#MEAction Community Call:
UK Government's Interim Delivery Plan for ME/CFS

#ME ACTION UNITED KINGDOM

#ME ACTION SCOTLAND

HOUSEKEEPING

- Recording to help with our response
- Make yourself comfortable and leave if you need to
- Stay on mute when you're not speaking
- Try to keep contributions to maximum 2 minutes
- Respect
- Confidentiality

TIMINGS

- 6.05-6.10: Housekeeping and introduction
- 6.10-6.25: (Brief!) Overview of the interim delivery plan
- 6.25-6.30: Submitting an individual response to the consulation
- 6.30-7.00: Discussion - your thoughts and ideas (by section)

TIMELINE FOR CONSULTATION

- Full consultation published 9th August
  - Closes at 11:59pm on 4 October 2023

- Easy read consultation document published 4th September
  - Consultation closes at 11:59pm on 30 October 2023

- Commitment to publish the final delivery plan later this year

STRUCTURE OF INTERIM DELIVERY PLAN

Ministerial foreword

Executive summary

1. Introduction
2. **Research**
3. **Attitudes and education of professionals**
4. **Living with ME/CFS**
5. **Agreed actions**
6. Next steps

Supporting information

Research

- Key Problems:
  - Low capacity and capability to respond to research needs
  - Low awareness of need for research
  - Lack of funding of biomedical research
  - Lack of trust between funders, academics and people with ME
- Aim: Build on recent work, e.g., DecodeME's genetic research
- Research Working Group set up for period of two years to deliver change (differs from the other working groups)

RESEARCH – PROPOSED ACTIONS

Working Group has identified six rapid actions for delivery by spring 2024:

- **Research strategy**
    - DHSC workshops with funders, academics and people with ME/CFS
    - Landscaping review of national and international work and establish evidence gaps
- **Building capacity and capability of the research community**
    - Raise awareness of research funding opportunities
    - Charity/patient group collaboration to ensure effective patient and public engagement
    - Develop case studies to show good practice and improve applications
- **Raising awareness of ME/CFS and building trust between stakeholders**
    - Initiatives to educate clinicians and practitioners about ME/CFS

ATTITUDES AND EDUCATION OF PROFESSIONALS

- Many children and adults with ME/CFS feel they have not been believed, supported or treated equally across all settings and professional groups.
- Some people with ME/CFS have had positive experiences with professionals but other people have not.
- There are limited education and training opportunities for any professional groups on ME/CFS. Professional awareness of the updated NICE guideline could be improved.

ATTITUDES AND EDUCATION OF PROFESSIONALS – PROPOSED ACTIONS

Intentions:

- **Consider** how to increase knowledge of public sector professionals' attitudes. Raise awareness and use of new NHS e-learning module and updated NICE guideline on ME/CFS.
- **Request and ask** NHS and Medical Schools Council to encourage shared learning and ask medical schools to raise awareness.
- **Encourage** SEND and medical condition organisations to signpost to the NHS England e-learning on ME/CFS on their websites.

Attitudes and education of professionals – Proposed actions continued

Commitments:

- **NHS England** will develop e-learning module on ME/CFS and update webpage.
- Update the guidance on education for children with health needs who cannot attend school.
- **The British Association of Social Workers** will support awareness-raising about needs of people with severe/very severe symptoms of ME/CFS.
- **The General Medical Council** will include ME/CFS in the scope of the Medical Licensing Assessment that will be launched in 2023.
- **The Royal College of Physicians** will ensure training on ME/CFS keeps pace with research and guidance in the core postgraduate training for primary and secondary care physicians
- ‘Language matters in ME/CFS’ guide’ will be produced by health professionals and people with ME.

Living with ME/CFS

Areas that need to change:

- Better general awareness of ME to enable people with ME and their carers to feel supported, believed and less alone.
- Better support for children and young people to access education and appropriate social services support.
- Better healthcare provision for diagnosis, treatment and ongoing care, including for non-ME healthcare needs.

LIVING WITH ME/CFS – PROPOSED ACTIONS (1)

- Update NHS England web pages on ME and identify how best to raise public awareness of ME.
- Roll out online guidance on ME to healthcare professionals, schools, local authorities and children's social care professionals.
- Consider with stakeholders how to improve local service provision, and accessibility of services for people with Severe ME.

LIVING WITH ME/CFS CONTINUED

Areas that need to change:

- Better access to social care
- Changes to welfare support (UC/ESA and PIP/DLA)
- Better support to help people into employment

PROPOSED ACTIONS

- Increase awareness of how to get social care and how to complain if care isn't good enough.
- Big changes to Health & Disability benefits for ALL conditions from 2026.
    - (Note: Work Capability Assessment descriptors consultation out now)

NEXT STEPS AND SUPPORTING INFORMATION

Next steps:

- New ME/CFS delivery group including government officials, people with ME and their carers, service staff, relevant experts and representatives of stakeholder organisations.
  - Will meet every six months.
- Research Working Group will continue to meet.

Supporting information:

- Language use in relation to ME/CFS - a personal perspective.

SUBMITTING YOUR OWN RESPONSE

- The more responses the better!
- Don’t be intimidated. You are the expert on your experience of ME.
- You **do not** have to answer all the questions.
- You can do it in chunks and your answers will be saved.
    - Copy the address of the page you are on from the address bar in your browser, save it/bookmark it to return to it.
- You can request a paper copy by emailing mecfs@dhsc.gov.uk, or someone can do this on your behalf.

- #MEAction webpage with FAQs and preview of questions: https://www.meaction.net/2023/08/10/dhsc-consultation-faq

STRUCTURE OF CONSULTATION SURVEY

- About you
- About the interim delivery plan
  - Research
  - Attitudes and education
  - Living with ME/CFS (split into quality of life, support for children and young people, health services, adult social care, welfare support, employment)
- Agreed actions
- Use of language
- About the consultation process

QUESTION STRUCTURE IN CONSULTATION SURVEY

To what extent do you agree or disagree with the contents of this chapter/the actions for...?
Multiple choice: Strongly agree/Agree/Disagree/Strongly disagree

What, if anything, do you think could be improved about this chapter?
(Select all that apply)
Multiple choice: Some content is missing/Some content does not reflect my experience/Some content could be simpler or clearer/Some content could be more detailed

Do you have further comments? (250 words maximum)
Free text

250 WORDS LOOKS LIKE THIS
(JUST UNDER HALF A PAGE OF A4 AT 12PT FONT)

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A NOTE ON LANGUAGE

Try to mirror the language used in the plan where possible. This could help it to be picked up in analysis.

Some keywords you might want to use are:

- Severe and Very Severe ME
- Research funding
- Funding commitments
- Compulsory healthcare education

DISCUSSION

THANK YOU!

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