Action for M.E. Consultation Response

My full reality: the interim delivery plan on ME/CFS

Introduction

My full reality: the interim delivery plan on ME/CFS was published by the Department of Health and Social Care (DHSC) on 9 August 2023. Consultation on the plan was open to UK residents aged 13 and over and closed on 4 October 2023.

Various team members of the charity have been involved in the working groups and the Chief Executive was a member of the Steering Group responsible for oversight of developing the Delivery Plan.

We have had meaningful engagement throughout development of the Plan. This included ensuring the views and experiences of children and adults with whom we work, and the wider community were reflected in our input. We welcome the work of DHSC and cross-government colleagues to produce a Plan that highlights the stigma and exclusion of people with M.E. and the focus to redress this.

There has been an overwhelming response to the Consultation, and we support the calls for action from our colleagues in other ME/CFS charities and Forward-ME members. These include:

- Increase action to directly and immediately improve people’s day-to-day lives, supported by professionals in the health, social care, education and benefits sectors
- Increase education for healthcare professionals and medical students to improve their understanding of M.E. and its impact
- Fully implement the Delivery Plan to ensure longer-term impact
- Increase research funding and wider activity to support the research community

We have therefore decided to focus on one key call relating to research, rather than widely represent the feedback/input we have had previously in the Plan’s development and the feedback we’ve received from the Community (which has been submitted through their direct engagement with the Consultation). Additionally, we call on the Government to ensure full implementation of the actions contained within the Delivery Plan. People with M.E. have seen very little progress to tackle the issues which the Plan clearly identifies. To improve outcomes for people with M.E. and enhance their lives, urgent action must be taken, and Action for M.E. will continue to work collaboratively to support delivery and advocate for our community.

KEY POINT:

RING-FENCED FUNDING IS URGENTLY NEEDED TO ACCELERATE M.E. RESEARCH

Within the Plan, there are four problem statements and six rapid actions (Appendix 1) for the ensuing months and a commitment to developing longer-term actions which should achieve change. While not explicitly stated within the Plan, there remains a 'chicken and egg' situation with funders citing a lack of applications and/or high-quality actions that compete with other disease areas. Researchers cite the pointlessness of applying given the lack of funding awarded and some imply that stigma and/or a lack of priority is given to funding M.E. research. This dynamic has existed for over a decade despite the work of funders and the UK ME/CFS Research Collaborative. Redressing this dynamic is critical, and the mainstream funders have identified the short-term actions which will provide a foundation on which to build.

A decision was taken for the Plan to focus on ME/CFS and not include Long COVID. While there were good reasons for this decision at the time, consideration should now be given to maximising the investment in Long COVID research alongside research into M.E./CFS, given the emerging evidence that identifies that there is a distinct sub-group of people with Long COVID that have ME/CFS-like symptoms. Research varies, with results between 40 – 75%[i] [ii] [iii] [iv] [v]. There continues to be a lack of experienced Principal Investigators in the M.E. field and there are unexplored opportunities for exploiting cross-over with other fields e.g. those who have diversified into Long COVID research to expand research while ensuring research quality and rigour.

Funding was provided for the DecodeME Study, which was described as a 'door opener' for further research. However, we must provide the foundation for research across the Top 10+ Research Priorities identified through the ME/CFS Priority Setting Partnership. There are plenty of precedents for "intramural" funding (not response-mode funding), e.g. dementia (https://ukdri.ac.uk/about-us/our-funders), metabolic diseases (https://www.ukri.org/about-us/mrc/institutes-units-and-centres/mrc-metabolic-research-laboratories-mrc-metabolic-diseases/), Musculoskeletal Ageing (https://www.ukri.org/about-us/mrc/institutes-units-and-centres/mrc-versus-arthritis-centre-for-integrated-research-into-musculoskeletal-ageing/), prion diseases (https://www.ukri.org/who-we-are/mrc/institutes-units-and-centres/mrc-prion-unit/).

Further precedent of funding to accelerate research is highlighted in the recent project report on the Rare Diseases Research Landscape, which reveals £1.1bn of funding in rare disease.[vi] "A rare disease is defined as a disease or condition that affects fewer than 1 in 2,000 people within the general population. Funding for rare disease research accounted for:

- 7% of the total number of awards funded
- 7% of the total value of funding through NIHR programmes and the MRC joint research portfolio

This investment represents almost £627 million by the two organisations between the years 2016 and 2021, across 698 studies."

As a point of note, initial findings from the DecodeME questionnaire data (https://openresearch.nihr.ac.uk/articles/3-20/v4) indicate a notable gender disparity in the prevalence of ME/CFS, showing that ME/CFS is significantly more common in females. Additionally, females are more likely to experience severe symptoms, with this likelihood further increasing with age if they have had the condition for more than 10 years and adds weight to the discourse around inequalities in research funding.

Conclusion

Urgent action is needed to accelerate research into ME/CFS and ensure commensurate focus and funding to drive understanding and ultimately identify treatments for people with M.E. We eagerly await an update from DHSC regarding the process for oversight of the delivery of the Plan and ensuring full implementation.

Action for M.E. will continue to work collaboratively with the mainstream funders and others to accelerate research into ME/CFS.

Appendix 1 – Interim Delivery Plan: Research

Problem Statements

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 remains 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.

Six Rapid Actions

1. The 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 Priority Setting Partnership (PSP) Top Ten Plus 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.
2. The 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.
3. The Medical Research Council (MRC) and the National Institute for Health and Care Research will raise awareness of research funding opportunities for researchers and highlight the PSP Top Ten Plus 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 Ten Plus 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.
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.
5. The DHSC will support the Research Working Group to develop case studies of research which show good practice, including effective PPIE. This will show exemplars to researchers and funders to improve the research application and review process.
6. The DHSC will support the Research Working Group to engage with the initiatives to educate clinicians/practitioners about ME/CFS (for example, the Health Education England e-learning 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.

References

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