency or recognition of the wasted years already endured is no recipe for progress.

Many of the symptoms of the failed and flawed government and healthcare policies of past decades have been described in the interim report but the aetiology for these symptoms has not even been approached.

So lessons are not necessarily learnt and the same lack of actions to cure these issues are set to be repeated.

This needs quickly to move from a mode of documentation to one of action and implementation.

We may be somewhat critical of this initiative that has been ongoing for a year now and the workings of this initiative.

But throughout our history as a charity over 17 years of working every day on this we have seen these items come and go, raising hopes for people with ME only for nothing to happen and the abysmal state of research, services and perception allowed to remain and perpetuate a stigma that has no sense but feeds certain vested interests.

It is all too easy to present yet another item that purports to be something that will change lives and provide a feel-good feeling to all that a new dawn has come, while using more time and delay.

UK governments over the past decades have had plenty of opportunity to address the deficiencies in researching and treating ME.

The CMO report of 2002 [[13](#)] listed a set of seven areas where actions needed to be completed.

1. Recognition and definition of the illness
2. Treatment and care
3. Health service planning

4. Education and awareness

5. Research

We took a look at these in 2007 [[14](#)] and none of them had been accomplished.

One can judge oneself how similar the DHSC interim report's main action plan might be to what was required from the CMO over twenty years ago.

Yet here we are.

Similarly, in 2006 the Gibson Inquiry report [[15](#)] provided a number of recommendations

We commented on this report [[16](#)] that –

‘The challenge now will be to harness the momentum generated by this Inquiry to proceed with proper funding for biomedical research and a will to find a cure for this illness.’

The chance was lost.

So we are a little circumspect in believing the contents of yet another document when we merely see more words – more time wasted – as it could go on like this for years. And so it has done.

We have not been comfortable to just fall in line and end up with toothless activities being discussed, shielded from the gaze of patients due to no publication of minutes or progress and, crucially, no funding for research.

A year to prepare an ‘interim’ report and a request for a survey of views – both of which could have been made a long time ago – is not good enough.

Following our initial meetings we were less than impressed at the way this was going. Still a year later we feel the scale of progress, scope and ambition is quite underwhelming.

Our input to the first meeting proposed avoiding reinvention and using what existed and funding that [[4](#)].

Our proposal for supporting and developing the centre of excellence for ME produced no actions or support. Yet this, we feel, will be the only credible way of making rapid progress in research.

We have long called for a Centre of Excellence for ME and have been working on that since 2011. Now all components are present – except for adequate funding.

At least the APPG for ME finally, eventually included a reference to our work by also commenting that ‘centres of excellence’ would be desirable.

This all underlines that the big push from this initiative should be to expedite a strategy of biomedical research into the disease – ideally taking place at a location that has all facilities available such as the centre in Norwich Research Park which already has many years of experience of research into ME.

It may be years before anything might emanate from this report.

Meanwhile, the points we made early on in our first interaction still hold true for us as the quickest way to expedite progress in research – and doing this will result solutions in the other areas of education and awareness being attained.

Another document requesting patients to fill in a form – something that, if planned properly, could have been done a year (or a decade) ago.

Words but no actions. Promises but time passes. Lethargy instead of urgency.

The government web page states – “[The government is keen to build on the work already done by the National Institute for Health and Care Research and Medical Research Council, such as the DecodeME study.](#)” yet the work in Norwich Research Park by Quadram Institute and UEA (including all the initiatives to set up European collaboration, young researchers, international research meetings) are ignored.

The DHSC states that after publication of the final delivery plan, a new ME/CFS delivery group will meet every 6 months to agree how to monitor performance, discuss progress with the delivery plan actions, share learning and consider how to address challenges.

Experience has shown how any sense of urgency is lost the longer things drag on. Without clear objectives followed by fixed actions then this may just turn into a similar charade as the hapless and pathetic MRC expert panels that used to meet and achieved nothing.

And this is really the salient point.

With non-specific action points that do not force actions to be taken but merely suggest that they will be taken, it will fall to this unknown, yet to be decided Delivery Group to follow up and ensure that these actions are taken, and in a timely way.

Yet who really believes that this group will have any power (or motivation) to force actions?

What we see is a long drawn-out process that becomes as ineffectual as wishing that time will stop still for the moment - open to the vagueries of politics and economics and, still, vested interests.

As we stated in September 2022 the risk is that we end up with no actions but just documentation – full of promises, plans, words.

And the key point that Sajid Javid made clear at the start – that little elephant that keeps roaming around this room - is that there is no new money for research.

This report may satisfy some who happily accept a pace of change slightly faster than the status quo or those seeking to justify salaries.

For us, as a charity seeking solutions in order that we do not have to exist at all, this report is another document to add to the list and only time will tell if it is as ineffectual as all of the other 'initiatives' that have masqueraded as progress over the years.

Meanwhile we are losing an opportunity to make progress by not investing in and supporting what we already have established. We do not want reinvention – we need to build on, and fund what we have established as the quickest route to achieving progress, rather than building an extensive list of funding requirements that will likely not be funded [3].

Failing this we require unassailable commitment from government, strict implementation of agreed actions and adequate funding for research.

We do not need more soundbites and vague promises just to make people feel better and believe that finally progress is coming.

**The slogan for UK policy on ME should be 'Invest in ME Research' – not 'Catharsis'!**



## References

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- 3 [DHSC Consultation document: the interim delivery plan on ME/CFS](#)
- 4 [Submissions and Comments from Invest in ME Research to UKCRC](#)
- 5 [A overview new story from Minister of State for Health, Will Quince](#)
- 6 [A Consultation description containing links to two other documents](#)
- 7 [A page called Consultation document: the interim delivery plan on ME/CFS](#)
- 8 [A survey for people to complete and submit](#)
- 9 [An online version of the survey for people to complete and submit](#)
- 10 [An 'easy read version of this consultation' which then has two links to two more documents](#)
  - 10a [Our plan to improve the lives of people with myalgic encephalomyelitis/chronic fatigue syndrome \(ME/CFS\): what do you think?](#)
  - 10b [Our plan to improve the lives of people with myalgic encephalomyelitis/chronic fatigue syndrome \(ME/CFS\)](#)
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- 21 [Invest in ME Research Input to UKCRC Research Working Group Meeting 1 September 2022](#)
- 22 [NICE Guidelines 2021 Review](#)
- 23 [So long, Covid clinics](#)
- 24 [Medical Students in ME Research](#)
- 25 [RESTORE-ME Clinical trial for ME](#)
- 26 [Removing Isolation from Young People with ME](#)
- 27 [Meeting with Dr Martin McShane Director of Domain Two, NHS Commissioning Board](#)

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