

INFORMATION FOR STAKEHOLDERS

Progress with developing a draft Delivery Plan on Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS)

December 2022

Introduction

The purpose of this publication is to provide a summary of the activity underway since 20 September, to develop the draft cross-government Delivery Plan on ME/CFS. Previous Department of Health and Social Care (DHSC) information bulletins cover the period from June to 20 September 2022. Many organisations have published this information on their websites – for example:

[ME/CFS Delivery Plan: latest update | Action for ME](#)

[DHSC release progress update. - #MEAction Network](#)

[Work underway to support the development of a Delivery Plan on ME/CFS | The ME Association](#)

[DHSC TASK GROUP UPDATES | Forward ME \(forward-me.co.uk\)](#)

Timetable for publication of the draft Delivery Plan

The [Written Ministerial Statement](#) published in May stated that the Delivery Plan would be published later this year and set out our two core principles – ‘firstly, that we do not know enough about ME/CFS, which must change if we are to improve experiences and outcomes. Secondly, we must trust and listen to those with lived experience of ME/CFS’.

To do justice to the second principle, people with lived experience of ME/CFS (including those living with ME/CFS and their families and carers) have acted as co-chairs of the different working groups and also participated as members. We were also grateful that a number of additional people with lived experience were able to join the five workshops we held between September and October 2022. We are also incredibly grateful to the clinicians and professionals, who have shared their insight and expertise from working directly with people ME/CFS and their families, often alongside managing busy clinical schedules and challenging work requirements.

Everyone needed time to read the information we distributed, in order to contribute effectively to discussions and we also offered attendees the opportunity to send back feedback after the meetings, allowing time for reflection, rest and recovery as well. The variety and detail of the views and information provided back to us has been impressive and we want to thank everyone involved so far. We recognise the effort and energy involved from people with lived experience of ME/CFS, to undertake this work on top of the normal demands of everyday life.

This has meant that the draft Delivery Plan was not ready for sharing more widely by the end of this year, as originally intended. We are now aiming to publish it as soon as possible in 2023.

Research update

The Research Working Group has agreed the proposed set of problems to be addressed in relation to research on ME/CFS and a description of a successful future research environment. Initial rapid actions to help move the research community towards this future state have been proposed and agreed by the group. Three sub-groups have started to meet, to take forward more detailed discussions about i) research strategy, ii) research capacity and iii) building trust and relationships between researchers and people with lived experience of ME/CFS.

Attitudes and Education Working Group

Group members have sent feedback to DHSC on the first set of suggested actions for this section of the Plan. These views were collated; some actions had a high level of support but other actions were less popular, as members pointed out difficulties in making them happen or possible side-effects that would be detrimental.

DHSC officials have met with colleagues within the Department and other external organisations to discuss how these actions could be taken forward and which would have most impact. For example, meetings were held with colleagues from Health Education England, the General Medical Council, the Medical Schools Council and Royal Colleges. Further meetings of the Working Group in November and early December have helped DHSC to refine the actions further.

Living with ME/CFS Working Group

The five topic-based workshops were completed in early October. Between 20 – 30 people attended each workshop, including members of the Working Group, additional people with lived experience (e.g., from local patient networks and smaller national charities), representatives of ME/CFS services and policy leads from relevant national bodies.

After some introductory speakers explained the context, the group split up into several smaller groups to discuss what the desired future would be like and what actions would help to achieve that future. Afterwards, participants were invited to provide further suggestions and comments to DHSC.

All of the material has been reviewed and summarised to support the content of the draft Delivery Plan. The relevant government departments are considering the evidence generated by the workshops and exploring relevant actions, as follows:

- DHSC – Health Services (children and adults), Adult Social Care, Quality of Life
- Department for Education – Children Social Care and Education (all levels)
- Department for Work and Pensions – Welfare and Employment

Engagement Advisory Group

This Group has met twice since 20 September to discuss how to best engage with the wider community about the draft Delivery Plan, once it has been published by DHSC. A number of options are being considered by the Task and Finish Group.

Delivery Plan Task and Finish Group

This oversight group has met monthly since September to hear about the progress being made by the individual working groups and resolve issues relevant to the content of the draft plan and wider engagement. This Group agreed that more time would be necessary to produce a draft ready for publication and wider engagement. The group will continue to oversee the development of the plan and inform next steps in the plan's development.